



**VIRTUAL
2020**

ALZHEIMER'S DISEASE INTERNATIONAL
VIRTUAL INTERNATIONAL
CONFERENCE

10-12 DECEMBER 2020

34th Virtual International Conference of
Alzheimer's Disease International

10-12 December 2020

Hope in the age of dementia.

New science. New knowledge. New solutions.



Abstract Book

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Plenary Abstracts

Plenary 1: Dementia why we all need to do more

Date: Thursday, 10 December 2020

Time: 8:00AM - 9:30AM (GMT)

Introducing Germany's "National Dementia Strategy"

Nils Dahl, Federal Ministry of Health, Germany

Abstract:

The presentation will introduce Germany's National Dementia Strategy which was developed between 2019 and 2020. Governmental actors of different policy areas and of all administrative levels, as well as over 70 relevant organisations and interest groups were involved in the process of drafting the strategy. Four priority fields of action were identified: 1) building dementia-inclusive communities by strengthening structures that enable the social participation of people with dementia, 2) improving support for persons living with dementia and their family caregivers, 3) improving medical care, nursing care and long-term care for people with dementia, and 4) promoting research, innovation and collaboration to increase our knowledge on the prevention and therapy of dementia.

All involved actors agreed on 27 goals and 162 measures to substantially improve the situation and living conditions of persons with dementia and their families. Therefore, many measures focus on enhancing the quality of everyday life in their communities and the quality of care in various care settings.

The implementation of the strategy will be monitored to ensure sustainable improvements and to allow necessary adaptations to new challenges such as the current COVID-19 pandemic. The strategy's goals are interlinked with other governmental strategies such as the so-called "Concerted Action for the Care Workforce" ("Konzertierte Aktion Pflege" or KAP) which was signed in 2019 to improve training, working and remuneration conditions for professional carers.

The presentation's goal is to share the experience of developing a national dementia plan, discuss examples of the strategy's goals or particular measures, and enhance the exchange of experiences between countries that have already implemented their individual strategy or that plan similar steps in the future.

Plenary Abstracts

Plenary 2: The road to awareness and friendliness

Date: Thursday, 10 December 2020

Time: 10:40AM - 12:10PM (GMT)

Media's Role in Raising Dementia Awareness

Dishen Kumar, Astro Awani, Malaysia

Abstract:

One of the challenges in Malaysia (and LMICs) is the stigma that surrounds dementia. It is challenging for adult carers, and even more so for young carers, to reach out for help and support. How can media help bridge this gap to reduce stigma and increase awareness?

In today's world of challenges, staying resilient in the pursuit of our own happiness and goals is not an easy feat: especially for today's youth who are growing up in a fast-paced ever-changing environment, marginalised and underprivileged. Young carers are missing out on school and 'growing up' and some, who are starting out with their own lives are juggling work and social lives, when they are faced with the task of having to take care of a family member living with dementia. Media needs to come in here to help increase awareness and promote youth volunteerism. With the majority of people consuming media daily and through different platforms, there needs to be a right balance and formula to be able to reach out to the mass audiences online with the right message.

The lack of awareness and support places an enormous burden on carers as they have little knowledge about care, and fewer resources to understand how to deal with the challenging behaviours of a person with dementia— especially in Lower Middle Income Countries (LMICs).

The presentation sheds light on the issues and challenges of how media can play a crucial role in increasing awareness and promoting youth volunteerism. These days young carers are also aiding others while they themselves are learning and growing as individuals. Media can help these carers get the support and encouragement they need to continue to be there for their dependents.

Malaysia is on the cusp of getting policymakers and communities to address youth issues. These matters will only escalate with the number of people living with dementia getting higher. At the same time, young carers will be another alarming social issue Malaysia and the LMICs will face in a decade (or less) if this issue is not looked into, now.

Malaysia has been developing their first National Dementia Action Plan 2020-2030, there are several recommendations to support youth carers and youth volunteerism and youth engagement programmes as part of school extra-curricular activities, etc.

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Plenary Abstracts

Plenary 2: The road to awareness and friendliness

Date: Thursday, 10 December 2020

Time: 10:40AM - 12:10PM (GMT)

How we are making our newspaper dementia friendly in Japan

Masahiko Yamamoto, Asahi Shimbun Social Welfare Organization, Japan

Abstract:

The Asahi Shimbun has been trying to be a dementia friendly paper since last year. Our sales department is encouraging delivery staffs becoming Dementia Friends, and now there are over 5000 delivery staff made it. Another department made a virtual reality system that is very easy to understand how the people with dementia could see the world. They show it at commercial company and high schools. My organization start dementia friendly kids lesson at elementary school to study about the basic information of dementia and use virtual reality system that how people with dementia can see the world. We have some more experiments to become dementia friendly paper.

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Plenary Abstracts

Plenary 2: The road to awareness and friendliness

Date: Thursday, 10 December 2020

Time: 10:40AM - 12:10PM (GMT)

Understanding and acceptance of dementia: Where are we now?

Emily Ong, Alzheimer's Disease Association, Singapore

Abstract:

The Alzheimer's disease movement, despite its forty-one years of presence, has yet to successfully stop the highly stigmatised and discriminatory attitudes towards people with dementia and their families. Society still largely believes that people living with the condition are not capable of communicating in a meaningful way, and are highly dependent on others. This assumption of incapacity continues to be the greatest barrier between those who are capable of advocating for themselves, and their direct and full participation in matters related to dementia.

While many measures have been implemented to raise public awareness and build an inclusive community, like World Alzheimer's Month and dementia friendly initiatives, the general level of understanding and acceptance of dementia is shallow and much remains to be improved. High functioning individuals living with dementia have their diagnosis brought into question, proxy interviews with care partners are still seen as the best way to investigate issues pertaining the condition, mass media continues to paint a 'pathetic' depiction of suffering and use insensitive language, and many service providers and researchers continue to treat individuals with dementia as passive participants of programs and research projects.

There is an urgent need to re-evaluate the approaches taken to build a dementia informed society that accepts dementia as one of the major causes of disability, and understands the importance of incorporating perspectives of people living with dementia into dementia care planning, services and policies targeted at improving outcomes for those diagnosed and their families.

Plenary Abstracts

Plenary 3: The science of risk reduction

Date: Friday, 11 December 2020

Time: 7:00AM - 9:00AM (GMT)

From FINGER to SINGER - the Singapore experience

Dr. Christopher Chen, National University of Singapore, Singapore

Abstract:

– Background and objectives of the study / Introduction

Multi-domain lifestyle intervention - combining healthy nutrition, physical activity, cognitive training and vascular risk factor management - may represent a promising therapeutic strategy for delaying frailty and cognitive decline. Hence, the Singapore Geriatric intervention study to reduce physical frailty and cognitive decline (SINGER) study aimed to establish the most appropriate multi-domain lifestyle interventions for Singaporean seniors, optimise recruitment procedures and thus provide a strong basis for a larger scale, randomised controlled trial testing the efficacy of these multi-domain lifestyle interventions in reducing cognitive decline and frailty.

– Methods

The SINGER pilot is a proof-of-concept feasibility study comparing the acceptability and practicality of two different combinations of interventions : the original FINGER intervention, and the modified SINGER intervention which was adapted to the Singaporean context. These interventions were in 4 domains: nutrition, physical exercise, cognitive training, and vascular risk factor monitoring. We aimed to recruit a total of 70 dementia-free elderly subjects with mild to moderate level of frailty, conduct 12-week group and individual training sessions at a hospital based centre, followed by 12-week self-managed home-based training sessions. Outcomes were assessed at 3 months and 6 months after randomisation.

– Results / Positive impact

The planning process and results of this study will be discussed together with plans for further studies in Singapore.

– Conclusions / Perspectives

It is important and possible to assess the feasibility of multi-domain lifestyle interventions in a multi-cultural setting

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Plenary Abstracts

Plenary 3: The science of risk reduction

Date: Friday, 11 December 2020

Time: 7:00AM - 9:00AM (GMT)

What policies might prevent dementia?

Prof. Gill Livingston, University College London, UK

Abstract:

The number of older people continues to rise, especially in low and middle income countries, as premature mortality decreases. However, while there are certainly more people living with dementia, the age specific incidence of dementia has fallen in many countries, while it has risen in others, thus suggesting that dementia can be modified. Decreases in dementia rates are probably due to educational, socio-economic, health-care, and lifestyle changes. Overall, there is growing evidence for many potentially modifiable risk factors for dementia, some of which we discussed in the 2017 Lancet commission on dementia prevention, intervention and care. These were education, hypertension, hearing impairment, smoking, obesity, depression, exercise, diabetes and social contact. . There is now, additionally, evidence for other risk factors and this has enabled us to complete new reviews, meta-analyses and a more comprehensive life-course perspective of dementia prevention which I will discuss here. Overall I will provide an updated overview of the evidence about the main potentially modifiable risk factors for dementia, including the evidence for interventions. I will discuss how risk varies in the lifecourse, including new currently unpublished evidence. I will discuss the concepts of communality and how this is important and differences in low and middle income countries The potential for prevention is high and this is particularly so in low and middle-income countries (LMIC) where more dementias currently occur.

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Plenary Abstracts

Plenary 3: The science of risk reduction

Date: Friday, 11 December 2020

Time: 7:00AM - 9:00AM (GMT)

Mind-ADmini - A multi-domain intervention to prevent progression to dementia: participants' experiences of being involved in the pilot.

Mr. Roman Szydlowski, Stockholm, Sweden

Abstract:

In this presentation, one MIND-ADmini participant from Sweden will talk about his experiences of taking part in a multi-domain lifestyle preventive intervention, the MIND-ADmini pilot study. The study is a European collaboration on prevention of Alzheimer's disease. MIND-ADmini is the first study to test the feasibility and adherence to a healthy lifestyle intervention for patients in the early stages of Alzheimer's disease. MIND-ADmini is a 6-months randomised controlled pilot-study adapted from the FINGER-study. The study is happening in 4 countries (Sweden, Finland, France and Germany). The multi-domain intervention is intensive and demanding, and so far 96 participants have enrolled. This presentation will explore the experiences from a man with newly diagnosed prodromal Alzheimer's disease who participated in MIND-AD pilot trial in Sweden. Examples will be presented of facilitators and barriers to participate and how the intervention was organized. The different areas explored will cover the multi-domain healthy lifestyle intervention adapted from the FINGER-model, which includes physical, cognitive, and social activities, healthy diet and monitoring vascular and metabolic risks.

Plenary Abstracts

Plenary 4: The journey: Diagnosis, treatment, care and support

Date: Friday, 11 December 2020

Time: 10:10AM – 11:35AM (GMT)

Making sense of detection of cognitive disorders: How early is early enough?

Dr. John Morris, Washington University, St. Louis, USA

Abstract:

Objectives: The AD8 informant-based screening instrument has been validated with molecular biomarkers of Alzheimer disease but has not yet been validated by the confirmation of neuropathological Alzheimer disease. A concise and accurate screening test for Alzheimer disease dementia can aid primary care physicians in detecting individuals in need of diagnosis and management. We compared the ability of the AD8 with other dementia screening instruments to detect neuropathologically-confirmed Alzheimer disease.

Methods: The longitudinal older adult cohort of the Knight Alzheimer Disease Research Center at Washington University in St. Louis includes 230 participants, ranging in age from 50-91 years at baseline, who later had neuropathological assessments confirming the presence of Alzheimer disease. Four dementia screening instruments, administered at the baseline assessment, were evaluated for their ability to predict Alzheimer disease: the AD8, the Mini-Mental State Examination, and subjective memory complaints in the participant, either self-reported or reported by the participant's informant.

Results: The average age of the cohort at baseline was 80.4 years; 48% of the cohort were women. All four instruments predicted future neuropathological Alzheimer disease. However, the AD8 demonstrated superior sensitivity and better combined Positive and Negative Predictive Values compared with the other three instruments.

Conclusion: Although all four screening instruments accurately predicted neuropathological Alzheimer disease, the AD8 had the greatest sensitivity. The characteristics of the AD8 are favourable for its use as a brief and accurate screening test for Alzheimer disease dementia.

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Plenary Abstracts

Plenary 4: The journey: Diagnosis, treatment, care and support

Date: Friday, 11 December 2020

Time: 10:10AM - 11:35AM (GMT)

Social customs, expectations and religion in shaping the care provided

Dr. Hamed Al Sinawi, Oman Alzheimer's Society, Oman

Abstract:

Dementia can be defined as a set of symptoms that includes a memory disorder and impairment in other cognitive functions, mood and other behavioral disorders. These symptoms have an impact on the person's ability to reason and adapt and disrupt social and relational daily life. As the disease progress, the person loses his ability to expresses their spirituality and practices their faith. This may be a source of distress to the person with dementia and their caregivers. Dementia is a global issue with more people around the world living with Dementia. Social customs, expectations and religion are an important element in dementia care and they vary among different communities, yet such concept remains an under-researched. For many faiths, religion is considered an important source for comfort helping the person with dementia and their caregiver accept the diagnosis and cope with the stressors that accompany the different stages of dementia. It also enables caregivers to provide care regardless of the different challenges. People who practice Islam, for example, consider dementia " God's will "that should be accepted yet this does not prevent the community from seeking treatment, because they believe that God enabled us to create treatment so we should use it. In other faiths, religious figures may act as a counselor to help ease the stress on the family. This talk will explore the role social customs, expectation and religious believes in determining the care provided to people with dementia.

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Plenary Abstracts

Plenary 4: The journey: Diagnosis, treatment, care and support

Date: Friday, 11 December 2020

Time: 10:10AM - 11:35AM (GMT)

How to build a human friendly environment

Mr. Michael Schmieder, Sonnweid AG, Switzerland

Abstract:

People with dementia have very different needs to their environment. This depends on the stage of the disease, but above all it has to be taken in account the different origin, the kind of socialization, the personal developing. A lot of different concepts exist how people realize their own environment.

Some important topics have to be considered when you talk about architecture and dementia:

- people with dementia have very different needs for their habitat
- a person with dementia is an aesthetically sensitive being.
- during the illness the needs to the environment change, because of that we need different concepts concerning the stage of the disease
- people in precious, beautiful environments perceive themselves as valuable
- a positive designed environment increase the well
- being and reduce conduct disorders
- employees prefer to work in a beautiful environment
- people with dementia need enough space to move and feel save
- avoid needless noise or eliminate it (noise, smell, hectic rush)
- The 4 elements air, water, terra, fire can be the base for people with dementia to perceive themselves better

The lecture is based on these principles and shows the various concepts and their architectural implementations using the example of Sonnweid in Wetzikon Switzerland and MaVida Park in Velden in Austria.

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Plenary Abstracts

Plenary 4: The journey: Diagnosis, treatment, care and support

Date: Friday, 11 December 2020

Time: 10:10AM - 11:35AM (GMT)

Getting a dementia diagnosis and caregiving resources in Africa

Dr. Violet Okech-Helu, Kenyatta National Teaching and Referral Hospital, Kenya

Abstract:

Healthcare systems and services in African countries have improved greatly over the last few decades. Many Africans now enjoy longer lifespans in the context of increased urbanization and a shift from traditional foods to Western style diets. Kenya, in East Africa, has a rising population of people aged sixty-five years. A significant proportion of the ageing population are starting to experience dementia.

The author is a Consultant Psychiatrist and Counsellor at Kenya's largest teaching and referral hospital, KNH. She highlights the early signs and symptoms that alert families in this context about possible dementia in their loved ones and common pathways to care. She also examines the resources available and gaps in practice and policy that could enhance the quality of life for people living with dementia in the African context.

Violet has been a dementia caregiver herself, to her late mother, Dementia Warrior, Turfena Awuor Okech. Dr. Okech-Helu currently serves as the pioneer Dementia Ambassador to ADI, for Kenya Psychiatric Association.

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Plenary Abstracts

Plenary 5: Hope springs on solid foundations: Research, innovation, data and information systems

Date: Saturday, 12 December 2020

Time: 7:00AM - 8:30AM (GMT)

National Dementia Plan of Korea. Past 15 years, and coming 5 years.

Seong Yoon Kim, Asan Medical Center, Department of Psychiatry, Republic of Korea

Abstract:

As in the case of other developing countries, the number of the elderly population in Korea has been rapidly increasing for the last 20 years. The Korean government, therefore, has been working hard with healthcare experts to establish a comprehensive, and cost-effective national dementia plan for the elderly for a long time.

In this session, the development history of Korean national dementia plans and their achievements of the past 15 years will be given briefly, and new features of the 4th National Dementia Plan (2021 ~ 2025) will be introduced. This long term national plan and its implementation would have not been possible without the support and booster effects of the "Dementia Management Act" (2012) or "National Responsibility for Dementia" declaration in 2017.

Several unique features in Korea also played a major role in establishing and implementing the National Dementia Plan development. One of them is the obligatory public medical insurance system which started in 1977, though fully established in 1989. By mandating people to join the national medical insurance system for more than 30 years, the government now has a very big and detailed picture of every illness, help seeking pathways, medical expenditures. Another important drive for the National Dementia Plan was the blossoming of Regional Dementia Support Centers driven by local governments of Korea in the early 2000's. These regional dementia support centers were enthusiastic in educating, preventing, and heightening the awareness about dementia, as well as early detection of the illness in the community. They acted like a connecting hub between the community and the medical hospitals or elderly care centers.

By sharing this experience of our dementia care policies, I hope we can build a more effective dementia prevention, treatment, and care system around the globe.

Plenary Abstracts

Plenary 5: Hope springs on solid foundations: Research, innovation, data and information systems

Date: Saturday, 12 December 2020

Time: 7:00AM - 8:30AM (GMT)

Hope: Oops!, there goes another rubber tree plant.

Eileen and Dubhglas Taylor, Dementia Alliance International (DA), Australia

Abstract:

<center>Hope: Oops, there goes another Rubber Tree Plant. </center>

<center>Eileen M Taylor and Dubhglas A Taylor </center>

As the Frank Sinatra's song Lyrics go:

<center>Next time you're found, with your chin on the ground
There a lot to be learned, so look around
Just what makes that little old ant
Think he'll move that rubber tree plant
Anyone knows an ant, can't
Move a rubber tree plant
But he's got high hopes, he's got high hopes
He's got high apple pie, in the sky hopes
So any time you're gettin' low
'Stead of lettin' go
Just remember that ant
Oops, there goes another rubber tree plant</center>

According to Greek Mythology, Prometheus, a fire god and divine trickster, steals fire from heaven and bestowed it upon mortal mankind. Zeus, the king of the gods, is not too happy with this and chains Prometheus up and add one more punishment, the worst thing he can think of: Woman. (This is definitely, pre-feminism).

The vengeful leader of the gods, Zeus gives the woman, Pandora (Lit. gifts) to Epimetheus, Prometheus's brother as a bride. His wedding gift is a jar (later a box) full of everything terrible that one can possibly imagine and tells her never to open it. So, guess what she does? Yeah, she opens it. And hey presto all kinds of terrible plagues, afflictions and diseases (the top ten currently are – Ebola Virus, Alzheimer's Disease, HIV – AIDS, Necrotizing Fasciitis, Lung Cancer, Multiple Sclerosis, Smallpox, Bubonic Plague, Parkinson's Disease, and Huntington's Disease, to name a few) released onto mankind.

Only one thing remains in the jar – wait for it – HOPE!

Not to undermine any of these devastating conditions or others (including poverty, war and terrorism, broken relationships, myriads of abuse, racism, pollution, etc.) our focus today is on Dementia (including Alzheimer's and myriad of other dementias).

Neurological Researchers are wanting to provide this ideal of Hope for the many people living with dementia and their families. Together, these world scientific leaders have gained some understanding of the dementias and the structures involved, it is HOPED that ongoing research may lead to new ways to understand the cause(s) of the disease, diagnose, treat, or perhaps prevent or block disease development.

Research is an important part of our modern world and particularly in medical and social research

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offering the promise of hope. For people living with a dementia and their care partners and families, we live in hope. Hope for a CURE and Hope for better CARE for people living with dementia!

I'd like to share a bit about my journey and experiences about being a participant in clinical dementia research and how it drove me to pursue the ideal of Hope.

I wish I'd said it first. "Hope – Hope in the face of difficulty. Hope in the face of uncertainty. The audacity of hope! In the end, that is God's greatest gift to us... A belief in things not seen. A belief that there are better days ahead!" Barack Obama.

On our Dementia Awareness Advocacy Team's (DAAT) Facebook page our page standard was:

HOPE... Is powerful, It's Real... It's all we have...

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Plenary Abstracts

Plenary 6: COVID-19 and dementia panel discussion

Date: Saturday, 12 December 2020

Time: 8:35AM - 9:35AM (GMT)

Doing dementia differently

Jason van Genderen, Australia

Abstract:

How one family living with dementia used the power of storytelling to bring over 50 million people into their home!

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Plenary Abstracts

Plenary 6: COVID-19 and dementia panel discussion

Date: Saturday, 12 December 2020

Time: 8:35AM - 9:35AM (GMT)

Advocating in the time of pandemic – the French experience

Lorene Gilly, France Alzheimer and related diseases, France

Abstract:

Sharing France Alzheimer's experience regarding the visits in the nursing homes, the continuity of care, the closure of respite facilities and the consequences of the main governmental safety measures including police fines and the recognition of cognitive impairment.

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Plenary Abstracts

Plenary 6: COVID-19 and dementia panel discussion

Date: Saturday, 12 December 2020

Time: 8:35AM - 9:35AM (GMT)

Worst hit: dementia during Coronavirus

Fiona Carragher, Alzheimer's Society, UK

Abstract:

A summary of Alzheimer's Society's globally received impact report; 'Worst Hit: dementia during coronavirus'. This report provides an in-depth analysis of how people affected by dementia in England and Wales have been hardest hit by coronavirus, and examines what needs to be done in the future to ensure the same tragedies do not happen again.

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Plenary Abstracts

Plenary 6: COVID-19 and dementia panel discussion

Date: Saturday, 12 December 2020

Time: 8:35AM - 9:35AM (GMT)

Dementia and Covid 19: the use of new and old resources to face future challenges

Mario Possenti, Federazione Alzheimer Italia, Italy

Abstract:

The SARS CoV-2 pandemic has highlighted the shortcomings of our social and health system. Those who are in conditions of greater fragility, and among them people with dementia, have had to face a very difficult period, often alone or without the necessary aids. From this situation we must learn new approaches and recover the forgotten ones to enhance the resources present in all territories so as to create proximity networks that can support those living with dementia.

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Plenary Abstracts

Plenary 6: COVID-19 and dementia panel discussion

Date: Saturday, 12 December 2020

Time: 8:35AM - 9:35AM (GMT)

Reflections in a pandemic world

Jason Foo, Alzheimer's Disease Association (ADA), Singapore, Singapore

Abstract:

Since the start of the COVID-19 pandemic in 2020, the Alzheimer's Disease Association (ADA) in Singapore has faced new and multiple challenges during the course of serving the needs of people with dementia and their caregivers amid a global crisis.

The pandemic saw fresh, heightened and acute needs for support among the dementia community. The lockdown also dealt major disruptions to ADA's operations. The global economic impact meant their revenue took a big hit as well, with much less resources to go around to sustain their programmes and services.

In this session, ADA's CEO, Jason Foo, will share his organisation's journey of self-discovery in those initial months of the pandemic, and how his organisation – despite the steep learning curve – used the opportunity to innovate and discover new approaches to doing things going forward.

Plenary Abstracts

Plenary 7: Supporting those who care

Date: Saturday, 12 December 2020

Time: 11:45AM - 1:15PM (GMT)

Challenges of converting economic evidence into better policy and practice

Prof. Martin Knapp, London School of Economics and Political Science, UK, UK

Abstract:

Growing numbers of people living with dementia are prompting governments and other decision-makers to look for responses – whether prevention, cure or care – that are effective, fair and affordable. This leads them to look carefully at economics: what does dementia cost, what resources are needed to deliver good interventions, and do they represent best use of scarce resources?

I will briefly summarise why decision-makers need to understand the economics of their actions, and then highlight common challenges of moving from evidence to recommendations to action to impact. I will discuss some ways around those challenges.

The first challenge is simply insufficient evidence. Despite rapid recent growth in cost-effectiveness and related studies, many areas remain unexplored, especially in low- and middle-income countries. Even when evidence exists, it may not be robust enough to support reliable policy or practice; or it may not be transferable from the context in which it was gathered (e.g. a study in a large US city) to other contexts (e.g. a rural area in sub-Saharan Africa).

An intervention may look effective for people living with dementia or carers, but simply be unaffordable: there is not enough money or enough trained staff. Current excitement about disease-modifying medications will quickly be tempered if few people can afford them. Relatedly, apparent savings found in research might not be 'cashable' in the real world: effective support for carers might reduce their time inputs (to which economic evaluations often attach monetary value), but not actually release resources transferable to other uses.

A further challenge is linked to budget silos. Effective interventions might have big consequences for other sectors or budgets; for example, spending by the health sector could lead to savings in social care, or allow family carers to maintain their paid employment. These disjunctions can create disincentives to choose the most efficient overall course of action.

Some economic effects of dementia and responses to it may get missed, including impacts on the health and wealth of family members and other unpaid carers. Although less 'visible', these impacts may nevertheless be pivotal in shaping lives and generating wellbeing.

Economic consequences spread across more than one budget year can also create difficulties for organisations that need to 'balance the books' every 12 months. Elected governments are often reluctant to allocate scarce resources for benefits only seen in the distant future: their horizons are often confined to electoral cycles.

Responses to overcome these challenges can be of various kinds. They require: action from the research community; coordinated, cross-sector, cross-departmental strategy from government; recognition of the plight of marginalised communities and individuals, even in universal health and care systems; and ways to encourage investment across budget 'silos' and for the long term.

Plenary Abstracts

Plenary 7: Supporting those who care

Date: Saturday, 12 December 2020

Time: 11:45AM - 1:15PM (GMT)

Celebration of caregiving in dementia: Beyond burden to mastery

Dr. Wee Shiong, Lim, Institute of Geriatrics and Active Aging, Tan Tock Seng Hospital, Singapore

Abstract:

There are only 4 kinds of people in the world: those who have been caregivers, those who are currently caregivers, those who will be caregivers, and those who will need caregivers. In many countries, family caregivers remain the cornerstone of care for persons with dementia (PWD), with foreign domestic workers increasingly assuming this role in many Asian societies. Ensuring the continued sustainability of this informal care system is critical, as it provides a viable and precious resource that represents the only "workforce" of sufficient size and distribution to meet the projected burgeoning care demands of PWD. The travails of caregiving are well documented and have been likened to a hero's journey with three major transitions: Crossing the threshold to assume the caregiver role; trudging on the caregiver journey; and settling into a new normalcy. Caregivers have to contend with myriad psychological, physical, financial, and social stressors and not surprisingly, not all may emerge victorious on the hero's summit in the caregiving journey. Prior studies in diverse Asian and Caucasian populations that examined the factor structure of Zarit Burden Interview have consistently depicted the three key dimensions of role strain, personal strain, and worry about performance (WaP). Specifically, WaP remains an under-emphasized form of burden that ranges from "inadequacy" and "worry" through to more severe degrees of "self-criticism" and "guilt." The emerging construct of caregiver grief has been described as a key challenge faced by family caregivers in a recent systematic review. Grief response to losses in the caregiving context has been shown to exert an independent effect above and beyond burden on baseline and longitudinal caregiver depression. In contrast, mastery focuses on the extent to which one's life is regarded as being under one's control. It is a robust, malleable, potentially translatable and underutilized construct which can reduce the deleterious impact of caregiving stress. This plenary will provide an evidence-based exposition of recent insights into caregiving burden; caregiver grief; the complementary and potentially protective resource of mastery; and how we can translate these insights into daily practice to promote mastery and transformational growth in the caregiving learning journey. The talk will end with a haiku that pays tribute to the worldwide community of caregivers who are like "twinkling stars in the dark night, lighting up our days."

Plenary Abstracts

Plenary 7: Supporting those who care

Date: Saturday, 12 December 2020

Time: 11:45AM - 1:15PM (GMT)

Namaste Care program for maintaining quality of life in advanced dementia

Ms. Joyce Simard & Prof. Ladislav Volicer, University of Western Sydney, USA

Abstract:

Background and objectives of the study: People with advanced dementia are often unable to attend activities in care homes. They may be isolated in their rooms or sitting in the corridors or placed in front of a television set. Namaste Care is a program developed for people with advanced dementia that provides meaningful activities that enhance their quality of life.

Methods: There are two main principles of Namaste Care (1) Namaste Care takes place in a space that is free from distractions as possible, lights are lowered, relaxing music is playing, and the scent of lavender permeates the room. (2) A unhurried loving touch approach is used in all interactions with the person and activities of daily living (ADLs) are offered as meaningful activities. This program was designed for people with advanced dementia, who cannot participate in traditional activities. People in care homes are placed in reclining chairs, assessed for pain and warm blankets are tucked around them. The loving touch approach is provided by the Namaste carer who gently massages the persons' hands, arms and legs. Hair is lovingly brushed. The carer is not wearing gloves and is gently speaking to the person as they are being offered these meaningful activities.

Positive impact: People with advanced dementia become used to being touched and when they are not in the Namaste Care program, they rarely reject care. The calm environment and loving touch improve communication, decrease agitation and improve symptoms of depression. Namaste Care allows decrease of psychotropic medications and increases job satisfaction of caregivers. Families are encouraged to participate in Namaste Care and studies find that they visit more often and are more satisfied with the care that is provided. Namaste Care helps families, who often feel helpless, to get involved with their relatives as the Namaste Carer teaches them how to offer hand massages or read favourite poems or bible passages to them..

Perspectives: Namaste Care was developed for the person who lives in a care home however it can also be taken to the bedside and offered individually. Many hospices are offering the loving touch and creating a calm environment wherever the patient is living, at home in a care home or an inpatient hospice unit. This program is provided until the person dies. Namaste Care can be implemented without additional staff and with very limited expenses. It is now offered in 11 countries.

Oral Presentation Abstracts

ID: 134 / OS26: Diverse populations

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Dementia, Marginalised communities, Stigma, Prison, Dementia awareness\

Prioritising prisons and dementia? Exploring the double stigma of people with dementia in prisons

Sophie Nadia Gaber, Birgit Heuchemer

Karolinska Institutet, Sweden

Abstract:

Background: Every three seconds a person is diagnosed with dementia. However the experiences of people living with dementia or memory issues, and even their existence, in prison or forensic institutions, remains largely unknown. Age is a primary risk factor for dementia and research indicates that prison populations are ageing to mirror ageing trends in the general population. Furthermore, due to the complexity of caring for older people with multiple physical and cognitive health issues, a prisoner aged 50 years or over, costs three times as much as a younger prisoner. This compels both a fiscal but also an ethical imperative to raise awareness about people with dementia or memory issues in prisons and forensic institutions.

Objective: To explore the experiences of older people living with dementia or memory issues in prisons or forensic institutions in Sweden and the UK.

Results: Interviews with older ex-prisoners, as well as professionals working with prison and forensic populations, shed insight into the “double stigma” of living with dementia and memory issues in prison. Prisons were described as being “built for young people” which intensified the challenges of ageing in prison, especially among females. Prison life was compared to “Groundhog Day” due to the lack of cognitive and social stimulation or orientation in one’s surroundings. Specific social, environmental, physical, and cognitive factors in prison were identified as potential risk factors for the development of dementia as well as the perpetuation of the stigma of living with dementia. The risk factors are in opposition to the recommendations based on research to prevent dementia and to reduce cognitive decline.

Conclusion: People living with dementia and memory issues in prison or forensic institutions remain a marginalised population who are at risk of intense stigma. Consequently, it is important to learn about the existence of this population and their experiences in order to promote effective dementia diagnosis and care, in addition to minimising stigma.

Oral Presentation Abstracts

ID: 135 / OS20: Dementia friendliness

Abstract Topic: Dementia friendliness

Keywords: Dementia, Social participation, Technology, Dementia-friendliness, International

Exploring participation of older people living with and without dementia in Sweden and the UK

Sophie Nadia Gaber¹, Louise Nygård¹, Anna Brorsson¹, Anders Kottorp^{1,2}, Camilla Malinowsky¹

¹Karolinska Institutet, Stockholm, Sweden; ²Malmö University, Malmö, Sweden

Abstract:

Background: Globally approximately 50 million people live with dementia. In both Sweden and the UK, the majority of people with dementia live in the community with ever-increasing opportunities to participate in activities at home and in public space. According to the Convention on Human Rights of Persons with Disabilities (CRPD), people with disabilities including dementia have the right to participate in all aspects of society. However expanding opportunities to participate in society require engagement with an increasingly complex technological environment. Sweden has among the highest rates of technology use among over 65-year-olds. This research sheds new insight into the potential of technology to be a facilitator to participation but also an exacerbator of the “digital divide”. This is aligned with the UN Sustainable Development Goals which seek to “leave no one behind”.

Objective: To explore how patterns of participation in public space relate to access and use of Everyday Technologies.

Methods: In Sweden and the UK, people living with mild dementia (n=99) and people with no known cognitive impairment (n=98) were interviewed using structured questionnaires, to explore the access and use of a range of Everyday Technologies e.g. kettle, smartphone, self-service check-out, public transportation, and to map participation in public space. Analyses were undertaken using classical and modern test theory.

Results: Based on the Swedish and UK samples, both people with and without dementia use a range of Everyday Technologies and participate in activities and places in public space, albeit in different ways. The results indicate specific places (for leisure activities) and technologies (portable technologies e.g. Smartphones, Tablets) that may benefit from being adapted to facilitate a more accessible and sustainable society, in accordance with the CRPD. A short film was developed based on the findings to capture the journey of an older person living with dementia as they participate in places and activities in Stockholm, encountering the real-life challenges and opportunities of using ET in public space.

Conclusion: The research, including the short film, contribute knowledge about the participation, including digital participation, of older people living in Sweden and the UK, in order to provide an evidence-based context for the development of age- and dementia-friendly technologies, as well as health and social care interventions.

Oral Presentation Abstracts

ID: 141 / OS13: Dementia and public policy I

Abstract Topic: Dementia policies and public policy

Keywords: #centarzademenciju, #demencijaubih, #nacionalniplan, #sarajevskaizjavaodemenciji

Sarajevo statement on dementia in western Balkan countries – example of regional cooperation and challenge for policy makers

Osman Kućuk

Alzheimer Association A&R / Alzheimer Udruženje AiR, Bosnia and Herzegovina

Abstract:

Introduction

Western Balkan Region, in the last 30 years, had have focus on developing of the national states and passed through the period of war. That fact is in the all established states had have impact on the creating of health and social policy which in the focus of their care and financial alloactions puts „war veterans and invalids, civilian victims of war, families whose male member are missing, childrens without one/both parents“. This group bind for theirselves the all health and social state resources. On that way, state policy, make compensation for their non-creativity in creating of better and more righteous society with opportunities for that group of society. The fact that at the same time dementia has become an epidemic of all newly-established societies goes unnoticed. The state systems and different institutions are absolutely not prepared to face with dementia which they "push under carpet". They don't develop the new policies and not creating the new solutions and on that way, they complicate already hard situation and position of PwD. In that clime is very hard talk and is still harder work on the dementia field.

Topic

Presenting of Sarajevo Statement which is originated as result of meeting on the high level where participated: WHO Regional office for Europe, Government representatives from Western Balkan States, experts and NGO under patronate of ADI and in organization of Alzheimer Association AiR. This is an historic document which originated on base "Global action plan on the public health response to dementia 2017-2025". Declaration defined dementia as a public health and social challange of Western Balkan societies and seek sistematic support which need to be implemented through three linked approaches: policy, service delivery and information and research. The goal of Sarajevo Statement is to give tool to all stakeholders in promotion of dementia and in developing of National Dementia Plans(NDP) through the authority support of ADI and WHO and their endeavor that the all countries in the world adopt NDP till 2025. and using of positive possibilities in WB Region created by the close cooperation of experts and NGO's how they could change trends and include dementia issue in the health and social system in the all societies and initiate the common solutions or initiate competition between WB countries to make better solution through adoption of NDP.

Conclusion

As result of Sarajevo declaration, today BiH has:the medications for dementia is free of charge, the state changed view on PwD and in the procedure is new classification where dementia will be bearer of disability, mixed working group prepare document "Program of doing on dementia field" which will be official Government document to adopting of NDP which will be part of a wider strategy as "Strategy on public health".

Oral Presentation Abstracts

ID: 144 / OS28: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: Caregivers, Dementia, Family

Perceptions and experiences of family caregivers in caring for a person with dementia in Brunei, a country with collectivistic family values

Fang Lien Foo¹, Asmah Husaini¹, Deeni Rudita Idris¹, Shyh Poh Teo²

¹Universiti Brunei Darussalam; ²RIPAS Hospital, Brunei Darussalam

Abstract:

Background: Dementia affects cognition and function, resulting in increasing dependence on caregivers. Although patients may experience negative feelings towards the diagnosis, caregivers also have their share of impactful changes to psychological and physical states. **Objectives:** To explore family caregivers' perception and experiences in caring for a person with dementia in Brunei Darussalam, a country which emphasizes collectivistic family values and filial piety.

Design: Qualitative research guided by phenomenological approach that sought to provide insight to the experience of caring for family members with dementia.

Methods: Individual in-depth semi-structured Interviews were conducted, which were audio recorded, transcribed and analyzed thematically.

Results: 5 family caregivers were interviewed. Three themes emerged: (i) 'Care... not a choice', (ii) 'Being with 'dementia'', and (iii) 'Just have to deal with it'. Caregiving was viewed as a non-negotiable family commitment in the study's cultural setting, which was influenced by social factors, such as lack of alternative long term care services for people with dementia. The themes explored the impact of caregiving and dementia on family dynamics and personal self. Caregivers' perceptions and feelings towards the loss of the person's old self and methods for coping were evidenced by avoidance of the diagnosis and consequences of dementia.

Conclusion: Family caregivers in collectivistic cultures like Brunei experience lack of family support and have poor understanding of dementia, leading to a distressing experience. This signifies the need for community-based interventions to improve family support and considering development of additional formal support services for people with dementia.

Oral Presentation Abstracts

ID: 145 / OS10: Design, architecture and the built environment I

Abstract Topic: Environment and architecture for dementia

Keywords: community, participation, destination, mobility

Participation in the community among people with and without dementia: destinations and perceptions of challenges

Habib Chaudhury¹, Tanveer Mahal², Kishore Seetheraman³

¹Simon Fraser University, Canada; ²University of Sydney, Australia; ³Simon Fraser University, Canada

Abstract:

Background and objectives of the study: Availability of community-based destinations and amenities can facilitate healthy aging by supporting older adults' functional abilities and enabling their participation in society, especially for those experiencing declining cognitive, mental, social and physical capacities. Older adults with dementia face challenges in their outdoor mobility and there are concerns of their not being able to continue going outside for everyday activities and social participation. The objective of this study was to identify patterns of visits to community destinations and activities, and perceptions of risks.

Methods: This study used a survey tool called ACT-OUT (participation in ACTivities and places OUTside the Home for older adults), specifically designed to examine the out-of-home-participation of older adults living with or without dementia, to collect data on specific places and activities that individuals participate in over time. Thirty (30) cognitively intact participants and 29 participants with dementia were recruited in Vancouver, Canada.

Results: Findings indicate that participants with dementia had abandoned visiting a few places over time (e.g., bank, cemetery, buildings of worship), whereas there were no change in participation in taking transit to destinations such as supermarkets, entertainment and cultural places. Both group of participants were most likely to abandon recreation and physical activity places, although a greater number of persons with dementia reported that they would likely abandon these places in the future than cognitively intact participants. Medical care settings were the next most likely domain of destinations to be abandoned by persons with dementia.

Positive Impact and Conclusion: This study adds to our understanding of the out-of-home places visited by persons living with and without dementia and the patterns of changes in those visits over time. The findings of this study will be useful for health and social care professionals including occupational therapists, social workers, as well as family caregivers, in recognizing the relative importance of certain out-of-home places and activities over others and the challenges faced by persons with dementia in getting to those places. The findings can also inform program and service providers to develop targeted interventions to support continued engagement by older adults with dementia and cognitively intact older adults.

Oral Presentation Abstracts

ID: 146 / OS09: Cognitive reserve

Abstract Topic: Cognitive reserve, brain resilience and dementia prevention – NEW

Keywords: Group exercise · Social engagement · Multi-tasking · Executive function · Memory

Multi-year square dancing is associated with superior executive function but not memory in middle-aged and older Chinese women: a propensity score matching analysis

Jing Liao^{1,2}, Yung-jen Yang³, Dong Xu²

¹Department of Medical statistics, School of Public Health, Sun Yat-sen University; ²Sun Yat-sen Global Health Institute, Institute of State Governance, Sun Yat-sen University; ³Taiwanese Society of Geriatric Psychiatry

Abstract:

Background: Evidence to date has suggested the critical roles of physical activity and social engagement in cognitive preservation. Group-based dancing that combines exercise and prosocial features may generate physical and cognitive benefits.

Objectives: Our study investigated the association between multi-year habitual square dancing and domain-specific cognitive function, and the relative importance and joint impact of physical activity and social activity on cognition.

Methods: Using the propensity score matching method, we compared executive function, episodic memory and overall cognitive performances of 145 amateur female square-dancing participants (aged ≥45 years), to their sociodemographic and health status matched 222 non-dancing counterparts, selected from the China Health and Retirement Longitudinal Study.

Results: We found a positive association between multi-year square dancing (average eight years) and overall cognitive performances (Average Treatment Effect (ATE)=2.84, 95% CI: 1.65, 4.02), which was apparent in executive function (ATE=2.29, 95% CI: 1.51, 3.07) but not in memory (ATE=0.55, 95% CI: -0.13, 1.23). The hypothesized synergic effect of physical activity and social activity on cognition was only observed in group-based exercises that combined these two components simultaneously.

Conclusions: The widely accepted and low-cost square dancing may be an ideal candidate for cognitive preservation, especially for executive function of older adults.

Oral Presentation Abstracts

ID: 147 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: information needs, diagnosis, Memory Clinic

Exploring the information needs of people with mild dementia and their care partner, post-diagnosis at a new Zealand memory clinic.

Lara Suzanne Hitchcock^{1,2}

¹University of Otago; ²Canterbury District Health Board, New Zealand

Abstract:

Background: It is essential that information needs are met throughout the dementia continuum to improve the quality of life of both the care partner and person with dementia. A crucial information opportunity is soon after diagnosis to enable both parties to make sense of the diagnosis and plan for the future. Limited research exists on identifying the information needs of people living with dementia and their care partner post-diagnosis of dementia, particularly from the perspective of the person with dementia, and there has been none identified involving a New Zealand Memory Clinic.

This study aimed to explore the information needs of people with dementia and their care partner, and their experience of gaining verbal and printed information following the diagnosis of dementia at a Memory Clinic. The broader objective is to use the findings to inform clinical practice.

Methods: This study utilised the qualitative Appreciative Inquiry research framework. The sample was randomly selected and comprised of six dyads of people diagnosed with dementia who attended a Memory Clinic in 2016 and their care partners. Data were collected through one-to-one semi-structured interviews and thematically analysed.

Results: The attitudes of the healthcare professional had a positive or negative effect on how care partners experienced receiving information. The healthcare professional's attitude was less of an issue for the person living with dementia; however, the person with dementia valued being given information in a clear and easy to understand way. Information needs are individual regarding amount, format and environment, but a strong theme was that more information is needed about progression at the mild stages of dementia, to allow the person to plan for the future. Care partners highlighted the stress they were under and, despite finding the local dementia organisation beneficial for support and information, there was a need for ongoing Memory Clinic follow-up.

Conclusions: This study contributed to the minimal research available and identified that people living with dementia and their care partners have individual information needs, and that it is essential to be flexible and responsive to meet these needs to enable the person with dementia to live well. Some people living with dementia want more information on their diagnosis; however, many are reliant on their care partners for information. Healthcare professionals also need to be aware that many care partners of those in the mild stage are experiencing significant carer stress and need ongoing, face-to-face contact and information post-diagnosis, to enable them to meet and respond to the changing needs of the person living with dementia throughout the continuum.

Oral Presentation Abstracts

ID: 151 / OS10: Design, architecture and the built environment I

Abstract Topic: Environment and architecture for dementia

Keywords: guidance document, elderly- and dementia-friendly, environment, features, Singapore

Developing a guidance document on elderly- and dementia-inclusive environment in Singapore

May Yeok Koo

Nanyang Polytechnic, Singapore

Abstract:

Singapore is faced with a fast ageing population. Between 2020 to 2030, the number of people aged 65 years and above in Singapore will triple. Those who are aged 60 years and above will increase two-fold from 19.5% (1.1 million) in 2017 to 40.1% (2.6 million) in 2050 (United Nations, 2017). Of this, 1 in 10 people who are 60 years old and above has dementia (Subramaniam et al 2015). This has significant impact on intergenerational families as most elderly persons and people with dementia are still cared for at home by their families.

Arising from the aforementioned, the Elderly- and Dementia-Friendly HDB Review Team comprising Alzheimer's Disease Association (ADA), Housing and Development Board (HDB) and Nanyang Polytechnic (NYP) was formed in July 2018 to develop a document which is based on a series of focus group, site visits and literature review aimed to provide guidance on elderly- and dementia-inclusive features; covering both the internal (apartment) and the external environment. The team hopes to make meaningful use of the valuable inputs and contributions from the different stakeholders (e.g. persons with dementia, informal and formal caregivers, public officers and private organizations) in paving the way for a more elderly- and dementia-inclusive Singapore.

Oral Presentation Abstracts

ID: 155 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: Lived experience, living well, identity, barriers

This is our story : Aotearoa/ new Zealand experiences of living with dementia

Catherine Hall

Alzheimers New Zealand, New Zealand

Abstract:

Background:

The voice of people living with dementia about barriers to living well and support that works is fundamental to health/social policy and service development. Current services in Aotearoa/ New Zealand have, in the main, been informed by health professional and policy makers perspectives. Evidence is needed on what works to support people through diagnosis, learning about dementia, access to services and life choices.

Methods

The aim of the research was to understand the lives of people living dementia and how their experiences were influenced by their family, community and the wider New Zealand society. This presentation reports themes from interviews with 49 people who have been diagnosed with dementia and family carers. An advisory group of people living with dementia guided the research process. The multi-stage thematic analysis process involved people living with dementia.

Results

People living with dementia talked about the challenges and frustrations of the diagnostic process with criticism of primary health providers knowledge about dementia and of the support available. A meaningful life became something to work towards rather than being taken for granted. Personal identities, individual and family, were redefined, relationships with friends changed at times, independence was valued and new roles adopted. Barriers to support services included lack of knowledge of what was available and the service flexibility to meet diverse needs culturally and related to stage of dementia. There was increased stress for families as the dementia progressed and relationships and roles changed accordingly.

Conclusions

The findings that people with dementia struggle to access appropriate health and support services and function in disabling environments make an important contribution to Alzheimers New Zealand advocacy work. A Dementia Declaration: Our Lives Matter has been developed by Alzheimers New Zealand Advisory Group

Oral Presentation Abstracts

ID: 163 / OP2: Dementia and the equitable society

Abstract Topic: Dementia and equitable society – NEW

Keywords: migration, EU, dementia, dementia strategy, prevalence

People with dementia and migration background - a comparative description of their situation in the EU

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¹German Center for Neurodegenerative Diseases (DZNE), Germany; ²University Medicine Greifswald, Germany

Abstract:

Background. The proportion of elderly people with migration background increases, therefore it can be assumed that the proportion of people with migration background and dementia will increase as well. So far, there are no prevalence data for dementia and migration on an European level and it is not known how countries in Europe target the topic of dementia and migration in their national dementia strategies and migrant organizations as well as in national guidelines for diagnostic and therapy.

Research question. Prevalence data on dementia and migration will be determined for the 28 EU and 4 EFTA member states. Guidelines regarding diagnosis, treatment and care, national dementia strategies, health care services, communities and migrant organizations will be evaluated regarding dementia and migration.

Method. Prevalence data will be estimated based on dementia prevalences of the countries of origin. Interviews with experts, literature analysis, Delphi-Panels and expert workshops will be used to analyse guidelines, national dementia strategies, health care services, communities and migrant organizations.

Expected results. An extensive collection of information about dementia and migration in the different EU-countries, depicting prevalences, guidelines on therapy and diagnostic, health care services and dementia as a topic of interest in migrant organizations will be provided. From this collection the EU-Atlas on dementia and migration will be created.

Discussion. Obtaining this information can help to uncover gaps in the health care systems and communities on an European level. This can serve as a starting point to see where action must be taken and may therefore lead to better health care for people with migration background and dementia.

Oral Presentation Abstracts

ID: 170 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: Hearing impairment, low- and middle- income countries (LMICs), dementia, psychiatric epidemiology, 10/66 Dementia Research

Hearing impairment and dementia in later life: 10/66 cohort study

Ji Hee Kim^{1,2}, Matthew Prina¹, Anamaria Brailean¹

¹King's College London; ²London School of Hygiene and Tropical Medicine

Abstract:

Background

Evidence on the association between hearing impairment and incident dementia is emerging. The current study aims to investigate on the prevalence of hearing impairment, its correlates, and the association between hearing impairment and incident dementia in low- and middle- income countries (LMICs).

Methods

Age and gender standardized prevalence of hearing impairment was determined for Cuba, Dominican Republic, Puerto Rico, Peru, Venezuela, Mexico, and China as a part of the 10/66 Dementia Study). The cross-sectional association between hearing impairment and potential correlates was studied for seven LMICs. The pooled effect estimates of the association between hearing impairment and the correlates across the countries were analyzed. The longitudinal relationship between hearing impairment at baseline and incident dementia was explored.

Results

Based on cross-sectional analyses, the standardized prevalence of hearing impairment was diverse across countries, ranging from 9.8% and 21.3%, and the prevalence was higher later in life for both males and females in all countries. Based on the meta-analysis of cross-sectional data, older age (70-74: OR 1.29, 95% CI 1.11-1.50, $I^2=0\%$; 75-79: OR 1.89, 95% CI 1.62-2.19, $I^2=62.3\%$; 80+: OR 3.08, 95% CI 2.66-3.58, $I^2=76.2\%$), male (OR 1.44, 95% CI 1.30-1.59, $I^2=42.0\%$), depression (OR 2.21, 95% CI 1.83-2.67, $I^2=0.0\%$, $I^2=0.0\%$), diabetes (OR 1.18, 95% CI 1.04-1.33), heart problems (OR 1.31, 95% CI 1.17-1.47, $I^2=6.5\%$), and dementia (OR 1.50, 95% CI 1.29-1.74, $I^2=20.4\%$) were associated with hearing impairment. The longitudinal analyses revealed positive association between hearing impairment and incident dementia, particularly in male participants (HR 1.67, 95% CI 1.31-2.14, $p<0.001$).

Conclusions

This study showed that hearing impairment increases the risk of incident dementia, emphasizing the importance of hearing health among older adults. Future studies on the long-term effects of hearing aids use as a potential intervention for cognitive decline and dementia risk reduction is recommended.

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Oral Presentation Abstracts

ID: 174 / OS33: Psychosocial interventions

Abstract Topic: Psychosocial interventions

Keywords: inter-generational programs, nursing home

One tribe, one space – the art of authentic inter-generational interactions

May Wong, Imelda Anthony

St Joseph's Home, Singapore

Abstract:

This presentation attempts to share the learning gained from developing and improving the quality of the inter-generational programs (IGPs) within a nursing home in Singapore. We are a nursing home that pioneered a co-located infant and childcare centre in 2017 in Singapore. Using three existing programs run by the allied health services department and the infant and childcare centre, we evaluated the structure and impact of these three IGPs when we first began and compared it to how we are currently improving upon them. We will share the lessons learnt by the two teams involved in IGPs and the elements we believe will strengthen the quality of our current and future IGPs. The three chosen IGPs are storytelling, creative art and physical exercise. All programs have common outcomes for both children and elderly – building and supporting language and listening skills, motor skills and creative and aesthetic expression. The two groups engaged in our IGPs are elderly residents with moderate dementia from the dementia residential unit with an average age of eighty years old, and the children from the childcare centre aged between three to four years of age.

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Oral Presentation Abstracts

ID: 205 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: visual arts, functional art, cognitive decline, brain function

Aparador de recuerdos: an exploration merging visual art into a functional design to address cognitive decline among Filipino elderly

Verlyn Anne Basaysay Kim

University of Santo Tomas, Philippines

Abstract:

This study aims to focus on creating a wooden cabinet that combines unconventional application of visual art along with video and sound media which can be safely used by Filipino elderly, not only for storage but also as a tool that they can interact with - triggering brain function through multi-sensory elements. This approach was applied to visualize the two kinds of memory we know of that usually tends to decline when one grows old - memory as the brain function, and memory as elements remembered from the past. The expected output will showcase a combination of visual representations which will focus on Filipino elderly having lived in the Philippines' culture, beliefs and style along with video and sound collection that is personally connected to the user. This research could contribute to expanding the capability of visual art, which when used properly and combined with function, can help address some of the naturally occurring issues such as cognitive decline among the elderly.

***I am currently a thesis student of University of Santo Tomas Graduate School under Master of Fine Arts major in painting and sculpture, and I would like to use my creative skills and knowledge to create a functional art piece to help elderly people experiencing cognitive decline which may lead to dementia**"*

Oral Presentation Abstracts

ID: 210 / OS18: Education, training and formal carers

Abstract Topic: Formal carers education and training

Keywords: dementia, sexuality, intimacy, inappropriate sexual behaviour, nursing home

Managing sexual behaviours in dementia – a guide for caregivers in nursing homes and the community

Intan Sabrina Mohamad^{1,2}

¹Tung Shin Hospital, Malaysia; ²Hospital Rehabilitasi Cheras

Abstract:

Background

Dementia can change expressions of sexual needs and affection in persons with dementia due to cognitive and communicative deficits. People with dementia are often thought as asexual beings with no mental capacity to engage in sexual activities. Caregivers face challenges in managing people with dementia with perceived 'inappropriate sexual behaviours' (ISB).

Objective

To review the current literature on staff perceptions and responses in nursing home sexual behaviours in people with dementia.

Methods

An online search was conducted using PubMed from 1992 to 2019 using keywords like 'dementia', 'intimacy', 'sexuality', 'inappropriate sexual behaviour' and 'nursing home'. Studies not related to dementia were excluded. General themes were collated and categorized into five sub-themes: i) roles and responsibilities of caregivers ii) barriers to sexual expressions iii) non-pharmacotherapy iv) pharmacotherapy and v) policy and ethics.

Results

Of the 23 studies identified, 10 studies investigated staff perceptions and responses to sexual behaviours in nursing homes. Staff adopt a role of facilitator, informant, distractor, empathizer and safeguarder. Barriers to sexual expressions and activities include capacity to express sexuality and intimacy needs, sexual dysfunction, physical limitations; knowledge, attitude and perceptions of nursing staff and fellow residents; and institutional policy and procedures to address intimacy needs. Deficits in communication and expression of affection such as intimacy-seeking and disinhibited behaviour may be perceived as 'inappropriate sexual behaviour' (ISB); prompting unnecessary pharmacotherapy and social isolation. 'Guarding discomfort' amongst staff is influenced by their own level of comfort in dealing with sexual behaviours, familiarity with patients and ethos within the organisation. There are no randomized-controlled trials comparing different pharmacological agents in the management of ISB. Seven studies reported reduction in ISB using antidepressants, antipsychotics, anticonvulsants and antiandrogens. Non-pharmacological interventions do not always stop sexual disinhibition in dementia.

Conclusions

Sexual behaviors are associated with dementia severity, communication deficits and unmet sexual needs. Healthcare professionals need to adopt a neutral and noncensorious position when dealing with sexual issues in people with dementia. Dementia care should include services to support sexual expression, modifying activities, behaviours and expectations in order to reduce burden and enhance couplehood in spite of dementia.

Oral Presentation Abstracts

ID: 214 / OS06: Other syndromes and new and future treatments

Abstract Topic: New and future treatments

Keywords: Alzheimer's Disease, Natural Products, *Sideritis scardica*, *Crocus sativus* L, Mass Spectrometry

Alzheimer's disease: evaluating natural products as disease-modifying agents

ANTHONY TSARBOPOULOS

National and Kapodistrian University of Athens, Greece

Abstract:

Background and objectives of the study

Alzheimer's Disease (AD) is a progressive neurodegenerative disease, the most common form of diagnosed dementia (> 50 million AD patients worldwide), and the sixth main cause of death in the USA. Senile plaques, composed mainly of amyloid β (A β) and neurofibrillary tangles (NFTs), composed of tau protein, have so far been the main focus of research in this progressive disease. Most AD drugs have been developed around the A β buildup theory, although all attempted clinical trials have been unsuccessful. Natural products with neuroprotective activities are believed to hold significant promise in preventing or treating AD. In particular, the Mediterranean diet has been linked to reduced risk for developing AD and mild cognitive impairment (MCI), and it is anticipated that components of that diet could demonstrate beneficial effects by preventing key AD pathogenetic mechanisms.

Methods

In this study, the beneficial effects of the *Sideritis scardica*("mountain tea") and the olive oil total phenolic content extracts will be evaluated utilizing two established *in vitro* AD neuronal cell culture models, namely the A β PP overexpressing SH-SY5Y-A β PP and the hyperphosphorylated tau expressing PC12-htau. In addition, the effect of trans-crocin-4 (TC4), the most abundant crocin component from *Crocus sativus* L., will be assessed utilizing the aforementioned AD neuronal cell culture models. Finally, the metabolic fingerprint and its associated alterations following i.p. administration of TC4 in male and female mice will be determined by an untargeted UPLC-HRMS metabolomics approach.

Results

The *S. scardica* extract presented significant effects on the A β PP processing and tau pathways. In specific, treatment of differentiated SH-SY5Y-A β PP cells led to a significant decrease in BACE1. This is in agreement with the reported down-regulation of BACE1 by apigenin (a component in our *S. scardica* extract), which has been shown to suppress amyloidogenesis and to ameliorate AD-associated learning and memory impairment. Moreover, treatment of PC12-htau cells resulted in a significant increase of the inactive pSer9-GSK3 β , thus suggesting that *S. scardica* could be a potential inhibitor of GSK3 β activation, and consequently of tau phosphorylation. Similarly, TC4 significantly decreased of β - and γ -secretases, whereas it was effective in suppressing the active forms of GSK3 β and ERK1/2 kinases.

Conclusions

Our findings demonstrate that the *S. scardica* extract and TC4 demonstrate a potent effect of suppressing key molecular pathways of AD pathogenesis. They modulate multiple steps of the A β PP misprocessing and tau hyperphosphorylation pathways, suggesting a promising tool towards the prevention and possibly the treatment of AD. This is in agreement with the recent finding (HELIAD) of a direct link between adherence to a Mediterranean style diet and low risk for cognitive disease development and lower dementia rates.

Oral Presentation Abstracts

ID: 218 / OS05: Informal carers support

Abstract Topic: Informal carers support – pre, during and post

Keywords: Finding meaning, dementia, family caregiving, qualitative, Chinese

Finding meaning in Chinese dementia family caregiving: a grounded theory study

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Abstract:

Introduction:

Caring for persons with dementia has been well documented as a stressful experience. Previous studies have suggested that caregivers who could successfully find meaning in caregiving are more motivated to care and have a better psychological wellbeing. However, little is known about the actual process of how caregivers of persons with dementia find meaning in caregiving. Understanding this process can provide insights to professionals in developing interventions to support those caregivers who are struggling with the demands arising from caregiving and are unable to find meaning in caregiving. This study therefore aimed to explore the process of how family caregivers of persons with dementia find meaning in caregiving and to develop a theory to map this process.

Methods:

This study employed a Grounded theory methodology. Twenty Chinese primary caregivers who were taking care of a family member with dementia at home participated in this study. Data was collected through unstructured interviews and was analyzed using the constant comparative method.

Results:

This study has uncovered that the process of finding meaning in dementia family caregiving is a dynamic process and consists of four stages including “awakening”, “coming to terms”, “reframing” and “revitalizing”. Caregivers go through this process with the goal to regain a sense of control over their caregiving situation and their own lives. By regaining control, these caregivers can maintain a sense of predictability over their care-recipients’ condition, a sense of competence in managing their caregiving situation and a sense of self-determination in making autonomous life decisions. This process lasts for around 10 to 20 months. Not all caregivers in this study were unable to complete this process. These caregivers were caught in the stages of “awakening”, “coming to terms” and “reframing”.

This study has also uncovered that the process of finding meaning in dementia family caregiving is affected by socio-cultural values. Chinese cultural values, such as Collectivism, harmony and interdependence, have influenced how the caregivers come to terms with their caregiving situation, make sense of their caregiving roles and reframe their attitudes to face the caregiving situation and their own lives. Family support has also been found as an important element that can facilitate caregivers to find meaning in caregiving.

Conclusions:

The findings of this study have contributed to the present understanding of finding meaning in dementia family caregiving by highlighting its dynamic nature and the influences of the Chinese socio-cultural context on this process. Significant implications for the development of cultural-specific and stage-specific interventions that aim to help caregivers of persons with dementia find meaning in caregiving are suggested.

Oral Presentation Abstracts

ID: 219 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: Risk prediction, dementia, epidemiology, low and middle income countries

Predicting dementia risk in low- and middle-income countries: external validation of current prediction models (results from the depec program)

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Abstract:

Background and objectives of the study/Introduction

To date, dementia risk prediction research has been exclusively undertaken in high income countries (HICs). Therefore, it is unknown whether dementia risk prediction models derived from cohorts in HICs can be used in low and middle income country (LMIC) settings. For research to move rapidly towards prevention, a key priority is to establish methods for early identification of high-risk individuals for targeted risk reduction. Given this, the objective of this study was to determine whether dementia prediction models developed in HICs are suitable for use in LMICs.

Methods

The study was undertaken as part of the NIHR Global Health Research Group on Dementia Prevention and Enhanced Care. Data were from the 10/66 Study; a longitudinal, population-based cohort of individuals aged ≥ 65 years from 7 LMICs: Cuba, the Dominican Republic, Peru, Venezuela, Mexico, Puerto Rico and China. Individuals without dementia at baseline ($N=11,143$; 62.6% female; mean age=73.8, standard deviation=6.6 and range 65-106 years), were selected for the analysis. Five dementia prediction models were tested: the Cardiovascular Risk Factors, Aging, and Incidence of Dementia Study (CAIDE) score, the German Study on Ageing, Cognition, and Dementia in Primary Care Patients (AgeCoDe) model, the Australian National University Alzheimer's Disease Risk Index (ANU-ADRI), the Brief Dementia Screening Index (BDSI) and the Rotterdam Study Basic Dementia Risk Model (BDRM). Discriminative ability of each model was tested using the c-statistic. Calibration was tested using the Grønnesby and Borgan test.

Results/Positive impact

Mean follow-up duration was 3.8 years (standard deviation=1.3 years) and there were 1,069 incident dementia cases. Performance of the models was mixed. Across the different countries, the CAIDE (c-statistic range: 0.52-0.63) and AgeCoDe (c-statistic range: 0.57-0.74) models were poor at predicting incident dementia. In contrast, the ANU-ADRI (c-statistic range: 0.66-0.78), BDSI (c-statistic range: 0.62-0.78) and BDRM (c-statistic range: 0.66-0.78) all had similar levels of discriminative ability compared to when they were mapped in HICs. This result suggests that these models transport well across different settings. Most models were well calibrated. With regard to country specific results, the models validated best in Peru and worst in China and the Dominican Republic.

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Oral Presentation Abstracts

Conclusions/Perspectives

Not all dementia prediction models developed in HICs can be extrapolated for use in LMIC settings. The results suggest that only the ANU-ADRI, BDSI and BDRM can be applied in LMICs without compromise to their predictive performance. Such models could be used immediately in LMICs to identify those individuals who would benefit most from further follow-up and ensure that the right people are targeted for risk reduction. Reducing the number of people with dementia will have significant personal, societal and economic benefits.

Oral Presentation Abstracts

ID: 225 / OS27: Risk reduction and prevention

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: risk reduction, prevention, nutrition, brain training, physical activity

Maintain your brain: a randomised controlled trial of an internet-based lifestyle intervention to prevent cognitive decline and dementia

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Abstract:

Background: The failure to find disease modifying interventions for Alzheimer's disease (AD) and other dementias and evidence that environmental factors can delay the onset of dementia, have led to increased interest in dementia prevention. An issue for a population-based lifestyle preventative approach is scalability. We describe an internet based multicomponent randomised controlled trial.

Method: Invitations to participate in MYB were emailed/posted to 96,418 persons aged 55-77 years from the *45 and Up study*, a population-based cohort study of one in ten people aged 45 years and older (n = 267,000) recruited from Medicare lists between 2006-2009. Participants were required to have risk factors rendering them eligible for 2-4 of the following modules: physical activity, nutrition, cognitive training and depression. Within each module activities were designed to address individual risk factors. For example, physical activity could target, aerobic fitness, strength or balance; nutrition could target poor adherence to a Mediterranean-type diet, being obese or underweight, or having a history of high cholesterol, high blood pressure, diabetes, alcohol excess or cardiovascular disease.

The 3 years RCT randomised participants into an active coaching group with 1-2 weekly exercises for each eligible module and an information group who receive static information on the web. In year 1, modules run for ten weeks followed by a 2-week break including testing. Participants in both groups receive booster sessions for their eligible modules until the end of Year 3.

Results: Of 14,064 who consented, 6,236 completed all baseline assessments and were randomised (Figure 1). Overall 16% met criteria for all four, 51% for three, 31% for two; and 2% for one module. Twenty-one participants (<1%) were excluded as they were not eligible for any module. The first year of the trial was completed in October 2019

Conclusion: Most persons aged 55-77 years old have risk factors for cognitive decline that may be amenable to preventative interventions. Lifestyle interventions have capacity to reduce the risk of cognitive decline and ultimately delay the onset of dementia. If successful, this study evaluating the efficacy of delivering and monitoring a multipronged internet intervention, is scalable nationally and internationally.

Oral Presentation Abstracts

ID: 228 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: Dementia, cognitive decline, sex difference, Asian, diabetes

Sex difference in risk factors for dementia and cognitive decline: results from the advance study in diabetes

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Abstract:

Background

Although diabetes is known to double the risk of dementia in older adults, sex difference in risk factors (RFs) for dementia or cognitive decline (CD) has not been explored in this high-risk population. This study examined the association between potential RFs and dementia and/or CD in a cohort comprised of type 2 diabetes (T2DM) individuals, including analyses on sex difference in these RFs.

Method

The Action in Diabetes and Vascular Disease: Preterax and Diamicron Modified Release Controlled Evaluation (ADVANCE) was a randomised factorial trial, consisting of 11140 participants with T2DM from 20 countries from 2001 to 2003.

A comprehensive list of RFs was considered in the analyses, including demographic, lifestyle, biological, major cardiometabolic RFs and prior medical history.

Mini-Mental State Examination (MMSE) scores were recorded at baseline and at each follow-up clinic visit. Diagnosis of dementia was based on the criteria in the *DSM IV*. CD was defined by a three-point drop in MMSE from baseline. Death without any CD/dementia was included in the analyses as a competing risk to address survival bias. This was achieved by using multinomial regression models to estimate the odds ratios (ORs) for RFs on multinomial outcomes: death without any dementia/CD; dementia and/or CD; and alive (neither dementia/CD/death) (reference category). Interaction terms for each RF with sex were used to obtain the women-to-men Relative ORs (RORs).

Results

Of the 11140 participants, 1827 had dementia/CD over the median five-year follow-up. The fully adjusted multivariate model showed old age, Asian origin (versus non-Asian origin), higher total cholesterol, higher waist circumference, prior stroke, microvascular disease and higher HbA1c were RFs for dementia/CD; while longer years spent in education, lower baseline MMSE were protective (All $P_s < 0.05$). Notably, Asian origin (OR=1.23, 95% CI 1.08-1.41), prior stroke (OR=1.38, 95% CI 1.12-1.70) and prior microvascular disease (OR=1.23, 95% CI 1.04-1.45) greatly increased the risk of dementia/CD.

In the sex difference analysis, RORs from the multivariate model indicated no significant sex difference for any RF in relation to dementia/CD.

Conclusion

In this T2DM cohort, Asian origin, prior stroke and prior microvascular disease greatly increased the risk of dementia/CD. No sex difference in the effect of any RF for dementia/CD was observed. Considering women are disproportionately affected by dementia, the study findings warrant further

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investigations into which explanatory factors pose elevated risk of dementia/CD in women, particularly in women with diabetes as a previous study found that women with diabetes are at greater relative risk of all-cause dementia than men with diabetes. Sound knowledge of sex difference in RFs, as well as sex-specific risk, is needed. In addition, further exploration on Asian and other race/ethnicity is required to identify RFs that may be accountable for any racial/ethnic difference.

Oral Presentation Abstracts

ID: 229 / OS27: Risk reduction and prevention

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: dementia, prevention, nutrition, clinical trial

DePEC – Dementia prevention and enhanced care: the feasibility of a mixed-methods, dietary intervention study to reduce salt intake and increase high-nitrate vegetable consumption among middle-aged and older Malaysian adults with high blood pressure

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⁴School of Medicine, The University of Nottingham, United Kingdom; ⁵School of Life Sciences, The University of Nottingham, United Kingdom; ⁶South East Asia Community Observatory (SEACO), Segamat, Johor, Malaysia

Abstract:

Background and objectives of the study

The global burden of dementia is progressively rising and is projected to become a serious health and economic problem in low and middle income countries given the inadequacy of health and social care systems in dealing with the complexity of dementia care. There is considerable interest on the effect that modifiable risk factors could have in preventing neurodegeneration, with accumulating evidence to support the role of diet and lifestyle factors. In South-East Asia, changes in eating and lifestyle patterns, influenced by westernised habits, have resulted in rapid nutrition and lifestyle transition trends and significant increases in the prevalence of cardiovascular and neurodegenerative non-communicable diseases (NCDs). Specific dietary risk factors have been identified as key contributors to NCDs in these countries, such as low vegetable and high sodium consumption. The aim of this study is to demonstrate the feasibility and the potential to deliver a dietary intervention to increase consumption of high-nitrate vegetables and reduce salt intake over a 6-months among Malaysian adults.

Methods

This is a randomised 2*2 factorial trial among 120 Malaysian adults aged 50-75 years with high blood pressure. The study is embedded within the South East Asia Community Observatory (SEACO) population, which is a health and demographic surveillance site in Segamat, Johor. Participants will be randomised into a low salt consumption, high nitrate consumption, combined low salt and high nitrate consumption or control group. The primary outcome focuses on the feasibility of implementation of this intervention. Secondary outcomes include blood pressure, cognition, body composition, physical function and biological sample collection (blood, urine, saliva) to assess adherence to the intervention. A subgroup of participants will complete post-study focus groups to explore the feasibility and acceptability of the intervention as well as barriers and facilitators associated with dietary change.

Results

Screening is currently underway, with the application of the study criteria to 1904 participants within the SEACO database. This study is important as it is the first 2*2 trial testing single and combined effects of dietary nitrate and salt reduction for the prevention of dementia in developing countries, uses a population based cohort as a sampling platform for recruitment into clinical trials and uses objective biomarkers to assess adherence to the dietary intervention.

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Conclusions

This mixed-method feasibility study will provide key quantitative and qualitative information on the delivery of a novel dietary intervention for the prevention of dementia in Malaysian adults with raised blood pressure. The study will estimate the effect size of the single and combined interventions on cognitive function and blood pressure, which will be instrumental in the design and calculation of the sample size of a larger, follow-on efficacy trial.

Oral Presentation Abstracts

ID: 231 / OS01: The global policy environment

Abstract Topic: Dementia and human rights – NEW

Keywords: human rights, meaningful engagement, person-centred

Nothing about us without us: creating the first Canadian charter of rights for people with dementia

Riley Malvern

Alzheimer Society of Canada, Canada

Abstract:

Background: There is a growing international movement towards a rights-based approach for people with dementia and those who care for them. While people with dementia have the same human rights as anyone without dementia, including the right to manage their own lives, they still face stigma and discrimination solely because of their diagnosis that can contravene these rights. People with dementia have strongly advocated for their inclusion in the decisions that affect them, but often report feeling excluded from these conversations. Consequently, the Alzheimer Society of Canada (ASC) invited people with dementia to create an Advisory Group to inform its work. In 2018, ASC's Advisory Group developed a Canadian Charter of Rights for People with Dementia. The Charter represents a cornerstone in ASC's efforts to support the implementation of both a person-centred and rights-based approach in the meaningful engagement of people with dementia.

Methods: Members of the Advisory Group led the development of the Charter. First, a global environmental scan was conducted to understand rights-based approaches to the meaningful engagement of persons with dementia. The scan built on the work of disability networks and included international approaches, relevant human rights legislation and an understanding of how a rights-based approach may work in a Canadian context. The groundwork for the Charter was laid through the combination of the following: lived experience of people with dementia, the environmental scan results, and existing ASC resources such as its position statement on meaningful engagement, "Meaningful Engagement for People with Dementia: A Resource Guide" and its ethical framework.

Results: The first ever Canadian Charter of Rights for People with Dementia was created by people with dementia for people with dementia and the organizations that support them. The Charter identifies the human rights of people with dementia that are often overlooked and can be used by those with lived experience to claim these rights. The Charter is an advocacy tool for dementia care practices and policy development, grounded in the existing human rights legislation in Canada.

Conclusion: Supporting the creation of a Charter to promote the rights of a person with dementia represents a natural evolution in ASC's work that is informed by people with lived experience. The Charter will continue to serve as an advocacy tool to challenge the stigma surrounding dementia and to encourage and support the rights of people with dementia being enshrined in public policies and organizational practices. The Charter is a living document that ASC's Advisory Group will continue to revise based on feedback from stakeholders. They will ensure that it continues to speak to the rights of all people with dementia, regardless of stage or circumstance.

Oral Presentation Abstracts

ID: 233 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: 'Safer walking technology', 'occupational identity', 'dementia'

Using GPS Safer walking technology to promote identity and well-being through engagement in meaningful outdoor occupations

Esme Wood¹, John Woolham², Gillian Ward³, Carol Percy¹

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Abstract:

Introduction

In the UK, GPS Safer walking technology is increasingly being used to support people with dementia to access the outdoor environment. Spending time in outdoor natural environments and maintaining connections to nature are important to our health and well-being. Access to the outdoors is sometimes limited for people living with dementia because of concerns about the risks of them becoming lost, particularly in natural outdoor environments such as woodland and green open spaces. This can prevent people with dementia engaging in meaningful outdoor occupations and lead to reduced quality of life. This study explores the use of using safer walking technology, through the lived experience of both people living with dementia and family carers. It sought to understand the potential of safer walking technology to support people with early stage dementia to maintain engagement in meaningful outdoor occupations.

Methods

This qualitative study was designed with the support of a stakeholder advisory group that included occupational therapists, people with dementia, family carers and older people with an interest in technology. The group had a central role in the design of the overall research, participant recruitment materials and semi structured interview schedule. Data was collected from 18 in-depth interviews with two groups of people; people living with early stage dementia and family carers of people with dementia. The interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results

People with dementia were at risk of occupational deprivation when unable to engage in meaningful outdoor occupations; but safer walking technology was used by participants to continue engagement in outdoor occupations that held meaning to them. Participants within the study used safer walking in technology to engage in a wide range of outdoor occupations including fly fishing, cycling, marathon training and dog walking. These occupations formed part of their identity and enabled them to actively maintain their own physical and mental health, with several participants also reporting a spiritual connection with being outdoors in nature.

Conclusion

Safer walking technology has the potential to enable maintenance of a healthy lifestyle for people with early stage dementia. It also supported their occupational identity and enabled them to retain choice and control over their lives.

Oral Presentation Abstracts

ID: 264 / OS31: Dementia and the equitable society II

Abstract Topic: Designing and evaluating the impact of funding programmes – NEW

Keywords: Theory of Change; Dementia care; Policy; Stakeholder engagement; Monitoring and Evaluation

Developing a theory of change to address the challenge of dementia care across and in middle-income countries

Erica Breuer¹, Adelina Comas-Herrera², Emily Freeman², Déborah Oliveira³, Cleusa P. Ferri³, Ishtar Govia⁴, Rochelle Amour⁴, Tiffany Palmer⁴, Christine Musyimi⁵, Elizabeth Mutunga⁶, David Ndeti⁵, Mariana López-Ortega⁷, Claudia Iveth Astudillo Garcia⁸, Yuda Turana⁹, Tara Puspitarini Sani^{9,10}, Imelda Theresia¹⁰, Suvarna Alladi¹¹, Meera Pattabiraman¹², Crick Lund¹³, Eileen Taylor¹⁴, Dubglas Taylor¹⁴, Martin Knapp², Emiliano Albanese¹⁵, Sara Evans-Lacko², Marguerite Schneider¹³

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Abstract:

Introduction: Despite the increasing evidence for the current and future burden of dementia in low- and middle-income countries, financing for dementia research is still inadequate or non-existent. To address this, the STRiDE programme aims to increase research capacity to improve dementia care and services in Brazil, Jamaica, Kenya, Mexico, Indonesia, India and South Africa. The inclusion of stakeholders, such as people living with dementia, their carers and policy makers in the development of research programmes is important to ensure relevant programmes that are likely to make an impact. Theory of Change (ToC) is an approach which is used to determine the steps and activities through which programmes will reach their impact, and how to measure whether this has occurred. We describe how we used a ToC approach to co-develop the STRiDE programme, develop a monitoring and evaluation framework and make explicit the strategic direction for dementia care, treatment and support both across and within STRiDE countries.

Methods: We used a multi-stage ToC development process which included 1) an initial STRiDE programme ToC workshop with STRiDE programme partners and investigators (n=36 participants); 2) one ToC workshop within each STRiDE country with national and regional stakeholders including researchers, clinicians, policy makers, people living with dementia and their carers (Mean=28 participants); 3) revising the STRiDE programme ToC as a result of the country ToC workshops; 4) comparing the STRiDE programme ToC with WHO guidelines and action plan; and 5) review of the final ToC by the programme partners and the STRiDE International Advisory Group.

Results: The ToC development process resulted in an overall STRiDE Programme ToC and seven individual country ToCs which we will describe in the presentation. The STRiDE Programme ToC outlined the strategic direction for the STRiDE programme and dementia care, treatment and support in middle-income countries, which included key building blocks such as having a national dementia plan, adequate health and long-term services, and valuing the contributions of people living with dementia in planning for dementia. The ToC made clear the anticipated contribution of STRiDE to the dementia care, treatment and support and provided the basis for the monitoring and evaluation

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framework to measure impact. The seven STRiDE country ToCs outlined a strategic direction for dementia in each of the STRiDE countries and the contribution of STRiDE to this impact. In each country, some participants in the STRiDE workshops were invited to participate in STRiDE National Advisory Groups to provide oversight of the programme.

Conclusions: The multi-stage ToC development process was a systematic way to develop a monitoring and evaluation framework, provide strategic direction to the programme and include stakeholders across and within countries.

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ID: 268 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: Well-being, QoL, Hope, Thrive

Dementia and wellbeing: helping us thrive

Christine Thelker

Dementia Alliance International, Canada

Abstract:

In this presentation, I will discuss what wellbeing, and relate it to the quality of life of people with dementia. Wellbeing is said to be more than just happiness, it is feeling fulfilled, developing our personhood, having life satisfaction, career, home, family, purpose, feeling happy, healthy, and socially connected. In 1947 the World Health Organization defined Quality of Life as “a complete physical, mental and social well-being. The quality of life references the general well being of individuals and societies; the standard indicators of quality of life include, wealth, employment but also the built environment, physical and mental health, education, recreation and leisure time and social belonging. However, from the moment of diagnosis both well being and QoL are shattered; few get any support, little follow up, and given the bleak task to go home and get our affairs in order in readiness to die. The results: social isolation, no employment, and physical and mental health deterioration. Hence our well being diminishes and our QoL is non-existent. When we stop addressing the needs and desires of the person living with dementia, and society decides what’s best for us, there is no hope. More people living with dementia are now standing up and saying that’s not good enough. We are changing the perceptions and busting the myths that dementia is not what it looked like 20 years ago, and we have the right to live our best lives just like all of you. We no longer accept being written off by society, locked away, and segregated. Wellbeing and QoL means having access to quality care, rehabilitation, and any other modalities that help us to live positively; it means the right to work, to live independently in our communities. It means helping us do the things that provide us purpose. There needs to be a change in how the diagnosis is delivered, to ensure that those diagnosed are leaving their medical appointments knowing there is hope, and still much life to be lived. We also need the tools to help them make that possible. Currently people are left to go home and try to figure out “What now”, and “What’s next” on their own, it can take many months before they are ever connected with any type of dementia organization. This creates despair, loss of hope, feelings of shame, and the downward spiral into depression that is so prevalent in persons living with dementia. An environment that provides hope, purpose, and enables well being and purpose is what we must all strive for. If organizations worked cooperatively and collaboratively with each other, and people with dementia, those of us living with dementia could maintain living in our communities for longer. This would then also reduce the stress on caregivers. We need communities and health care professionals alike to be educated and able to embrace those living with dementia to continue to be productive valuable assets to their families and communities. Doing this together, we can all thrive.

Oral Presentation Abstracts

ID: 278 / OP1: Registries

Abstract Topic: Registries

Keywords: Longitudinal observational studies; participant engagement

Registries and observational longitudinal studies of brain aging in Québec: does participant engagement increase satisfaction and retention rate?

Serge Gauthier¹, Pedro Rosa-Neto¹, Sylvie Belleville², John Fisk³, Pierrette Gaudreau², Richard Milne⁴, Judes Poirier¹, Julie Robillard⁵

¹McGill University, Canada; ²Université de Montréal; ³Dalhousie University; ⁴University of Edinburgh; ⁵University of British Columbia

Abstract:

Background and objectives: Registries of interested persons and observational longitudinal studies once the participants have been enrolled are important components of the current strategy to understand the multiple factors at play in brain aging. Four cohort studies are under way in the province of Québec involving young adults from families with autosomal dominant Alzheimer's disease (AD), mid-life adults at risk because of late onset AD in first degree relatives, and older persons with age as the main risk factor. The four cohorts have complementary objectives, ranging from understanding the role of nutrition in healthy aging to the epigenetic factors modifying genetic risks. The participants are invited to undergo neuropsychological testing, blood and spinal fluid collection for biological tests, and brain imaging procedures, at repeated intervals. The participants are asked at the time of consent how they want clinically relevant data to be disclosed to them, and if their data can be shared with other researchers after removal of their name and all other means of identification from the data set (Thorogood et al, *Alzheimer's & Dementia* 2018, 14, 1334-43). Longitudinal data collection is essential to fully understand factors modifying brain aging, thus it is critical for participants to remain engaged and active in the cohorts.

Methods: We wish to assess the participants' satisfaction with the procedures they undergo, and explore the relationship between satisfaction and willingness to remain in the cohort studies (retention rate). Participant committees are being established and their input will be gathered in a forum similar to the one pioneered by Robillard & Feng seeking the community view of various ethical aspects of the research process (*J Alzheimers Dis* 2017, 59, 1-10). Questionnaires on motivation to participate, experiences in the study as a whole and of specific procedures such as the *SPEAR Questionnaire* developed by Richard Milne will be discussed and pilot tested for cultural appropriateness.

Results: The four cohort leaders have agreed to a joint effort to establish if participant engagement will lead to a measurable level of satisfaction and increase retention. Five study participants have volunteered for the project to date.

Conclusions/perspectives: The success of longitudinal observational studies is dependant on participants' satisfaction and engagement, and we will compare the experience gained in the province of Québec four cohorts with the cohort being built by the Canadian Consortium on Neurodegeneration and Aging, and the MRC Dementias Platform UK.

Oral Presentation Abstracts

ID: 280 / OS25: Dementia policies and public policy II

Abstract Topic: Dementia policies and public policy

Keywords: Dementia, delisting, treatment, people with dementia, caregivers, government decision, consequences

Delisting of "anti-Alzheimer's drugs": An exclusive survey confirms the distress caused to people with dementia and their caregivers

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France Alzheimer and related diseases, France

Abstract:

Since June 2019 and the decision of the French government to stop the reimbursement of the four drugs used to treat Alzheimer's disease and related disorders, France Alzheimer has repeatedly raised the alarm to draw attention on the growing distress caused to the 3 million of families affected. To make their voices and truths heard, the French organisation conducted a national survey between October 9 and November 16, 2018 and questioned 2,547 people:

- 2,463 caregivers
- 84 people with dementia

Left with no alternative solution, people with dementia and their caregivers are suffering the full consequences of the total delisting of the so-called "anti-Alzheimer's" drugs. In response to the French Government's intransigence, this national survey has been conducted to raise awareness of the issue.

Its results show three direct and worrying consequences:

1. **The sudden cessation of the treatment is causing a brutal increase of the cognitive impairments.** This deterioration was reported by 52% of respondents.
2. **Families already under pressure now have to pay considerably more for these treatments out of their own pockets:** 2 out of 3 respondents were taking at least one of the four drugs when the announcement on delisting was made. 70% of them have no plans to stop their treatment. The main reason given, by 62.5% of the respondents was the effectiveness of their treatment. 20% have stopped their treatment and 10% expect to stop soon, mainly because of the excessive cost, especially given that VAT on these drugs has increased by 8 percentage points.
3. **The therapeutic relationship between doctor and patient has broken down.** Only 55% of those who have decided to stop taking their treatment will continue to see a specialist, 38% have already stopped doing so, and 7% are considering it.

For the sake of people with dementia and their families, the Government must now prioritise research. Part of the financial effort must be devoted to clinical research required to offer patients long-term solutions that are fully funded and appropriate for their needs. This vision is shared by 68% of the caregivers who responded and 77% of the people with dementia.

Oral Presentation Abstracts

ID: 284 / OS22: Diagnostic tools

Abstract Topic: Diagnostic tools

Keywords: Dementia, Prevalence, Multicultural, 10/66

Diagnostic accuracy of the 10/66 dementia assessment tool in Māori, Fijian Indian, Samoan and Tongan elders with memory problems living in south Auckland, new Zealand

Adrian Martinez Ruiz^{1,4}, Susan Yates¹, Rita Krishnamurthi², Fuafiva Fa'alau¹, Mary Roberts³, Seini Taufu³, Jacinta Fa'alili³, Ngaire Kerse¹, Margaret Dudely¹, Gary Cheung¹, Sarah Cullum¹

¹University of Auckland; ²Auckland University of Technology; ³Moana Research; ⁴Instituto Nacional de Geriátria de México

Abstract:

Background: The 10/66 dementia assessment tool is a standardized language-fair, culture-fair questionnaire used in population-based studies. It was developed for use in non-English speaking communities in order to accurately measure the prevalence of dementia. We have translated and adapted the 10/66 dementia assessment tool into a culturally fair instrument for use with Māori, Fijian-Indian, Samoan and Tongan elders living in New Zealand (NZ).

Method: The translated and adapted versions of the 10/66 dementia assessment tool will be administered in the selected ethnicities. Each ethnic group will include 30 subjects with dementia and 30 subjects without dementia. The results of the 10/66 dementia assessment will be evaluated against the "gold standard" which will be clinical dementia diagnosis given by dementia specialists at a memory clinic and geriatric outpatient services in South Auckland.

Result: Data is still being collected. The final results will be presented at the conference, however preliminary results for both Fijian-Indian and Māori communities showed that the 10/66 dementia assessment has good diagnostic accuracy (sensitivity and specificity both being above 85%).

Conclusion: We will test a culturally appropriate and scientifically rigorous method to calculate the prevalence of dementia in an inter-ethnic community that includes Māori, Fijian-Indian, Samoan and Tongan elders living in NZ.

Oral Presentation Abstracts

ID: 285 / OS22: Diagnostic tools

Abstract Topic: Diagnostic tools

Keywords: Dementia, brief cognitive test, Montreal Cognitive Assessment, score mapping.

A 4-item case-finding tool to detect dementia in older persons

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Abstract:

Objectives: Brief cognitive tests are recommended in clinical services outside of specialized memory clinics, as case-finding tools to reduce the diagnostic gap of dementia. Although the Montreal Cognitive Assessment (MoCA) is among the most widely-used brief tests in specialized memory clinics, its length precludes routine use in non-specialty clinics. This study investigated whether a small subset of MoCA would suffice to match the performance of the full MoCA in detecting dementia, and hence may be useful in non-specialty clinics.

Design: Cross-sectional test research.

Setting: Alzheimer's Disease Centers across USA.

Participants: Participants aged ≥ 65 years (n=8,773).

Measures: Participants completed MoCA and were evaluated for dementia. The study sample was split into two – the derivation sample (n=4,386) was used to develop a short-variant of MoCA that best distinguish dementia (using the best-subset-approach with tenfold-cross-validation); while the validation sample (n=4,387) verified its actual performance using area-under-the-receiver-operating-characteristic-curve (AUC).

Results: A 4-item cognitive test was identified, comprising *Clock-drawing*, *Tap-at-letter-A*, *Orientation* and *Delayed-recall*. It demonstrated excellent performance in distinguishing dementia from non-dementia (AUC 94.2%), and was comparable to that of MoCA (AUC 93.8%) even across education subgroups. It explained 85.9% of the variability in MoCA, and had scores that could be mapped to MoCA with reasonable precision. At the optimal cut-off score of <10 , it demonstrated 87.9% sensitivity and 87.6% specificity in detecting dementia.

Conclusions and Implications: Using rigorous methods, this study developed a brief cognitive test that is free-of-charge, takes <5 minutes to complete, covers the key cognitive domains, and has standardized instructions to allow its administration even by non-physicians. This brief test is well-suited as a case-finding tool in non-specialty clinics (such as in primary care and geriatric clinics), and may improve care-integration with specialized memory clinics that utilize MoCA.

Oral Presentation Abstracts

ID: 305 / OS30: Innovation, technology and entrepreneurship

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Dementia, Cognitive Stimulation Therapy, touch-screen technology, agile development, MRC Framework

The development of thinkability: an individual cognitive stimulation therapy (iCST) touch-screen app for people with dementia

Harleen Rai, Justine Schneider, Martin Orrell

University of Nottingham, United Kingdom

Abstract:

Introduction

There is a need for more complex interventions to better support people with dementia and carers. Cognitive Stimulation Therapy (CST) is an example of such an intervention. It is a psychological treatment for people with mild to moderate dementia, which has shown to improve cognition and quality of life. It is currently available in both a group and individualised format called iCST. A computerised version of iCST, which can be used on tablets, could be even more beneficial by providing mental stimulation through both the principles of CST and interactive technology on consumer devices. In this, a rigorous approach to development is paramount to the successful uptake of the intervention. Therefore, the aim of this study was to develop the iCST app through the use of appropriate frameworks, methods and the involvement of people with dementia, carers, researchers, and a software development company.

Methods

The iCST app was developed according to the Medical Research Council framework and the Centre for eHealth Research roadmap while using an agile approach. Hence, the app was developed in three successive phases (or 'Sprints') and the relevant stakeholders evaluated a prototype at each phase. During the development cycle we organised two PPI meetings (n = 12), one informal consultation (n = 3), four focus groups (n = 16), individual interviews (n = 10), and an ongoing feasibility trial.

Results

Findings from each 'Sprint' were used to inform the development of a successive prototype. Sprint 1 helped establish the theory and evidence base behind CST and technology, and gave insights in the attitudes of people with dementia and carers towards a potential iCST app. People liked the idea of the iCST app but would need for it to be free of jargon. The involvement of a family member/friend would be helpful. This feedback, and existing CST/iCST materials, helped create prototype v1.0. Sprint 2 helped evaluate prototype v1.0 in a small informal consultation in order to develop prototype v2.0 based on the feedback which included improvements in the lay-out and navigation. Sprint 3 was useful in obtaining feedback on prototype v2.0 through a qualitative study in terms of the quality, usability, and perceived effectiveness. Participants highlighted the sophisticated design and a need for more content. This led to the development of prototype v3.0 taken forward in a randomised feasibility trial.

Discussion

This study proved that an agile approach towards technology development where all relevant stakeholders are involved, is effective in creating suitable technology. In addition, the results have added to our previous knowledge of non-computerised CST. The iCST app is a worthwhile addition to current CST resources and its release will help make CST more interactive and accessible to users around the world.

Oral Presentation Abstracts

ID: 308 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: Dementia, cognitive impairment, Oman

Demographic and clinical characteristics of patients with cognitive impairment attending geriatric clinic in Oman

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Sultan Qaboos University, Oman

Abstract:

BACKGROUND: Epidemiological studies from different parts of the world showed that the population of the elderly is in the rise. This has led to an increase in the diseases commonly seen in this age group, including dementia and other cognitive disorders. As a result, Elderly mental health services should address the particular needs of these patients while considering the specific cultural and social values. At present there is no community mental health provision for the elderly in Oman and care is provided in secondary care hospitals.

AIMS: This study aims to outline the demographic and clinical characteristics of patients with cognitive impairment consulting a geriatric clinic in Oman. Particularly, it describes the common presenting complaints and prevalent psychiatric and medical disorders in these patients.

METHODS: The data was collected by reviewing the electronic medical notes of 105 new patients attending the clinic over a 6-month period. The diagnosis was based on the International Statistical Classification of Diseases 11th Edition (ICD-11) and the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5).

RESULTS: Most of the patients seen were females (53.3%) who were widows (50%) and mainly cared for by their children. The common, presenting complaints in these patients were cognitive symptoms (38.1%), behavioral challenges (27.1%) and psychotic symptoms (11.2%). Alzheimer's disease (69.2%) dominated the confirmed cases of dementia. The studied patients commonly had hypertension (31.8%) or diabetes mellitus (19.6%) as medical comorbidities.

CONCLUSIONS: These results are consistent with previous studies done in different parts of the world. We need to strengthen our knowledge and skills to better manage cases of dementia and other cognitive impairment, and the numerous symptoms caused by them.

Oral Presentation Abstracts

ID: 309 / OS25: Dementia and public policy II

Abstract Topic: Dementia policies and public policy

Keywords: health system preparedness, disease-modifying treatment

Preparedness of health systems in six countries to deliver a disease-modifying treatment for Alzheimer's disease

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Abstract:

Background and objectives of the study

Prior research has evaluated the health system infrastructure for the delivery of a disease-modifying treatment (DMT) for Alzheimer's disease and projected substantial delays in accessing treatment should one become available. We analyzed whether and to what degree changes to institutional arrangements (e.g., policies, incentives and regulations) could improve capacity and readiness for delivery of a future DMT in six countries.

Methods

Policy analysis based on desk research and expert interviews in France, Germany, Italy, Spain, the U.K., and the U.S. focusing on planning for and coverage of dementia services, ability of providers to adapt to a surge in demand for services and provider capabilities along the patient journey from diagnosis to treatment.

Results

No country has a national or regional plan to prepare their delivery systems for the advent of a DMT or advance planning to budget for the expected increase in dementia-related spending. Spain and the U.K. have expert-led initiatives to inform the policy dialog. Systematic screening for cognitive decline is not recommended or covered in any of the countries under study, but all of them include initial evaluation of memory complaints in primary care settings in their recommended benefits. However, the evaluation is often not performed because of limited knowledge, lack of tools and fatalistic attitude.

Patients with suspected cognitive decline have access to specialist memory services in all six countries, which are led by geriatric psychiatrists (Germany and U.K.), neurologists (France, Italy and Spain) or a mix of specialists (U.S.). Scale and scope of memory services vary substantially within and across countries, with only France and the U.K. attempting to standardize services. Only Italy and Spain cover biomarker testing based on PET scans or CSF tests for routine care. Memory services operate at capacity in all countries with wait times of at least two months, and have limited flexibility to scale up due to low numbers of dementia specialists, lack of budget and complex planning processes. Psychiatry-led services tend to be less prepared for the medicalized requirements of a DMT delivery. While no country would have sufficient infrastructure to deliver an intravenous treatment today, experts did not expect problems with scaling up infusion capacity, if funding were provided.

Conclusions

Institutional preparedness for the advent of a DMT needs to be improved in all countries of our sample. In particular, primary care providers need to be better enabled to evaluate memory complaints with training and tools, such as simple cognitive tests and blood-based tests for Alzheimer's biomarkers, as workforce and budget constraints limit the ability to scale up specialist services. Such improvements would also improve access to and quality of memory care in the absence of a DMT.

Oral Presentation Abstracts

ID: 310 / OS28: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: Living alone, social isolation, without carer

Living alone with dementia

Kate Gordon, Mike Splaine

Splaine Consulting, United States of America

Abstract:

Introduction: Millions of people with dementia are living alone with no known supports. People with dementia who live alone do not manage daily activities as well or at all when they feel lonely. In the absence of readily identifiable informal supports (e.g., unpaid assistance from family or friends), the person will need to rely on social services, medical, and legal professionals for assistance to remain safe in their home. Presenters will share practical guidance and tools for helping a person living alone who does not have informal supports, including people with dementia who have a caregiver that cannot provide support.

Methods: Practical strategies will be showcased for: identifying people who are living alone without support; assessing risk; building trust; identifying family and friends willing to help; determining decision-making capacity; and options for helping the person maintain their independence. Examples rely heavily on the experience of US-based community service providers serving people with dementia living alone and with no known supports. In addition, a model for hosting a community-based, solutions-building workshop will be shared. This model has been used throughout the US in urban and rural communities and features conversations with persons who are navigating life alone with dementia, an overview of data on single person households, health and social risk factors such as social isolation, and ethical dilemmas to consider. Solutions from social services, health care and technology sectors will be featured.

Conclusion: Practical strategies can be used to address certain prominent challenges that service providers face when working with individuals with dementia who live alone.

Oral Presentation Abstracts

ID: 311 / OS07: Models of care

Abstract Topic: Models of care

Keywords: Dementia, hospitals, readmission prevention, delirium

Reducing hospital readmissions of persons with dementia

Michael Splaine, Kate Gordon

Splaine Consulting, United States of America

Abstract:

Persons with Alzheimer's disease and related disorders have other health issues as an estimated 75% have at least one additional chronic condition. Flare ups of these conditions, made more difficult by the underlying cognitive impairment, may lead to emergency department visits and unplanned hospital visits.

A hospital stay for any aged person results in loss of muscle mass and tone, some function and increased risks of acquired infection and institutional care. In the US a person with ADRD who is hospitalized likely will have another 2 visits in that same year. Persons with ADRD in their medical record comprise 40% of rapid (under 30 day) readmissions back to hospital, resulting in more loss of ability and risk of institutionalization.

Recognizing the risks to its clients, Nevada Senior Services has embarked on a hospital readmission reduction program by developing Hospital2Home, by adopting an evidence based through RCT model of transitions in care, coupled with respite coaching and additional educational activities for persons living with dementia and their families about preventing hospitalization/coping better with hospital stay and for more successful post hospital care.

This symposium will share the story of identifying and selecting an evidence based intervention and adopting it into practice at Nevada Senior Services, core educational objectives and information about the caregiver and staff education programs and preliminary evaluation results indicating a 2% rapid readmission rate among Hospital2Home clients vs 35% among all seniors in the community served.

Oral Presentation Abstracts

ID: 313 / OS10: Design, architecture and the built environment I

Abstract Topic: Consumer empowerment

Keywords: Venue assessment

Re-orienting a environmental assessment tool for use with people living with dementia

Dennis Frost

DAI, Southern DAG, Australia

Abstract:

This tool builds on the work of Prof. Richard Fleming's 'Environmental Assessment Tool' (E.A.T.) and reframes it for use by lay people and more importantly with and by people living with Dementia. It has been developed by a person with Dementia in collaboration with many others living with Dementia.

The need for this tool was identified by observations of buildings that had previously been audited using the E.A.T. by people experienced in its application revealed two important issues. Firstly, general members of the public had difficulty in identifying the same issues and more importantly people living with Dementia were able to identify additional aspects of the environment that negatively impacted on their ability to interact in that environment. This tool differs from the E.A.T. in three ways. Firstly, it is structured to follow the path that may be taken though the built environment from approach to exit, providing a more natural and intuitive experience for the user. Each of these areas is then viewed against eight functional domains of the E.A.T with the addition of an extra domain of 'Human Interaction'. This additional domain emphasises the importance of good communication.

This tool has now been tested against several public buildings, small retail business and hotels. It has been effective in small businesses because there are generally less internal obstacles to conducting an environmental audit and identifying and implementing simple solutions. It also has had the benefit of raising awareness and understanding of Dementia.

Oral Presentation Abstracts

ID: 316 / OS30: Innovation, technology and entrepreneurship

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: dementia, research, patient-centered, partnership

Empowering partnerships between people with dementia and researchers: a network building and training initiative

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Abstract:

Despite the demand and recent proliferation of efforts to meaningfully engage patients and their carepartners (CP) in research partnerships, the voices of People Living with Dementia (PLWD) as co-researchers and participants have been noticeably absent in the United States. Presumptions of incapacity, stigma, and a lack of innovative methods to facilitate participation have contributed to the silence. Building upon the key recommendations made in October 2017 at the US National Research Summit on Dementia Care to “Fund more research on how people living with dementia and their caregivers can be partners with researchers”, LiveWell’s Empowering Partnerships Project was designed to create and implement a 2 day training to this end.

Founded in 1990, LiveWell Alliance, based in Connecticut, USA is a dementia services provider, national pioneer and thought leader committed to positively transform the way PLWD are viewed, engaged, and supported. Funded by a Eugene Washington PCORI (Patient-Centered Outcomes Research Institute) Engagement Award, a project team comprised of PLWD, CPs, researchers and dementia professionals have worked in partnership to grow a network of PLWD, family CPs, researchers, and local/national stakeholders all working toward a common goal: to enhance the participation and engagement of PLWD in all aspects of research - through the training of PLWD, CPs and researchers.

Over the course of the 2-year project, a multi-stakeholder group is executing these project activities

1. Catalyze the development and growth of the Dementia Peer Coalition (DPC) – an emerging peer to peer organization led by and for PLWD. The DPC focuses on: peer support, advocacy, community awareness raising, and research opportunities. DPC members interested in research are participating in the 2-day Empowering Partnerships Training and becoming a sustainable network of PLWD who prepared to engage as key partners in all aspects of the research process.
2. Develop and implement a 2-day training program for PLWD, CP, and researchers to partner in research, including a guide to assess capacity to participate (October 2019)
3. Develop a strengths-based inventory to assess the abilities and capacities of training participants (including PLWD), to maximize learning and understanding.
4. Identify and prioritize research topics important to PLWD
5. Compile training materials and lessons learned in a *Program Implementation Toolkit* to address critical knowledge gaps and create opportunities for project replication

This session will highlight project background, recruitment efforts, training details, strengths-based assessment, training session outcomes, and lessons learned. Perspectives of PLWD and project participants will be shared through testimonials and videos. Resources and recommendations for project replication will be addressed.

Oral Presentation Abstracts

ID: 326 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Dementia, LMIC, post-diagnostic care, carer support

Post-diagnostic dementia care and support in low and middle income countries: the Malaysia perspective

Susan Hrisos¹, Michaela Goodson², Louise Robinson¹, Emma McLellan¹, Heather Yemm¹, Lynne Corner¹, Chin Ai-Vyrrn³, Shahrul Kamaruzzaman³, Tan Maw Pin³, Roshaslina Rosli³

¹Newcastle University, United Kingdom; ²Newcastle University Medicine Malaysia (NUMed), Malaysia; ³University of Malaya, Malaysia

Abstract:

Background

The number of people living with dementia (PwD) worldwide is increasing, particularly in low and middle income countries (LMICs), where little is known about existing post-diagnostic care and support. We aim to better understand healthcare pathways for PwD in Malaysia, and to identify key priorities for providing timely, quality and accessible care and support to all. Data collection and analysis is ongoing and will be completed by March 2020.

Methods

Qualitative interview study with care providers and facilitators (health and community care professionals, paid carers, traditional medicine practitioners, faith healers, community leaders, NGOs). A topic guide, piloted in Malaysia and peer reviewed by all LMIC partners, elicits understandings of dementia and dementia care, barriers and facilitators to care for PwD and carers, and perceptions of key priorities for developing efficient, feasible and sustainable dementia care pathways. Verbatim transcription of audio-recorded interviews is followed by iterative, thematic data analysis.

Results

To date, 17 interviews have been conducted (11 healthcare professionals, 2 traditional medicine practitioners, and 4 senior citizen associations). Preliminary findings indicate that a dementia care pathway exists, but that it is not fully transparent. Despite the pathway PwD still present to the healthcare system with advanced dementia. Interviewees linked this to a public perception that symptoms of dementia are a normal part of ageing. Earlier detection of dementia is commonly opportunistic when consulting for other ailments with GPs, government clinic staff and general physicians who have some expertise in dementia. There was general awareness of the availability and limitations of dementia medications. The importance of supporting families to understand dementia, its progression and strategies to help them care for PwD was emphasised. Social care is largely the domain of families but additional community-based support is limited. Workforce factors that hinder early identification and management of dementia included lack of specialists, overburdened clinics, and limited knowledge of dementia and training in guideline use. Awareness raising for both the public and medical professionals, prevention, and more support from government are seen as key priorities.

Conclusions

This qualitative study provides novel insight into the availability, delivery and use of post-diagnostic care and support in Malaysia from the perspective of care providers. Interviews with service-users (unpaid family and friend carers, people with early-stage dementia) are also planned. The study will be replicated in two further partner LMICs (Tanzania and India) in early 2020. LMIC findings will be compared to dementia care in a high-income country (UK), and used to inform the co-development of country-specific dementia care guidelines that are relevant, appropriate and realistically achievable in each setting.

Oral Presentation Abstracts

ID: 332 / OS29: Informal carers training

Abstract Topic: Informal carers training

Keywords: Simulation, Education, Dementia, Caregiver, Alzheimer's

The McGill University dementia caregiver workshop - using simulation to educate caregivers

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¹McGill University, Canada; ²Caregiver Cross Walk; ³Centre intégré universitaire en santé et services sociaux du Centre-Ouest-de-l'île-de-Montréal

Abstract:

Background: Dementia is highly prevalent in older adults and can involve tremendous burden for patients, families and society. The large majority of dementia caregivers are family members who have little knowledge of the disease and the potential stresses and challenges. The increased demands placed on caregivers have been shown to have an impact on their physical, psychological, and emotional wellbeing. Our team has developed an interprofessional simulation-based workshop for dementia caregivers to better understand the disease and how best to intervene with their family members affected by dementia.

Objective: The goal of this workshop is to educate caregivers about dementia and the progression of the disease and related demands, in an attempt to prepare them for the challenges and complexities of the caregiving experience.

Methods: This full-day inter-professional workshop includes: (1) a presentation on dementia and its stages, facilitated by a geriatrician or neurologist; (2) a discussion on navigating the health care system, facilitated by a social worker; (3) an interactive session on the caregiving experience, facilitated by a former caregiver; (4) an observed standardized patient scenario in a simulated apartment highlighting safety hazards in the home environment, commented on by an occupational therapist; and (5) a debrief with workshop participants.

Results: Since its creation as a pilot project in Fall of 2017, our team has successfully hosted 9 workshops and engaged a total of 123 caregivers. On a 5-point Likert Scale, 98% percent of participants strongly agreed or agreed that the topics covered were very relevant and that the content was well organized and easy to follow. Further, 93% of participants said that the distributed material was helpful and confirmed that the trainers were knowledgeable and well prepared. Regarding the simulation session, 98% of the participants mentioned that it was realistic, 94% felt that the scenarios enhanced their learning experience and 99% said that the scenarios were easy to understand. On a scale of 1 to 5, the level of knowledge on dementia or Alzheimer's disease before and after the workshop went from 3.1 ± 1.9 to 4.2 ± 0.40 ($p \leq 0.001$).

Discussion: To our knowledge, this is the first simulation-based workshop available to dementia caregivers. With a few exceptions, the entire cohort of caregivers appreciated the content and felt that they had significantly improved their knowledge on dementia. Our future goals are to offer workshops 1) involving topics such as behavior disturbances, wandering, etc., 2) to professional caregivers and to several ethnic communities in their mother-tongue, 3) to a larger audience through online modules and distance blended learning, and 4) to medical students and other inter-disciplinary professionals (social work, rehabilitation, nursing, etc.) to ultimately better prepare them to work with persons with dementia and their families.

Oral Presentation Abstracts

ID: 334 / OS32: End of life and palliative care

Abstract Topic: End of life and palliative care

Keywords: End of Life, Cross-culture, Good Dying, Qualitative Study, Dementia

Cross-cultural conceptualization of a good end of life with dementia: a meta-qualitative study

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Abstract:

Background: Death with dementia is increasing worldwide and improving end of life with dementia is a pressing public health issue. Clarifying to what extent concepts of a good end of life with dementia vary between different cultures can inform international research and practice. Therefore, the purpose of this study was to assess cross-cultural commonalities and any differences in concepts of a good end of life with dementia.

Methods: Focus group and additional individual interviews with researchers of qualitative studies on end of life with dementia from the perspective of the person with dementia or the family caregiver, and analyses of code trees. We aimed at including researchers from across the globe. For purposive sampling, we contacted researchers in our international network, and we screened the literature in an attempt to find more researchers who performed qualitative studies from regions other than western Europe. The participating researchers contributed to interview sessions in spring 2019 in which we discussed what is important at the end of life for people with dementia based on their research findings. Thematic analysis and continuous comparative methods were used with iterative member checking. The study was approved by the Ethics Committee of the Graduate School and Faculty of Medicine Kyoto University (R1924-1).

Results: Sixteen researchers participated from the UK, Ireland, the Netherlands, Germany, Portugal, Canada, Brazil, and Japan representing twelve single datasets. We held three focus group sessions and subsequently, four individual interviews, in person or with video conferencing, and the participants provided structured and open-ended feedback on preliminary analyses via e-mail. Preliminary analysis identified eight main categories covering comprehensive concepts of a good end of life with dementia. Three basic requirements included "Pain and Symptoms Controlled," "Provided Basic Care," and "A Place Like Home". Five other categories referred to "Keeping Others' Life Intact," "Being Respected

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and Having (my) Preferences Met," "Being Connected," "Identity Being Preserved," and "Satisfaction with Life." These categories may cover different layers of physical, psychosocial, and spiritual and existential aspects. The importance of the categories differed between studies, in particular "Keeping Other's Life Intact."

Conclusions/Perspective: A wide range of themes are relevant to a good end of life with dementia regardless of the specific cultural context. Some indicate aspects that are particularly challenging to achieve for people with dementia. However, differences in importance of the themes may relate to the extent that they are modifiable such as through improving particular aspects of care, in addition to cultural values.

Oral Presentation Abstracts

ID: 346 / OS19: Economics of dementia

Abstract Topic: Economics of dementia

Keywords: health care spending, dementia in the United States

US healthcare spending on dementia – 1996-2016

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Abstract:

Background and Objective:

As the life expectancy of the United States continues to rise, so will the number of people living with dementia, as its prevalence increases with age. While Alzheimer's disease and other dementias have no known cure, the care needed to provide for this population is involved and often expensive. Despite this financial risk, little is known about how much is spent on dementia care, and where this funding comes from. For this research, we estimated healthcare spending on dementia, disaggregated by payer, age and sex group, and type of care from 1996 through 2016.

Method:

We extracted payer information from Medical Spending Panel Survey and categorized them into three primary payers-- public insurance, private insurance and out-of-pocket spending. We used a penalized spline regression to estimate the share of spending for each of the three payers by type of care, 154 conditions, year, age, and sex when necessary. We combined these estimates with spending by condition, age and sex group, and type of care data from the Institute for Health Metrics and Evaluation's Disease Expenditure project, which builds from 183 data sources to estimate health care spending from 1996 to 2016. The spending estimates by payer and type of care were scaled to official US spending estimates published in the National Health Spending Accounts.

Results:

In 2016, \$93 billion was spent on Alzheimer's and other dementias. Only diabetes mellitus and low back and neck pain were more expensive. Of this \$93 billion, \$90 billion was for patients 65 years and older, and \$49 billion was on those over 85. The bulk of this spending was financed through public insurance – 58% or \$54 billion, with private insurance covering 19% or \$17 billion, and out of pocket payments covering the remaining 23% or \$22 billion in 2015. While public insurance covered the bulk of this spending, since 1996 the growth rate for public spending on dementias has been lower than either out of pocket, or private insurance spending. In 1996 the total spending on dementias was \$39 billion. This almost tripling of the cost was spread across the three payers, but the increase was highest for private insurers at %15.6 annual rate of change, as compared to out of pocket payments which increased at 12.6% and public funding mechanisms with an increase of 7.5%.

Conclusions

In the already expanding landscape of US healthcare spending, it is important to recognize the ongoing and increasing resources needed to manage care for Alzheimer's and other dementias. While much of the spending is managed through public financing, the ratio of this is decreasing over time. As the spending on Alzheimer's and other dementias continues to increase, there will need to be an ongoing and data driven conversation about how this financial burden is paid for. Critical to this discussion will be insights into who has been paying for this care retrospectively.

Oral Presentation Abstracts

ID: 347 / OS20: Dementia friendliness

Abstract Topic: Dementia friendliness

Keywords: Air Travel, Dementia Friendly, International Collaboration, Accessibility, Inclusion

I-D-air travel: international dementia-air travel

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Abstract:

In our increasingly global world, air travel is an essential part of many people's lives – both personally and professionally. However, barriers in the built and social environments of airports and airplanes can lead to stressful and overwhelming situations for people affected by dementia. Bustling airports that lack signage can cause disorientation – making navigating the environment difficult –and airline staff who lack dementia-specific training can contribute to anxiety and frustration. By 2030, it is estimated that 75 million people will be living with dementia globally – meaning that the number of people potentially affected by these barriers will have grown significantly.

While the search for a cure for dementia is ongoing, the reality is that air travel needs to evolve to better support, acknowledge and include people affected by dementia through the application of “dementia-friendly” principles.

Many initiatives around the world are attempting to address these issues. In our increasingly globalized world, we must collaborate in order to fully support people living with dementia.

This session is presented by the International Dementia Air Travel working group (I-D-Air), highlighting worldwide initiatives that are improving the experience of air travel for people affected by dementia and other hidden disabilities. It will also address how we can ensure people living with dementia are directing the conversation and discuss our efforts to build stronger international relationships through collaboration and knowledge sharing to facilitate consistent application of best practice. I-D-Air is comprised of experts from across the world, including people with lived experience, advocacy organizations and researchers.

Oral Presentation Abstracts

ID: 351 / OS07: Models of care

Abstract Topic: Models of care

Keywords: challenges, dementia care, focus group, qualitative study, research priorities

Challenges and research priorities for dementia care in Malaysia

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Abstract:

Introduction: Like many middle-income countries, few studies to date have evaluated dementia care in Malaysia, with the focus of available studies primarily on epidemiological and laboratory research. Unfortunately, most persons living with dementia now live in lower and middle-income countries. To address this balance, focus group discussions and a forum discussion were held during a workshop to identify potential challenges and research priorities for dementia care in Malaysia.

Methods: Representatives from the academic sector, non-governmental organizations, clinical practice and policy-making bodies were identified through purposive sampling and snow-balling. As part of a larger programme of work looking at dementia care and prevention globally (National Institute for Health Research-Dementia Prevention and Enhanced Care), an open discussion was first held to identify the challenges for the delivery of dementia care in Malaysia and research priorities. Separate focus group discussions were then held simultaneously to further discuss individual research priorities using a semi-structured discussion guide. Individuals groups then contributed notes to a sticky board. Field notes were recorded by rapporteurs and discussions were audiotaped. Audiotapes were then transcribed, and thematic analyses conducted using the sticky board notes, collated field notes and transcripts of discussions.

Results: Forty-four individuals participated in the one-day workshop. Challenges identified included regulation and governance of care facilities, funding for research, lack of appropriate care models, limited research evidence, inadequate training and lack of human resources. The five main priorities area for research identified were: prevention and screening, human resources and training, awareness and health literacy, integrated care and regulation/governance of care and government strategy and policy journey. The specific areas, stakeholders and potential strategies were identified and tabulated.

Conclusion: While unique issues do exist, many issues surrounding dementia care in Malaysia are common across global settings. The outcomes of the workshop would be shared with existing stakeholders to inform the development of strategies to enhance dementia care research and implementation in Malaysia.

Oral Presentation Abstracts

ID: 359 / OS34: Registries II

Abstract Topic: Global Dementia Observatory (GDO) – NEW

Keywords: Prevalence, routine data, diagnosis

Can we use routinely collected health and social care data to estimate the prevalence of dementia in New Zealand?

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¹University of Auckland, New Zealand; ²Counties Manukau District Health Board; ³Auckland University of Technology

Abstract:

Background and objectives

Estimates suggest there are 62,000 people living with dementia in New Zealand, projected to reach 170,000 by 2050. But these figures are extrapolated from other countries' prevalence data and do not take into account inter-ethnic differences (other than age-structure). Partly due to the lack of country-specific data, the NZ Ministry of Health has not yet developed a plan for NZ. In order to plan services, the Ministry requires accurate data on the extent of dementia in all major NZ ethnic groups but this information is lacking as there has never been an NZ dementia prevalence study and there is currently no dementia registry or other mechanism to systematically monitor new cases.

One method of identifying cases of dementia is by data linkage of routinely collected health and social care data sets, collected for administrative purposes rather than for research. In NZ, such datasets might provide a cost-effective process to assess and monitor the extent of dementia and the impact of baseline characteristics and interventions on routinely collected outcomes such as hospital admission, utilization of state-funded home care services, care home placement and mortality.

The sparse research evidence available in NZ suggests that hospital services for dementia may be under-utilised, particularly by Asian communities. Missed cases may be picked up on routinely collected social care assessments for home care, for example a recent analysis of NZ InterRAI data found that over one third of people assessed as dementia level cognitive impairment had never received a specialist diagnosis of dementia. Before using administrative data as a proxy measure for dementia prevalence, we need to first assess the accuracy of these data against a 'gold standard' community-based dementia prevalence study for the same population.

Methods

We will present our methods to conduct a dementia prevalence study in a small geographical area of South Auckland and compare our findings with a dataset constructed from routinely collected health and social care for the same population. Within the population we will focus on two subgroups: a NZ European subgroup which we suspect will have reasonably accurate routinely collected data, and an Asian subgroup which we suspect will have poorer accuracy due to underutilisation of health and social care services for dementia. We will assess the sensitivity and positive predictive value of the routinely collected dataset against the population-based 'gold standard' in both subgroups to demonstrate the potential range of results.

Positive impact

The findings of our study will lay the foundations for robust information systems for dementia, which have the potential to be rolled out on a national scale. This will facilitate the monitoring of new dementia cases for future evidence-based policy development and culturally appropriate service delivery, thus improving the lives of many families living with dementia in NZ.

Oral Presentation Abstracts

ID: 360 / OS19: Economics of dementia

Abstract Topic: Economics of dementia

Keywords: financial exploitation, financial warning signs, dementia policy

A preliminary survey of people with dementia and financial exploitation in Taiwan

Su-Yuan Chan¹, Mei-Yin Li^{1,2}, Chia-Hsin Cheng^{1,3}, Yung-Jen Yang^{1,4}, Pei-Ning Wang^{1,5}, Wen-Chuin Hsu^{1,6}, Mei-Mei Niou¹, Chien-Hua Chuang^{1,7}, Huey-Fang Liu¹, Jui-Ying Tang^{1,8}, Hong-Jer Chang^{1,9}, Te-Jen Lai^{1,10}, Huey-Jane Lee¹, LI-YU TANG¹

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Abstract:

Introduction

As the number of people with dementia increasing rapidly, financial exploitation also increases. Taiwan Alzheimer's Disease Association (TADA) has established the Financial Security Task Force, with the aim of protecting people with dementia and their family from financial mistreatment. However, the actual situations of financial abuse of people with dementia in Taiwan remain obscured. Therefore, we conducted a study to investigate the real conditions of the financial exploitation of people living with dementia in Taiwan.

Methods

We applied an online-questionnaire survey on a purposive sample. Individuals who were family caregivers, people with dementia, and professionals from medicine, law, finance, and social welfare sectors were invited to participate. The questionnaire contains questions about how people living with dementia experienced financial exploitation, the actual loss, whether people with dementia and their family filed lawsuits, etc. A total of 74 cases were collected in the study.

Results

The study showed that when 74 people with dementia had a financial loss, 34 of them had no formal diagnosis, and 65 had no guardianship or assistantship declarations. Among 71 people with no (or not sure whether having) assistantship or guardianship declaration, their financial loss was mostly caused by family members (25 cases), scam gangs (17 cases), friends and colleagues (10 cases), salespersons (10 cases), strangers (10 cases), financial professionals (6 cases), care workers (4 cases), a law professional (1 case), and a social welfare professional (1 case). People abusing persons living with dementia tended to use frauds (48 cases). Their measures included financial services (24 cases), trades (21 cases), lending (16 cases), and investments (13 cases). In total, 50 people with dementia got movable property loss, 16 people got immovable property loss, and 6 people's identities were illegally used. However, only 24 respondents filed lawsuits.

Conclusions

Financial exploitation might be one of the early warning signs for dementia. It is quite common that people with dementia face financial mistreatment before assistantship or guardianship declarations, and even before diagnoses with dementia. Nevertheless, financial exploitation often causes people with dementia and their family a great economic loss. Promoting the warning signs and preventive strategies to professionals from medical sectors, social welfare sectors, financial institutions, household

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administrations, land administrations, law systems, and police agencies, is recommended for future policies.

Oral Presentation Abstracts

ID: 362 / OS27: Risk reduction and prevention

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: Cognition, Hormone replacement therapy, Elderly, Postmenopausal

Association between hormone replacement therapy (HRT) and cognitive function in a community dwelling older women: Bushehr elderly health (BEH) program

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Abstract:

Introduction: Cognitive impairment is an important health problem among older adults. The prevalence of dementia exponentially increases after age 60 years old. Levels of circulating estrogens appear to be associated with age-related declines in cognition function. However, the relationship between hormone replacement therapy (HRT) and cognitive function has not clearly been relevant. This study was designed to compare cognitive function in older women who have received HRT with who have not.

Methods and Materials:

The sample of this study was representative of aged > 60 years old women were selected using a cluster random sampling method based on the neighborhoods of Bushehr city, Iran. The history of HRT was gathered by interview. Cognitive status was assessed using Mini-Cog and Category Fluency Test (CFT) (number of animals that remembers and names by the subjects). Cognitive impairment defined as a problem in one of these tests and those had normal condition in all tests were assumed as subjects with normal cognition. Logistic regression models used for assessing the association between HRT and cognitive impairment.

Results:

Totally, 1135 older women from Bushehr Elderly Health Program that had completed data about HRT and cognitive impairment was considered for analyses. Mean age of the participants was 69.00 (standard deviation (SD) = 6.20). of total, 48 women (4.23%) had history of HRT that 35 (72.32%) less than one year, 11 (22.92%) women 1-5 years, and 2 (4.17%) women more than 5 years were taken replacement therapy. Median years of schooling was 4 years with interquartile range 0-9 years. The prevalence of diabetes in this group was 35.24%. The prevalence of cognitive impairment based on two instruments (Mini-cog, CFT) was 783 (68.99%). There was the history of stroke in 35 (3.04%) of the participants. In univariate logistic regression model there was an association between history of HRT and cognitive function (Odds Ratio (OR) 0.42; 95% CI 0.24 – 0.76). This association also was shown after adjustment for age, education, BMI, hypertension, and diabetes (OR = 0.49; 95% CI 0.27 – 0.89).

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Conclusion:

It seems that HRT has a protective effect on cognitive impairment in postmenopausal women and future studies should target these effects.

Oral Presentation Abstracts

ID: 366 / OS05: Informal carers support

Abstract Topic: Informal carers support – pre, during and post

Keywords: caregiver, care homes, involvement, role overload, self-efficacy

Family carers of people with dementia in care homes: trends in involvement, perceived role, role overload and self-efficacy

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Abstract:

Introduction The demand for long-term care provided in care homes is expected to rise in the coming years due to the growing number of people with dementia. Quality of care in these homes can be improved by implementing person-centered care. Family carers of people with dementia living in a care home contribute to person-centered care and quality of care by giving voice to preferences and needs of people with dementia when they are not able to anymore. Research has shown that family carers of people with dementia experience high levels of burden and this continues when the person with dementia moves to a care home. The objective of the current study is to examine trends in involvement, perceived role, role overload and self-efficacy of family carers in care homes for people with dementia.

Methods Data was derived from the Living Arrangements for People with Dementia study, a cross-sectional monitoring study that evaluates developments in care for PwD in care homes in the Netherlands, with four measurement cycles between 2008-2017. Data from measurement cycles 2-4 was used in the current study. Respectively 144, 47 and 49 care homes participated. The number of participating family carers was respectively 888, 392 and 401. Family involvement was measured by the number of hours per week that family carers visited the PwD and the type of activities they undertook. For measuring the perceived caregiving role, the Family Perceptions of Caregiving Role instrument was used. Role overload was measured with the Self-Perceived Pressure by Informal Care scale and a 37-item questionnaire was used to measure self-efficacy.

Results The number of hours that family carers visited the person with dementia did not change over time, however, a trend towards an increase of the variety of activities they undertook. Their perceived caregiving role did not change over time. Self-efficacy of family carers increased over time and they reported more feelings of role overload.

Conclusions This study showed that during the past decade, there is an increasing trend towards family carers undertaking more diverse activities with PwD in care homes. Although family carers felt more competent in their caring role, feelings of role overload also increased. Therefore, continuing attention is needed for family carers after a person with dementia moved to a care home.

Oral Presentation Abstracts

ID: 373 / OS28: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: technology, social connectedness, loneliness

T&SCon: the potential of technology to support social connectedness for people with dementia

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Abstract:

Background

This paper reports on an innovative project in Scotland that explored the potential of technology to promote social connectedness for older adults, including people with dementia. It is recognised that older people are particularly vulnerable to social isolation and the impact of dementia on social networks is often negative. Both loneliness and social isolation bring significant risks to wellbeing. Technology offers new routes to support social connectedness but also brings challenges and risks.

Methods

The project involved a participatory mixed methods approach that fed into a co-creation process. The project involved a systematic literature review, a scoping study of technology projects, analysis of the HAGIS large-scale health dataset and focus groups with 27 stakeholders, including people with dementia, from across Scotland. Two co-creation workshops engaged a wide range of stakeholders who helped to make sense of the data and to develop easily accessible guidelines on the use of technology to promote social connectedness.

Findings

We identified a wide range of technology-enabled services and interventions designed to support social connectedness. However, there is relatively little research evaluating the effectiveness of such interventions and while positive results are presented, it is not possible to generalise from many of these studies. The HAGIS analysis revealed a varied pattern of technology which suggests that those who are least socially connected may also be those least likely to use technology. The focus groups revealed information about current projects across Scotland. Reflections on the successes and challenges faced by these projects revealed the importance of: careful consideration of the target group; the breaking down of assumptions about who uses technology and who doesn't; and risks and opportunities of using technology. The co-creation workshops enabled refinement and further analysis of the data to support the recommendations presented below.

Conclusions

These recommendations emerged from the project for organisations and individuals using technology to support social connectedness for people with dementia: recognise potential users as individuals, avoiding assumptions about age, gender, disability etc., and protecting human rights; careful consideration of risks for individuals is needed but balanced presentation of risks is important; get staff and potential users on board from the start, involving them from the planning stages onwards; carefully assess infrastructure as well as devices for cost, accessibility, suitability and usability; users will need support and training to use new devices, peer-to-peer learning, hands-on demonstrations, and simple take-home instructions are recommended. The good practice guidelines developed in the project can be accessed freely and used to ensure effective use of technology to enhance social connectedness for people with dementia.

Oral Presentation Abstracts

ID: 374 / OS20: Dementia friendliness

Abstract Topic: Dementia friendliness

Keywords: community, generation, friendly, adolescents, school

Build up a dementia friendly generation. Involvement of adolescent students in “abbiategrasso dementia friendly community” project

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Abstract:

Schools and students can play a pivotal role in the development of Dementia Friendly Community (DFC). By educating young people about dementia it is possible to create a dementia friendly generation, one that is more aware of dementia and more supportive of people who live with dementia. Educating young people is a fundamental part of creating dementia friendly communities. It is become more and more likely that young people will come into contact with someone living with dementia. Thus, increasing the knowledge and awareness of adolescents becomes a primary goal of the communities in order to reduce the stigma towards people with dementia. Since the beginning of its experience to become Dementia Friendly Community, Abbiategrasso, the first pilot city for DFC in Italy launched by Federazione Alzheimer Italia in 2016, has involved adolescent students and their teachers. Thanks to a partnership with “IIS Bachelet” public high school, a project with different steps and target groups was designed and implemented since the second half of 2018.

The first action consisted in a training intervention for teachers to make them more aware and increase their knowledge about dementia. Then, two questionnaires were given to 44 adolescents students to detect their level of knowledge and attitudes towards people living with dementia. Starting from the results of these questionnaires, there were organized some discussion and training classes with geriatrics, neuropsychologists and sociologists. Adolescents expressed an interest in learning more about dementia and perceived awareness of dementia to be important within their age group. A significant number of the students had some personal experience of dementia and wished they had been more prepared.

These actions brought to a greater involvement of students in the activities of the DFC: they submit questionnaires on dementia knowledge and attitudes to their parents, planned and realized a “flash mob” in the city centre, draft and distributed a new questionnaire for the general population, contributed in defining a new social inclusion project for person living with dementia and their caregivers which also involves public library and Abbiategrasso municipality.

Next steps of this process of creation of a dementia friendly generation will be a more direct involvement in all the planned activities, creating also more opportunities to meet with people living with dementia, in order to promote intergenerational contacts.

Oral Presentation Abstracts

ID: 376 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: Fear of falling, Mild cognitive impairment, Influence factors

Factors influencing fear of falling in individuals with different types of mild cognitive impairment

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Abstract:

Introduction

Mild cognitive impairment (MCI) is considered an intermediate state between normal aging and early dementia. Fear of falling (FOF) is an important risk indicator for falls and quality of life in patients with MCI. However, there is currently no study comparing the factors associated with FOF in the different MCI types. Thus this study aimed to explore influencing factors of FOF in mild cognitive impairment due to Alzheimer disease (AD-MCI) and mild cognitive impairment due to Parkinson's disease (PD-MCI).

Methods

Seventy-one patients with MCI were evaluated from the neurological outpatient clinics of a medical center in Northern Taiwan. Participants were separated into two groups, AD-MCI (n=37) and PD-MCI (n=34), based on the disease diagnosis. FOF was assessed using the Activities-specific Balance Confidence Scale (ABC). Motor outcomes included: Tinetti assessment scale and Timed Up and Go (TUG) subtasks. Cognitive status included global cognitive function, executive function, attention and working memory, episode memory, visuospatial, and language were measured. The level of anxiety and depression were also recorded.

Results

FOF was significantly correlated with global cognitive function, attention and working memory, executive function, Tinetti assessment scale, walk speed, and TUG subtasks in the AD-MCI group. A stepwise regression found that attention and working memory was the most important factor influencing the FOF. In the PD-MCI group, FOF was significantly correlated with attention and working memory, executive function, anxiety, Tinetti assessment scale, and TUG subtasks. A stepwise regression found that turn-to-walk was significantly predictive of the FOF.

Conclusion

We noted that FOF in different types of MCI was influenced by different factors. Attention and working memory was the most important factor in the AD-MCI group whereas turn-to-walk was the most important factor in the PD-MCI group. Thus, therapies that aim to lower the risk of falling in AD-MCI and PD-MCI populations should address attention and working memory, and turn-to-walk respectively.

Oral Presentation Abstracts

ID: 379 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: Namaste Care, Severe Dementia, Quality of Life, Wellbeing

Implementation of namaste care for people with severe dementia living in care homes in the UK

Suzanne Lesley Mumford, Nori Graham

Care UK, United Kingdom

Abstract:

Background: The UK's largest independent provider of health and social care (Care UK) is implementing the Namaste Care Programme developed by Professor Joyce Simard in the US. Namaste Care provides a regular programme of comforting touch and sensory stimulation for people with severe dementia recognised to improve health and wellbeing.

The aim of the pilot study conducted in 3 care homes, was to identify the people, training, support and resources required to implement Namaste Care to this vulnerable group at high risk of unidentified pain and social isolation. The data was used to inform a project to rapidly scale delivery of Namaste Care a minimum of three times weekly, in each of a growing portfolio of 120 homes over a 12 month period.

Methods: The 3 care homes identified for the 6 month pilot each assessed 5 people living with severe dementia to receive Namaste Care. A visit with the home manager prior to training identified the environment and the resources required. The manager, plus up to 8 staff attended a one day training prior to implementation. Evaluation of the project was achieved through data analysis of a comprehensive set of physical metrics and completion of the quality of life in late-stage dementia (QUALID) scale, plus informal interviews with staff and the partners/family of people living with dementia.

Results: This small but data rich project of 13 people with severe dementia receiving Namaste Care identified positive trends reflecting the health benefits. The use of the QUALID scale completed every Friday revealed significant improvement in indicators of wellbeing.

Care staff and family members expressed feeling empowered to be able to engage positively using hand massage and sensory stimulation, creating opportunities for engagement and connection that they previously felt had been lost.

Conclusions: People with severe dementia in UK care homes are at high risk of unrecognised pain and social isolation. The Namaste Care Programme offers a simple and effective solution to supporting these unmet needs and significantly improves health and wellbeing. The results of the project have been used to inform the best way to scale consistent and sustainable delivery of the Namaste Care Programme across a large multi-site provider. In addition we identified that the following would support the success of implementation:

- Working in partnership with Namaste Care International, Professor Joyce Simard and Min Stacpoole supports the strength of our commitment to the quality of provision of Namaste Care.
- Creating a video training package and toolkit supports quicker adoption of Namaste Care by home managers

Developing this collaborative approach and training package has informed a comprehensive strategic plan for the scaled delivery of Namaste Care across the organisation (Care UK), supporting improved wellbeing, meaningful engagement and connection with people with severe dementia, their families and care colleagues.

Oral Presentation Abstracts

ID: 383 / OS07: Models of care

Abstract Topic: Models of care

Keywords: Namaste care, advanced dementia, care homes

Transforming every day care for people living with advanced dementia in care homes: findings from the process evaluation of namaste care intervention UK

Dawn Brooker, Isabelle Latham, Jennifer Bray, Nicola Jacobson-Wright, Faith Wray

University of Worcester, United Kingdom

Abstract:

Background: Namaste Care was developed initially in the USA by Joyce Simard. Through a daily programme of physical, sensory and emotional care, people living with advanced dementia are supported to engage with carers, family and their surroundings. Implementing change in practice is challenging for care homes. This presentation reports on emerging findings during the final year of a 3-year process evaluation of Namaste Care within 6 UK care homes.

Methods: 6 care homes, representing a range of size and registration, who wished to implement Namaste Care were recruited. Care homes were asked to implement Namaste Care either once or twice per day with residents with advanced dementia. They were supported through provision of standardised training. Interviews, diaries and observations were used to explore the impact and experience of implementing the intervention (acceptability, feasibility, cost and development). A variety of resident data on medication use (analgesia, anti-psychotics, sedatives); untoward incidences (falls, accidents) and service use (unplanned hospital admissions) were collected on a monthly basis as well as measures of agitation and quality of life. Daily recording of Namaste Care intervention and staff views of impact on participating residents were undertaken.

Results: 5 of 6 care homes successfully implemented Namaste for a 3-6 month period undertaking 523 sessions in total. Qualitative and quantitative data was collected from 52 residents, 27 staff and 10 family carers. Data demonstrates a positive impact on residents' lives on a number of measures for little additional cost. Reorganising care to incorporate Namaste is challenging, although care homes demonstrated a number of key strategies to implement successfully.

Conclusions Namaste appears beneficial and is possible to implement as part of care home practice. Implementation requires planning, purpose and persistence and these need to be considered an integral part of the intervention itself.

Oral Presentation Abstracts

ID: 385 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: value, dementia, CAMIE

Enhancing the value of care for patients with dementia in the acute hospital

Poh Peng Tay, Nai Ying Liu, Yeuk Fan Ng, Chin Yee Cheong, Philip Yap

KTPH, Singapore

Abstract:

Background

Patients with dementia (PWDs) suffer increased risk of behavioral disturbances, functional decline and diminished quality-of-life during hospitalization. Care for Acute Mentally Infirm Elders (CAMIE) is a 16-bed ward endeavouring to provide value-added care for PWDs. CAMIE care comprises moderating intrusive interventions, a physical-restraints-free policy, enhancing patient mobility and activity, and prioritizing patient needs over tasks.

Methods

We assessed the value of CAMIE care with: 1) Patient Value Compass (PVC) derived by aggregation and weighting performance on Clinical, Functional, Experience and Cost-to-Patient outcome indicators; 2) Optimal Care index (OCI)- sum of weighted outcomes per unit cost of resources used to attain the outcome.

Results

CAMIE patients saw gains in function (Modified Barthel Index-MBI)¹, well-being and QoL, and decreased agitation on discharge compared to admission. 1) Clinical Outcomes: Mean Pittsburg Agitation Scale decreased from 2.7 to 0.79; 2) Functional Outcomes: Mean MBI score improved from 47.31 to 55.58; 3); Experience Outcomes: a) Mean Bradford Well-Being score improved from 4.94 to 8.46. b) EQ-5D index score improved from -0.16 to 0.15; 4) Cost-to-Patient: ALOS decreased from 16.9days (usual care) to 14.8days (CAMIE) with estimated daily ward and treatment savings of \$325.50 per bed day saved. The PVC score increased from 60.7 to 82.2 and OCI demonstrated a 48.5% increase from 7.9 to 9.5.

Conclusions

CAMIE care has evidenced enhanced value for PWDs through improved clinical, functional and experience outcomes during hospitalization, and with cost-savings. The findings support the call for wider adoption of similar models of enhanced hospital care for PWDs.

Oral Presentation Abstracts

ID: 387 / OS23: Well-being and quality of life

Abstract Topic: Well being and quality of life

Keywords: Quality of life, care homes, routine measurement, care quality

Routine measurement of quality of life in care homes: feasible, achievable, and usable

Laura Jane Hughes, Nicolas Farina, Najj Tabet, Sube Banerjee

Brighton and Sussex Medical School, United Kingdom

Abstract:

Background and aims

The quality of care in the UK has been questioned with calls to improve services. Measuring the quality of life (QoL) of care home residents may offer ways to understand and improve both QoL and quality of care provided in care settings. However, QoL is rarely measured as a part of routine care practice in the UK. It is generally accepted that routine use of QoL instruments would be beneficial and feasible in improving patient outcomes. However, it is not known how often routine QoL assessments could be carried out in care homes nor have care staff been asked how often this could be done. We carried out a two-stage study to explore the views and opinions of care home staff about using a QoL instrument as a part of routine care, and to assess the use of such an instrument in practice.

Method

Stage 1: A qualitative study was conducted in three care homes in East Sussex, England. An inductive iterative approach was employed; semi-structured interviews with 35 care staff and two focus groups with four managers were carried out. All interviews and focus groups were audio recorded, transcribed and analysed using thematic analysis.

Stage 2: Eleven care staff from five care homes in East Sussex, England used the DEMQOL-CH (a QoL instrument) to rate 37 residents' QoL routinely as a part of normal care practice. The routine use of DEMQOL-CH is described and assessed. Changes to QoL over the study time-period are assessed.

Results

Stage 1: Interview and focus groups findings both identified two overarching themes; 'perceived benefits' and 'implementation'. Overall there was a great deal of positivity towards using a QoL instrument in routine practice. The perceived positivity and benefit of routinely measuring QoL in care was an important feature in how the instrument was seen as fitting into practice. Participants identified barriers to using such instruments and discussed how these could be overcome.

Stage 2: Care staff from four care homes were able to rate residents' QoL on a monthly basis. Significant differences were found in QoL scores across the study time-period. Clinically meaningful changes to QoL scores were found.

Conclusion

The findings suggest that that not only is routine measurement of QoL by care staff positively received, it is also achievable in practice. Staff believed that measuring QoL as a part of normal care practice could lead to improvements in QoL of residents and the quality of care provided. The routine measurement achieved by staff shows the feasibility of measuring QoL as a part of normal care practice and demonstrates some of the ways that care staff could use the information to understand the QoL in their care homes. Further research is needed to fully evaluate whether routine QoL measurements can produce positive changes for residents, staff, and care quality.

Oral Presentation Abstracts

ID: 389 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: Migration, Rural-to-urban, Older adults, Cognitive ageing, Cohort study

How does rural-to-urban migration influence the cognitive ageing trajectories of Chinese older adults: a prospective cohort analysis

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School of Public Health, Sun Yat-sen University

Abstract:

Background and objective of the study:

In China, alongside more and more rural young adults work and settle down in urban, their aged parents also migrate into urban. This rural-to-urban migration associated with changes in social environment and family interactions may significantly contributes to older adults' healthy ageing process. However, few studies so far have examined this phenomenon, particularly regarding cognitive ageing. Our study aims to investigate the impact of internal rural-to-urban migration on the cognitive function trajectory, and some possible risk factors behind this, using a nationally-representative longitudinal cohort of Chinese older adults.

Methods:

Participants aged 65 or above at first wave (2010-2011) of the China Health and Retirement Longitudinal Study (CHARLS) were included ($n=3876$, female=52.2%). Migrants were defined as these who lived in urban but had rural Hukou during follow-up period. Cognitive function was measured by an adapted Chinese version of Min-Mental State Examination (MMSE), and the scores were divided into total cognition, mental status and episodic memory. Multilevel linear models were employed to understand the impact of migration on cognitive ageing trajectory from 2011 to 2015 gender-specifically.

Results:

Finding indicated that migrants ($n=850$) had higher education and income, and more family interactions with child and grandchildren than their rural non-migration counterparts ($n=3026$). Female migrants additionally were more likely to participate in leisure activities. Models contained interaction terms indicated that all scores of cognitive dimensions declined with time (total cognition: female $b=-0.48$, $P<0.01$; male: $b=-0.53$, $P<0.01$), the differences of cognitive function decline rates between migrants and stayers were not significant both in female and in male. For female, migrants had better performance in baseline total cognition ($b=1.00$, $P<0.01$) and in mental status ($b=0.86$, $P<0.01$), but not in memory ($b=0.17$, $P>0.05$) than stayers, for male, differences of baseline cognitions between migrants and stayers were not significant. A series of adjusted models revealed that education attainment, caring grandchildren, participation in leisure activities were positive factors of female migrants' cognition.

Conclusion:

We found that rural-to-urban migration was only positively associated with female's baseline cognitive function, but not the rate of decline among Chinese older adults. The observed difference in cognitive function was largely attribute to caring grandchildren and participating leisure activities of female migrants, who tended to have more family and social interactions than their rural non-migrated counterparts.

Oral Presentation Abstracts

ID: 390 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: social isolation, end of life, cognitive functioning, risk factor, prevention, lifestyle, cohort study, oldest-old, epidemiology

Social network and cognitive functioning in the oldest old – results from the AgeCoDe/AgeQualiDe cohort

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Abstract:

Background: Social isolation is associated with faster cognitive decline and a higher likelihood to develop dementia. However, less is known about the association of social network and cognitive functioning in the oldest-old – the group that is at highest risk for both social isolation and dementia. We therefore aimed to investigate longitudinal effects of social network size on global cognitive functioning in a sample of dementia-free oldest-old individuals.

Methods: Analyses were based on data from follow-up 5 to follow-up 9 of the multi-centric, prospective German AgeCoDe/AgeQualiDe cohort. We used unadjusted and adjusted hybrid mixed effects linear regression models to estimate between-subject effects and within-subject effects of social network size (Lubben Social Network Scale/LSNS score) on global cognitive functioning (normalized Mini-Mental State Examination/MMSE score).

Results: A total of $n = 960$ dementia-free study participants at follow-up 5 were included. Mean age at observation onset was $M = 86.4$ ($SD = 3.0$), 67.8 % were women. Social isolation was prevalent in one third (32.5 %) of the study participants. While adjusting for confounders, there was a significant between-subject effect of social network size on global cognitive functioning (lower cognitive functioning in individuals with smaller networks; coef.: 0.46, 95%CI = 0.27-0.66, $p < .001$) and a significant within-subject effect, i.e. a decrease in an individual's social network was associated with a decrease in cognitive functioning (coef.: 0.23, 95%CI = 0.10-0.37, $p < .01$) over a mean follow-up time of 3.5 years. High education showed a protective main effect on cognitive functioning (coef.: 2.96; 95%CI = 1.66-4.25; $p < .001$), but it did not significantly interact with social network, hence not attenuating the negative effect of decreases in social network on cognitive functioning over time (coef.: -.04; 95%CI = -0.24-0.17; $p = .73$).

Discussion: Oldest-old individuals with smaller social networks showed lower cognitive functioning compared to individuals with larger social networks. In general, if decreases in individual social networks occurred, they went along with decreases in cognitive functioning. Our results confirm social isolation being a risk factor for cognitive decline and dementia, and they extend to suggest that this is the case even in oldest-old age. This emphasizes the importance of maintaining a socially active lifestyle into very old age. Likewise, we need to think of ways to effectively work towards the prevention of social isolation in late life.

Oral Presentation Abstracts

ID: 391 / OS06: Other syndromes and new and future treatments

Abstract Topic: Other syndromes and dementia – NEW

Keywords: cancer; comorbidity; cancer care

The care and support needs of people with dementia who are using cancer services

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¹Leeds Beckett University, United Kingdom; ²University of Leeds, United Kingdom"

Abstract:

Dementia and cancer are common among older people, making it likely that many people live with both conditions. People living with dementia and cancer may have complex care needs, making providing cancer care more difficult and complex. However, little research has been done in this area to inform practice and support people through this experience. This study aimed to identify the prevalence, characteristics, cancer treatment and care needs of people living with dementia and cancer within the United Kingdom. We undertook two studies. Study 1 used a large dataset from UK GP records. We identified the numbers of people with cancer and dementia, their characteristics, and what NHS services they used, comparing their data to people with only dementia or cancer. Study 2 used ethnographic methods to explore experiences of cancer care for people living with dementia. We used interviews, conversations and observations of cancer care to include the perspectives of people living with cancer and dementia, their families, and hospital staff. Study 1 found that 3.1% of people living with cancer also had dementia, and 7.3% of people living with dementia also had cancer.

The prevalence of dementia amongst people with the four most common cancers ranged from 2.3% (lung cancer) to 4.1% (prostate cancer). People living with dementia and cancer differed in important ways from people with cancer but not dementia. Study 2 identified a number of cancer care challenges for people living with dementia, including recognition of dementia, and difficulties around decision-making, care processes and care environments. Families played important and difficult to replicate roles in their relative's care. Where there were no family members to support care, this role was often filled by staff members. Navigating the pathways of dementia care and cancer care was difficult for people living with both conditions. This study provides the best available estimates to date of the size, characteristics and cancer care needs of people living with dementia within the United Kingdom. It highlights areas of good practice, as well as how hospitals and their staff can improve cancer treatment and care experiences for people living with dementia, and areas for further research.

Oral Presentation Abstracts

ID: 392 / OS06: Other syndromes and new and future treatments

Abstract Topic: New and future treatments

Keywords: Transcranial Pulse Stimulation, Acoustic waves, Shockwaves

Transcranial pulse stimulation, TPS reduces significantly the Alzheimer's disease symptoms

Pavel Novak

Storz Medical AG, Switzerland

Introduction

Acoustic waves, or shockwaves respectively are used in medicine since 1980. First application was for extracorporeal kidney stone disintegration. Meanwhile, low intensity acoustic waves proved to be efficient for the treatment of non-unions, tendon and muscular pain, wound healing, heart insufficiency, erectile dysfunction, aesthetic and finally also neurological indications. The working principle is the mechanical stimulation of biological processes called mechanotransduction resulting in increased cell metabolism, release of nitric oxide (eNO) and numerous growth factors like VEGF, BMP, TGF- β , GABA, BDNF and GDNF. There is also an anti-inflammatory effect and the stimulation of stem cells and the innate immune system. There are no significant side effects.

Method

Alzheimer's disease or dementia in general is multi modal disease resulting from different causes like deposition of dedicated proteins (tau, beta-amyloid), inflammation, reduced blood supply and others. This might be the reason why the pharmaceutical solutions failed till now. On the other hand, the acoustic wave stimulation, or TPS with its broad scope of effects is more efficient.

Results

First the effect of acoustic pulses on brain was tested in-vitro and on behalf of animal tests (Sprague-Dawley rats) the safety margins were evaluated. The multicenter clinical pilot study with 35 patients showed a significant improvement of the Alzheimer's disease symptoms of 20% measured with CERAD Plus battery of tests. The treatment consisted of 6 sessions in 2 weeks, with 6000 pulses per session, energy flux density of 0.2 mJ/mm² at 5Hz.

Perspectives

The device (Neurolith) has meanwhile the CE mark clearance in Europe. There are regulatory activities in further regions. Further clinical evaluation with placebo controlled, randomized trials is needed for improving the scientific knowledge. RCT trials are in Germany, Austria and Hong Kong. Further RCT will follow.

Oral Presentation Abstracts

ID: 398 / OS08: Community partnerships / Public-Private-People partnerships

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Dementia, tracking solution, involvement, workshops, development

Developing a dementia tracking solution - involving people with dementia and their carer

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Abstract:

The aim of this study was to develop a new dementia tracking solution for people with dementia and their family carer. Focus was on developing a solution which were user-friendly and had a high user-acceptability for both the person with dementia and the family. Thus, high reliability, precision and low battery use. The study was a public private innovation project involving users, a NGO, municipalities, universities and private companies in the Northern Denmark.

In the study, user-involvement including people with dementia and their family carers, were used to ensure their experiences and needs were met in the development of the tracking solution. In the study, both people with dementia and their families expressed the need for a new solution that supports people with dementia independently to engage in the local community without worrying the family. Some families had already experienced situations where they got worried about the safety of their relative with dementia. Many developed different strategies for avoiding situations where the person with dementia was not able to find their way. Both people with dementia and their carers empathized the importance of developing solutions that support the autonomy and freedom of people with dementia together with ensuring their safety.

Three workshops were held for people with dementia and the family carers respectively. Including two groups of people with dementia and one group of relatives. The three workshops focused on: Introduction and brainstorm for developing a new tracking solution, Introduction to possible new and existing tracking solutions and Evaluation and presentation of the developed tracking solution. Each workshop was planned in relation to the wishes and the competences of the participants and involved different creative and innovative methods.

The developed dementia tracking solution was evaluated positively by most of the participants and several were keen to test the solution. However, the participants were also critical towards the prototype of the solution and expressed a need for more features, another design and the possibility of individualisation.

Oral Presentation Abstracts

ID: 402 / OS26: Diverse populations

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: twinning, indonesia, netherlands, minority, communities

Accessing Indonesian immigrant as minority group in the Netherlands.

Amalia Fonk Utomo

Stichting Alzheimer Indonesia Nederland, Netherlands, The

Abstract:

Background

There are 16.151 registered Indonesian living in The Netherlands (source: Indonesian Embassy in The Netherlands). Around 800.000 Dutch people in 4 generations have Indo-European roots. Besides Indo-Europeans, around 40.000 people from Moluccan descent live in the Netherlands.(source: latitudes.nu) and 1.500 Indonesian are studying in The Netherlands.

Alzheimer Indonesia Nederland & Alzheimer Nederland have a collaboration under the Twinning Program of Alzheimer's Disease International. This is a three-year program for 2017-2019 and a renewal of the previous program and funded by the Dutch government. Part of the funding is directed to activities for Indonesians in The Netherlands.

Objective

To access Indonesian immigrant as minority group in The Netherlands.

Activities

In 2017 a foundation, Stichting Alzheimer Indonesia Nederland was created in the Netherlands to support and raise awareness within the Indonesian community living in the Netherlands about dementia and efforts in Indonesia.

Accessing Indonesian Communities: religious, art and culture, professionals and government sharing information about the foundation and developments in Indonesia by connecting to more than 20 Alzheimer Indonesia's chapters. By mid 2019 more than 2000 Dementia Friends and 50 volunteers are arranged in 8 cities: Groningen, Den Haag, Eindhoven, Amsterdam, Arnhem, Rijswijk, Zoetermeer, Rotterdam – The Netherlands and 2 cities in Indonesia: Jakarta and Malang.

The foundation also connected to home care and nursing homes, an Alzheimer centre at the University and Alzheimer Café and two migrant organisations. We found that it is useful to explain Indonesian culture and behavior with the aim to help them to make their care accessible to Indonesian people. This is useful for both home care and nursing home care.

Alzheimer Nederland received a three-year grant from the Ministry of Health to support the program financially in collaboration with Alzheimer Indonesia and Alzheimer Indonesia Nederland.

Conclusion

Indonesian population in The Netherlands is big. With it's diversity of culture and language, hopefully The Netherlands will continue the program for the future.

Oral Presentation Abstracts

ID: 413 / OS22: Diagnostic tools

Abstract Topic: Diagnostic tools

Keywords: Dementia, diagnosis, Tanzania, sub-Saharan Africa, task-shifting

Validation of a brief app-based dementia screening tool for rural primary healthcare workers in rural Tanzania

Stella-Maria Paddick^{1,2}, Marcella Joseph³, Sarah Urasa³, Damas Andrea⁴, Aloyce Kisoli³, Catherine Dotchin^{1,5}, John Kissima⁶, Irene Haule⁶, William Keith Gray⁵, Louise Robinson¹, Richard Walker^{1,5}

¹Newcastle University, United Kingdom; ²Northumberland Tyne and Wear NHS Foundation Trust; ³Kilimanjaro Christian Medical University College, Tanzania; ⁴Mirembe National Psychiatric Hospital, Tanzania; ⁵Northumbria Healthcare NHS Foundation Trust; ⁶Hai District Hospital, Boma'ngombe Tanzania

Abstract:

Background/Objectives

The majority of people with dementia live in low and middle income countries (LMICS). In sub-Saharan Africa (SSA), human-resource shortages in mental health and geriatric medicine are well recognised. Use of technological solutions may improve access to diagnosis. We aimed to assess the diagnostic accuracy of a brief dementia screening App for non-specialist workers in rural Kilimanjaro, Tanzania against blinded gold-standard diagnosis of dementia by DSM-V criteria. The App includes two previously-validated culturally appropriate low-literacy screening tools for cognitive (the IDEA six-item screen) and functional impairment (the IDEA-IADL).

Methods

This was a two-stage community-based door-to-door study. In phase I of the study, rural primary health workers approached all individuals aged 60 and over identified during a door-to-door census for App-based screening in 7 villages in the Hai district, Kilimanjaro Tanzania.

In Phase II of the study those screened were stratified and selected for second-stage assessment based upon App screening score. All those screen positive (probable dementia) 50% of borderline cases (possible dementia) and 10% of screen-negative individuals were selected from the 12 villages. Second stage assessment for major cognitive impairment took place blinded to App screening score and included clinical history, neurological and bedside cognitive assessment and collateral history from a close informant completed by a research doctor and MSc-qualified nurse.

Results

A total of 3011 older people consented to screening within the included villages (of 3122 identified during an accompanying census).

Of these, a total of 610 individuals (201 screen positive, 85 with a borderline score (possible dementia) and 324 screen negative controls) were evaluated in stage 2.

The area under the receiver operating characteristic (AUROC) curve was 0.75 (95% CI 0.74-0.83) for DSM-V dementia diagnosis with sensitivity 84.8% and specificity 58.4%. For those 358 with an informant present at screening, AUROC was 0.79 for combined cognitive and functional assessment.

Conclusions/Perspective

The pilot dementia screening App showed good diagnostic accuracy for dementia when administered by non-specialist rural workers in the community. Further validation in other similar settings is required, but this technological approach to dementia screening may be a good way forward in this setting.

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Oral Presentation Abstracts

ID: 415 / OS10: Design, architecture and the built environment I

Abstract Topic: Environment and architecture for dementia

Keywords: Environment and Architecture for Dementia, microtown, NewDirection Care, Independence and Autonomy

Independence and autonomy in a familiar environment at the world's first residential aged care microtown

Natasha Chadwick

NewDirection Care, Australia

Abstract:

Most people with dementia would prefer to stay in their own home for as long as possible. However, many are going into residential aged care facilities sooner because their households are not designed to help them live independently or because changes resulting from their conditions mean it is no longer safe for them to live alone. Yet staying in familiar surroundings with the right support is crucial for the health and wellbeing of people with dementia and complex care needs and can help them lead an active and independent life for longer.

NewDirection Care Bellmere is an Australian and world first, a microtown™ inclusive community for the elderly and those living with younger onset dementia and complex care needs. It recreates life in the real world allowing residents to lead as independent a life as they can in a familiar environment and is transforming the way we treat people with dementia.

NDC Bellmere resembles a typical Australian suburban community with 17 houses located on six streets across a secure two-hectare site. Just like any suburb, it has a town centre with a range of facilities and services such as a corner shop, café, beauty salon, cinema and wellness centre.

There are no locked doors or secure dementia units, and residents can walk, explore and socialise as they wish throughout the community. This innovative model provides a dementia-friendly and familiar environment where residents can live a full and active life as much as their condition allows.

At NDC Bellmere, our homes are just like any home on a typical suburban street with back yards, front verandas, living and dining rooms and ensuite bathrooms. There are seven residents per home who are placed there according to their lifestyles and values, who they are as individuals and the sorts of people they will get on best with socially.

Supporting residents are our House Companions™, a unique 24/7 role, another world first in residential aged care. On completion of training and a five-week induction programme, House Companions form part of each home's "family" unit providing assistance as needed with daily activities, such as cleaning, cooking, personal care and medication. They operate around our residents giving them the freedom they deserve.

There are no shower lists or regimented wake-up and meal times. Instead, House Companions help each resident determine their day-to-day patterns, menus, activities and outings. Residents can get up in the morning when they want, eat what and when they want to, receive guests and visit friends in the other houses – just as they've done throughout their lives.

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Residents enjoy a much better quality of life with this autonomy and independence in a non-clinical setting. The benefits we are seeing are outstanding and include greater contentment, a feeling of belonging, reduced medication (including antipsychotics), significant changes in responsive behaviours, increased appetite, weight gain, better sleep and more engagement with our community.

Oral Presentation Abstracts

ID: 432 / OS02: Attitudes and awareness I

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia-related stigma, RCT, Dementia knowledge, Australia

Dementia Stigma Reduction (DESeRvE): Randomised controlled trial to reduce dementia-related stigma in the general public

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¹Wicking Dementia Research & Education Centre, University of Tasmania, Australia; ²Centre for Research on Ageing, Health and Wellbeing, Australian National University, Australia; ³Department of Community Mental Health, University of Haifa, Israel; ⁴National Centre for Epidemiology & Population Health, Australian National University, Australia; ⁵Neuroscience Research Australia, Australia; ⁶School of Psychology, University of New South Wales, Australia

Abstract:

Introduction: Dementia is a highly stigmatised condition leading to significant effects on the health and well-being of people with dementia (PWD), and their carers. Stigma can also prevent people from seeking help, which results in people missing out on timely diagnosis and the utilisation of health and social services. The two main stigma reduction strategies that have been successfully applied to other stigmatised conditions such as mental illness are education and contact, which enhance awareness and understanding of the condition. This project therefore developed and evaluated an intervention program (DESeRvE) aimed at the general public to reduce dementia-related stigma utilising these two strategies.

Methods: 1024 Australians aged between 40 and 87 (M=60.8, SD=10.1) participated in the randomised controlled trial. 769 completed the intervention and 458 completed the 12 weeks follow-up assessment. DESeRvE examined four conditions (online education program (ED), contact through simulated contact with PWD and carers (CT), education and contact (ED+CT), and active control). Dementia-related stigma was measured with a modified Attribution Questionnaire and knowledge of dementia was measured with the Dementia Knowledge Assessment Scale at the baseline, and immediately and 12 weeks after the completion of the intervention.

Results: There were no significant group differences in relation to their demographic characteristics. All experimental groups improved significantly from baseline in dementia knowledge. Especially, the ED ($\beta=0.85$, SE=0.07; $p<.001$) and ED+CT ($\beta=0.78$, SE=0.08; $p<.001$) groups at immediate follow up and CT ($\beta=0.21$, SE=0.09; $p<.05$) and ED+CT ($\beta=0.32$, SE=0.09; $p<.001$) at 12 weeks follow up showed a significant difference from the control group. No significant improvement (reduction in score) was found for dementia-related stigma except for cognitive related stigma. A significant reduction was found in cognitive related stigma for the CT group. Sub-analyses were conducted using those with higher levels of dementia-related stigma, which have shown a significant reduction on stigma scores at both immediate and 12 weeks follow ups for all three experimental groups.

Conclusions: Learning about dementia via written materials and/or having (virtual) contact with PWD and carers can have a positive effect on the general public, especially in enhancing dementia knowledge. The results suggested that DESeRvE can be a valuable tool to enhance public's dementia knowledge and to change how people think about people living with dementia. However, how the public feel about and behave around people with dementia may be harder to change within a short time. Further research is needed targeting groups with higher levels of stigmatic beliefs and attitudes.

Oral Presentation Abstracts

ID: 435 / OS19: Economics of dementia

Abstract Topic: Economics of dementia

Keywords: BPSD, economics, Dementia Support Australia, behaviour support

Economic impact of behaviour support services for people living with dementia in Australia

Tom Morris, Colm Cunningham, Marie Alford, Sofia Rahman

Dementia Centre, HammondCare, Australia

Abstract:

Dementia Support Australia (DSA) is the leading provider for behaviour support for people living with dementia in Australia. Through a team of specialist dementia consultants and medical professionals, DSA delivers non-pharmacological and person-centred recommendations to address the underlying causes of behaviour in dementia.

The significant impact of DSA on behaviour reduction and improvement in the quality of life is well documented. However, no investigation has been conducted on the impact of DSA compared to other behaviour support programs, nor the economic impact of DSA to downstream health utilisation.

This paper reports on the recent (2019) independent economic evaluation of DSA services by KPMG. This analysis entailed the review of over 6,000 DSA client outcomes and characteristics, and the corresponding cost required to operate the program by the Australian government.

The findings from this analysis are significant. Not only did KPMG confirm the significant clinical impact of DSA on behaviour, but also identified that when compared to other dementia support services worldwide, DSA was likely to deliver **the** dominant intervention for behaviour support.

Importantly, DSA has a significant impact on downstream health utilisation (e.g. hospitalisations, medication use) of people with dementia. Specifically, DSA is likely to save the Australian government \$41 million annually.

The results of this economic analysis will be discussed in the context of aged care in Australia and worldwide, and how the DSA model of care and associated savings can be translated to a range of settings.

Oral Presentation Abstracts

ID: 440 / OP1: Registries

Abstract Topic: Registries

Keywords: Public involvement in research, Recruitment platform, Dementia research

Towards building a citizen science community: an Australia-wide dementia research participation and public engagement platform

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¹The University of Sydney, Australia; ²University College London; ³University of Exeter

Abstract:

Background and objectives

StepUp for Dementia Research is a research participation and engagement service, a “one-stop shop” to connect individuals (both with and without dementia) with researchers delivering studies into prevention, diagnosis, treatment and care in dementia. The establishment of such a community of interest will improve research efficiency and widen public engagement in research, leading to improved cognitive health and dementia literacy, and reduced stigma towards dementia in both the public and professionals.

People living with dementia currently have no systematic way of becoming involved in research. Recruiting participants in dementia research is costly and time-consuming. Delays in finding the right people for studies can result in studies taking longer to deliver, often requiring funding extensions and ultimately limit the effectiveness of research and evaluation when study samples are insufficient for robust analysis and generalisation of findings.

Positive impact

StepUp for Dementia Research is being modelled on the UK Join Dementia Research service, established in 2015. JDR has demonstrated its success in terms of increased research recruitment efficiency, access to research for the public and for researchers, public engagement, and attitudinal change in dementia and research participation. Our new online, telephone and postal service uses innovative matching technology to provide people with a way of registering interest in studies and allowing researchers to access matched volunteers, to speed up study delivery, and provide a better, more inclusive service for people affected by dementia. Since its official launch in June 2019, StepUp for Dementia Research has attracted a great deal of interest and support from individuals, various communities, organisations as well as dementia researchers across Australia. This presentation will report on the most up-to-date progress made through StepUp for Dementia Research in improving public participation in dementia research and its early implementation processes and evaluation outcomes. Implications for future research, global collaboration, policy and service delivery will be presented.

Perspectives

StepUp for Dementia Research aims to increase the speed and reduce the cost of research, and to improve opportunities for access by facilitating recruitment efficiency and broader community engagement. This innovative service has the potential to inform and guide dementia services and research policy development and lead to an inclusive and integrated system. By improving the quality of research and evaluation, the StepUp service can also make a significant contribution to addressing a major gap in building the evidence base to inform policy and practice and knowledge translation.

Oral Presentation Abstracts

ID: 454 / OS01: The global policy environment

Abstract Topic: Dementia and the Convention on Human Rights of Persons with Disabilities (CPRD) – NEW

Keywords: disability, rights, legislation, awareness, action

Hidden no more: dementia and disability, an all party parliamentary group (APPG) inquiry

Ella Robinson, Fiona Carragher

Alzheimer's Society, United Kingdom

Abstract:

The recent, and growing international, focus on adopting a rights-based approach to achieving change for people with dementia has largely been driven by people affected by dementia themselves. Seeking a rights-based approach, this study used the United Nation's Convention on the Rights of Persons with Disabilities (CRPD) as a basis on which to determine whether people affected by dementia are having their rights met.

The study set out to shine a spotlight on dementia as a disability in the UK. It identifies barriers that prevent people from living independently and aims to bring dementia rights into the mainstream – giving urgency and weight to the movement of change and providing a framework for action. Ultimately, the study seeks to enable and empower people with dementia to claim and advocate their right to access services and to be treated fairly and equally.

Dementia is internationally recognised as an acquired disability. Yet this project found that people with dementia in the UK are not having their rights met. The CRPD, widely ratified around the world, exists to protect and promote the human rights of disabled people – including health, employment, personal safety and independent living. Yet, far too little support and provision has been given to implement and deliver the CRPD.

We achieved one of the largest responses to any All-Party Parliamentary Group inquiry, highlighting the fundamental importance of the topic. The study's survey received 2,521 responses from people living with dementia, carers, family, friends, and professionals. Focus groups had input from 76 people with dementia and 11 carers and there were 28 written submissions and an oral evidence session.

The study revealed an overwhelming lack of awareness of dementia as a disability and a clear signal that society lacks the legislation and funding provisions to uphold the rights of people with dementia. Significant barriers identified were: employment, social protection, transport and housing. It is clear that the largely 'hidden' nature of the condition, as well as its varying impact and symptoms mean that the public, employers, organisations, governments and public bodies are not always aware of how best to support someone with dementia and therefore legal requirements, such as reasonable adjustments, are not always common place. This must change.

UK parliament is leading the way in this space, working to make the recommendations from the study a reality. However, with increasing numbers of people living with a diagnosis of dementia, it is essential that their rights are recognised and upheld, not only in the UK but worldwide. We want to create a global society where people with dementia feel supported to live a life they want to live, in dignity and without prejudice or discrimination. This requires action from governments, organisations and civil society to create a more inclusive society for people living with dementia.

Oral Presentation Abstracts

ID: 455 / OS19: Economics of dementia

Abstract Topic: Economics of dementia

Keywords: Carer, economy, research, women, workforce

The economic cost of dementia to English businesses

Morgan Griffith-David, Fiona Carragher

Alzheimer's Society, United Kingdom

Abstract:

Carers of people with dementia spend 82 billion hours providing informal care globally, according to ADI research, equivalent to 40 million full time employees. This is forecast to increase to 65 million full time workers by 2030.

Unpaid carers, predominately women, shoulder two-thirds of the cost of dementia to the UK economy. Many carers are forced to reduce their hours of paid employment or leave the workforce as a result of their commitment to care for someone with dementia. Carers are more tired and businesses have to deal with increased staff turnover, recruitment and training.

This study seeks to quantify the economic impact of dementia on businesses in England. Alzheimer's Society commissioned the Centre for Economics and Business Research (Cebr) to carry out the project. This research is being conducted by analysing data from the NHS Personal Social Services of Adult Carers, Labour Force Survey, and other datasets. This will enable the researchers to ascertain the number of hours committed to caring each week, employment status and various demographic factors. The project will also examine the disproportionate impact that caring responsibilities have on women in work – globally, women contribute 71% of informal dementia care hours and are more likely to provide intensive and inflexible forms of care supporting someone with dementia with activities of daily living that are harder to fit around paid work responsibilities. The team will derive an estimate for the number of people impacted by caring responsibilities and the impact on businesses.

This follows from a study conducted by Alzheimer's Society and Cebr in 2014 which found that the cost to businesses in England was £1.6 billion through reduction in work hours and loss of skills for those leaving the workforce. A new element in this year's research will be an assessment of the additional cost businesses face due to workers being less well rested and more distracted as a result of caring commitments, leading to a reduction in productivity. We will forecast the cost to business in 2040 and intervening years.

The evidence produced will strengthen the case that the government must invest in support for people with dementia and their carers. The Dementia Statements reflect that people affected by dementia believe it is a priority that they have a right to properly funded care and the Glasgow Declaration calling for the creation of a European Dementia Strategy and national strategies with allocated funding. We believe the state sector must recognise the impact of dementia on carers and the impact of an underfunded care sector that depends on unpaid carers has on the English workforce, businesses and the economy. Better care provision for people living with dementia is needed to reduce the cost of dementia to businesses and the economy.

Oral Presentation Abstracts

ID: 464 / OS08: Community partnerships / Public-Private-People partnerships

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Innovation, Collaboration, Fundraising, Industry, Inclusion

Insurance United Against Dementia

Charlotte Matier, Alice Hardy

Alzheimer's Society, United Kingdom

Abstract:

This talk will showcase the achievements of Insurance United Against Dementia (IUAD) – a pioneering initiative created in response to the breadth of issues faced by people affected by dementia.

Masterminded by Alzheimer's Society in collaboration with leaders of the UK insurance industry, IUAD takes a unique approach to deliver far-reaching impact. Working with firms, individuals and sector leading bodies, we are:

1. Raising £10 million for dementia research
2. Ensuring everyone in the sector has access to our services and that firms can better support employees with dementia or caring responsibilities
3. Creating a more dementia-friendly industry by improving financial inclusion. People with dementia have told us that cover can be too expensive, complicated, or unfit for purpose.

We pursued a sector-led initiative due to the challenges insurers face in relation to dementia. It presented a remarkable opportunity to create an integrated campaign that delivers on Alzheimer's Society's entire strategy – across support, society and research.

This talk will reveal how we united a board of senior volunteers to subvert traditional fundraising mechanisms and create strategic, cohesive partnerships. We will explain how our dedicated team has gained the trust of decisionmakers in some of the world's largest insurance firms. And we will share how we created a culture of unity, building a campaign that the 300,000 people in the industry are proud to support.

Through a genuine sense of ownership, IUAD has continually built momentum and engagement since its launch in July 2017. Our InsureTrek event united 25 insurance professionals to take on Mont Blanc, raising over £100,000. Sector-wide initiatives like this mean IUAD regularly features in trade press, cementing our place at the heart of the industry.

Corporate partners have been instrumental in shaping our impact. Attitudes towards dementia have changed, with Dementia Friends sessions helping to reduce stigma. People have told us they now feel able to talk about dementia with colleagues who understand what they're going through.

We're also ensuring people receive the right support. In partnership with the Insurance Charities benevolent fund, we've created a bespoke pathway for insurance workers – past and present – who will receive personalised support throughout their dementia journey.

IUAD is two years into its five-year adventure – raising £2 million and creating 15,000 Dementia Friends so far. But many more exciting achievements lie ahead. We're determined to overcome the insurance barriers that people with dementia face. By joining forces with an entire sector, IUAD has created a brand new way of funding research, raising awareness, and driving meaningful change. This type of campaign is unique not only to insurance and dementia, but across the charity landscape. We know

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that this can work on a broader scale and are excited to share the learnings that will help accelerate progress for people with dementia.

Oral Presentation Abstracts

ID: 471 / OS15: Risk Factors II

Abstract Topic: Risk factors

Keywords: Cognitive impairment, Triglycerides, Lipoproteins, Hydroxymethylglutaryl-CoA (HMG-CoA) Reductase Inhibitors

Cognitive impairment reversely associated with statins consumption and high density lipoprotein: the results of Bushehr Elderly Health Program (BEHP)

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Abstract:

Background

Relationship between lipid profiles also the consumption of statins with cognitive impairment are very debating. The aims of this study are determined the association between serum lipid profile, furthermore, statin consumption with cognitive impairment in a large community-based sample of older adults.

Methods

Bushehr Elderly Health Program (BEHP) is an ongoing longitudinal study with a representative sample of community-dwelling older adults ≥ 60 years that started since March 2013. The paper is the results of a cross-sectional approach to data collected in state II of this study. Demographic, lifestyle (smoking and physical activity), past medical and medications history data were collected by interviewing with the participants and one of their informant. Anthropometric and blood pressure measurements were carried out using standard protocols. Over-night fasting blood samples were collected. Lipid profiles, fasting plasma sugar, hemoglobin A1C were measured using auto-analyzer and calorimetric methods. Diabetes and hypertension were defined based on international guidelines. Cognitive assessment was evaluated using Mini-Cog (recall of three words and clock drawing test) also category fluency test (CFT) for the naming of animals. Cognitive impairment was defined by the problem in each of mentioned test (CFT was categorized by education levels; CFT <12 for education ≤ 4 years, CFT <14 for education level 5-11 years, and CFT <16 for education levels \geq diploma). Depressed mood was assessed using PHQ-9. Univariate and multivariable logistic regression model for the analysis of the associations.

Results

Totally, the data of 2340 older adults (1199 women; 51.24%) with mean age 69.30 ± 6.34 years were analyzed. Of the total, 1476 (63.08%) had cognitive impairment. In univariate models, cognitive impairment was not associated with lipid profiles and statins consumption. Whiles, in multivariable analysis after adjustment for, LDL, triglyceride, age, gender, diabetes mellitus, years of schooling,

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physical activity, smoking, hypertension, depressed mood, and history of stroke, the using statins and higher serum HDL levels reversely related to prevalence of cognitive impairment [odds ratio (OR) = 0.79 (0.62 – 0.99) and OR=0.99 (0.98 – 0.99), respectively. Moreover, in those participants who had a cognitive impairment, the CFT score significantly higher in subjects used statin than those did not consumed it, even the resulted were adjusted for age and sex.

Conclusion: It seems that the prevalence of cognitive impairment in subjects that used statins was significantly lower than those no consumed statins and the effect is independent of lipid profile and other confounder factors. This could be justified by the ability of statins to improve brain endothelial cell function independent to lipid profile.

Oral Presentation Abstracts

ID: 476 / OS18: Education, training and formal carers

Abstract Topic: Formal carers education and training

Keywords: Dementia, home care, training, qualitative research, co-production

A qualitative study exploring the skills, training and support needs of home care workers supporting people with dementia living at home

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Abstract:

Background: Most people with dementia want to remain living in their own homes. This is often made possible with support from home care workers. The home care workforce is in high demand globally, particularly in the care of people living with dementia. However low pay, stress, limited support and training, and high staff turnover make the work challenging.

Methods: We conducted 82 qualitative interviews with people with dementia (n=11), family carers (n=22), health and social care professionals (n=19), home care workers (n=23) and home care agency managers (n=7) in England. Our research questions were: What are the skills, training and support needs of home care workers to support people with dementia living at home? How should this training be delivered in practice? We conducted a thematic analysis that was carried out in an iterative process to look for key themes across the data.

Results: We identified three main themes that answered our first research question: Theme 1: '*navigating the care network*' had two subthemes: '*home care worker identity*', describing variation in how home care workers' role in the care network is perceived by different stakeholders: as professionals, as "one of the family", as an expert, and as an employee of the family or care agency. The second subtheme, '*deciding what gets done*' explored different expectations among stakeholders about what care work is performed and how, as well as who is in control of deciding this. Theme 2: '*Doing with, not doing for*' explored how home care workers did or did not facilitate their clients' autonomy and choice. Theme 3 '*caring for the care workers*' highlighted how the home care agency should support their staff with the challenges associated with the role. In answering our second research question, ideas for the process and delivery of training was comparable across key stakeholders, including a format that is participatory and interactive.

Conclusion: Future training programmes should focus on increasing shared understanding about the home care worker role; including opportunities for home care workers to develop and try out communication and relationship building skills to navigate complex relationships, and to facilitate discussions when there are different views. Other key training needs include understanding the nature of dementia and personhood, and strategies to promote autonomy and empowerment of clients with dementia. Home carers valued clear home care agency protocols, needs-focused care plans, and processes for scheduling consistent client visits to develop relationships of familiarity and trust. Findings from this research were used to inform the development of a co-produced training programme intervention for home care workers in England. Developing a co-produced intervention with key stakeholders (people with dementia, family carers and home care staff) aims to aid consistency and accessibility of training amongst the home care workforce in England.

Oral Presentation Abstracts

ID: 481 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Young onset dementia

Keywords: advance care planning, young-onset dementia, qualitative research, comparative study, family caregivers

Comparing advance care planning in young-onset dementia in the USA vs Belgium: challenges relate to societal context

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Abstract:

Background/ Objectives

Although dementia is usually associated with older adults, in up to 9 % of all cases the condition develops before the age of 65, captured by the term young-onset dementia. Wide consensus exists regarding the significance of advance care planning (ACP) for people with (young-onset) dementia. ACP is a communication process between patients, families and professionals in which preferences, values and goals for future (end-of-life) care are explored. Despite the recurrent hypothesis that younger persons with dementia and their caregivers have distinct needs and preferences regarding ACP, this topic remains a blind spot within current literature. Although it is generally recommended to involve family caregivers of persons with young-onset dementia in the process as soon as possible, their role, needs and preferences for ACP are unclear. Moreover, it is unknown whether the ideas, topics and preferences that arise during ACP communication differ throughout varying societal and legal contexts. Therefore, this study aimed to explore the engagement in and the conceptualisation of ACP from the perspective of family caregivers of persons with young-onset dementia and to identify potential similarities and differences in this area between American and Belgian persons with young-onset dementia and their family caregivers.

Methods

This study has an exploratory qualitative design: using the same interview guide for both groups, 28 semi-structured interviews were conducted. We purposively sampled 13 American and 15 Belgian adult caregivers with varying familial ties to the person with young-onset dementia. Verbatim transcripts were analysed through the method of constant comparative analysis.

Results/ Positive impact

Important similarities between American and Belgian respondents were: caregivers' unfamiliarity with the term ACP and what it entails, limited communication about advance directives, and caregivers' recommendation for professionals to timely initiate ACP to ensure their loved-one with young-onset dementia could participate. Major differences were: attention paid to those end-of-life decisions depicted in the legal framework of their respective countries, higher emphasis placed on financial planning by American caregivers than by their Belgian peers, and in case of consulting professionals for advance directives American caregivers turned to lawyers, whereas Belgian caregivers relied on physicians.

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Conclusions/ Perspectives

Specific nuances and challenges in terms of ACP in young-onset dementia arise from a particular societal and legal context on the one hand, and from patients' and caregivers' younger age on the other. Professionals' awareness of and responsiveness to these specificities could facilitate the ACP process and could make engaging in ACP more accessible to persons with young-onset dementia and their caregivers. Based on our interpretation of results, several recommendations for practice and policy are made.

Oral Presentation Abstracts

ID: 482 / OS02: Attitudes and awareness I

Abstract Topic: Attitudes, awareness and stigma

Keywords: volunteer work, attitude, volunteer

Attitudes towards people with memory related diseases as volunteers in Finland

Kaisa Erika Kauhanen, Päivikki Hannele Paakkanen, Emmaleena Niemi

The Alzheimer Society of Finland, Finland

Abstract:

Volunteering is work that is done on the basis of an individual's own free will and is traditionally organised hierarchically around the roles of helper and the person(s) being helped. Actors in this field are increasingly attempting to reform this hierarchy by adapting activities to be more orientated towards community action and by enabling a more diverse range of volunteers to participate in these activities. New forms of volunteering include supported volunteering and volunteering done as pair-work. This change has been slow due to organisational resistance to change or negative attitudes towards the various actors involved.

The Alzheimer Society of Finland has been working on a volunteer development and that has involved the further inclusion of persons living with memory related diseases in voluntary activities and working to improve attitudes towards volunteering in Finland.

The Finnish Pensioners' Federation was chosen as the research partner for this study through a desire for the survey to be conducted by a non-member organisation. Through its network of 400 local associations, the Federation represents a wide range of citizens of retirement age in Finland and the civic work they do around the country. The questionnaire was sent to all member organisations and their chairpersons, as well as to volunteer coordinators. A total of 316 completed questionnaires were returned.

70% of respondents were of the opinion that people living with a memory related diseases could potentially carry out volunteer work in their association. The areas in which the respondents viewed the inclusion of people living with memory related diseases in volunteering as being most appropriate included visiting care homes and other care facilities (70.5%) and in providing telephone assistance (70.4%). The areas with the least favourable responses were chairperson roles within the associations (4%) and help with running errands (13.6%).

The survey also examined the opportunities that volunteers have to share their experiences of living with memory related diseases with other people within the associations. While 50.3% of the respondents were of the opinion that the association volunteers did not share information with others, 38.6% considered it quite easy for people to share information about their experiences.

The take-home message from the responses in the free-form section of the questionnaire was that the prerequisites for the involvement of people living with memory related diseases vary greatly, often as a result of their stage of illness and occupational capacity. Our findings demonstrate that living with a memory related diseases does not prevent a person's involvement in volunteering, but requires appropriate roles for such volunteers and extra help and support as their illness advances.

Oral Presentation Abstracts

ID: 484 / OS15: Risk factors II

Abstract Topic: Risk factors

Keywords: Risk of dementia, Diabetes mellitus Type 2, Risk Prediction modelling, C-statistics, Calibration test

Risk prediction models to predict dementia in type ii diabetes: initial results of systematic review

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¹University of Edinburgh, United Kingdom; ²NHS Lothian & University of Edinburgh, UK

Abstract:

Background: Diabetes mellitus (DM) is associated with increased risks of 73% for all types of dementia, 56% for Alzheimer's disease, 127% for vascular dementia. Due to limited success in identification of effective treatments to cure dementia, the focus is now on evaluation of early intervention strategies to either prevent or modify its progression. One strategy is to identify high risk populations through risk prediction models. There is limited research on diabetes specific dementia risk predictors. The aim of this systematic review was to identify diabetes specific dementia risk prediction models and describe their predictive properties.

Methods: Ovid Medline, Cochrane Library, PsycINFO (Ovid), Embase, Web of Science, SCOPUS were searched till 2019 to identify diabetes specific risk prediction. Screening and full text review was performed by two independent reviewer. Data were extracted on study design, setting, number of predictors and model predictive accuracy measures.

Results: Four diabetes specific dementia risk prediction models were identified. The type 2 diabetes-specific dementia risk score included age, education, microvascular disease, diabetic foot, cerebrovascular disease, cardiovascular disease, acute metabolic event and depression with C-statistic of 0.736. Second model, developed in Chinese population, included age, sex, duration of type 2 diabetes, body mass index, fasting plasma glucose, HbA1c, stroke, postural hypertension, hypoglycaemia, coronary artery disease, anti-diabetes medications with C-statistics of 0.82, 0.79 and 0.76 for 3, 5 and 10 year risk of dementia respectively. The third model, the RxDx Dementia Risk Index, combined diagnosis and prescription information in a single risk score based on 31 disease conditions and showed excellent discriminative ability with C-Statistics of 0.80. The fourth model was based on constituted age, education, lower diastolic blood pressure, subjective complaints of memory dysfunction noticeable by others, and impaired medication, shopping, and travel outside a familiar locality. Receiver operating characteristic analysis revealed a satisfactory discrimination for AD specific for diabetic elderly subjects, with 95.2% sensitivity and 90.6% specific.

Conclusion: Models showed good discrimination ability and fall within the acceptable prediction range. The scores may be helpful in clinical settings as information on the majority of the individual predictors are readily available during patient care. There is need to both validate existing risk scores, improve on their predictive abilities and develop the simplest model which is still effective in a range of diverse settings and different population sub-groups with type 2 diabetes. Predictive performance may be improved by adding predictors such as APOE genotype, MRI findings, cognitive test results and biomarkers pertinent to diabetes.

Oral Presentation Abstracts

ID: 485 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: Dementia, nutrition, scoping review, dietary interventions, nursing home

Dietary interventions for people with dementia - can these improve the cognitive functions: a scoping review

Palle Larsen, Tina Louise Launholdt, Lene Moestrup

UCL, Denmark

Abstract:

BackgroundDementia is a major health problem worldwide, with one new case diagnosed every three seconds and an expected global prevalence of 75 million by 2030. The incidence of dementia appears to double by 2050, with demography showing an increasing size of the elderly population. An essential knowledge in the nutritional field is that the development of symptoms of dementia influenced by certain identified nutrients, and therefore it can be concluded that this also applies to people at risk of developing dementia. Primary focus have been the Mediterranean diet with a representation of studies at high evidence level showing a possible effect, but the area should be investigated further. Therefore, it is of interest to get an overview of the dietary field by doing a Scoping Review.

Review questions

The purpose of this Scoping review is to identify and describe qualitative or quantitative literature for people with or in risk for development of dementia, relating to non-pharmacological interventions including dietary intervention as a mandatory component of the intervention, in order to identify literature that can establish the basis for the preparation of a systematic review and possibly clinical guidelines.

Method

This Scoping review was prepared in accordance with guidelines described by Joanna Briggs Institute

Search strategy

An initial limited search on PubMed and CINAHL has been conducted to identify articles on the subject followed by analysis of keywords in the titles and abstracts and the index terms used to describe the articles. Initial keywords were dietary intervention, Dementia and non-pharmacological interventions.

The search strategy was tailored to each database and documented accordingly. The reference list of all included studies was screened for further studies and quotations of all included studies on the research issues have be sought and addressed for inclusion.

The databases searched include: PubMed, CINAHL , PsycINFO , Embase , Web of Science, Scopus and TRIP database, the JBI Database of Systematic Reviews and Implementation Reports, Cochrane Database of Systematic Reviews, Current Controlled Trials, and ClinicalTrials.gov and earch for unpublished studies.

Data extraction

Data extraction tables have been prepared by the reviewers to extract relevant data consistent with the objectives and have facilitated the identification of gaps in the literature.

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Results

We identified 4073 studies and 485 studies were included after screening of title. 22 categories were identified.

Conclusion

There are no effective dietary interventions that influence on cognitive function's in people with dementia. Four areas are of interest according to feasibility of dietary intake. These areas are: to optimize oral health, to secure optimal dietary intake according to the recommendations from the respective national borders of health's recommendations, to secure fluid intake and to be aware of intestinal function to prevent constipation.

Oral Presentation Abstracts

ID: 488 / OS02: Attitudes and awareness I

Abstract Topic: Attitudes, awareness and stigma

Keywords: Storytelling, Humor, Listening, Narrative

Exploring how the dynamics of story support people with dementia to give voice to their experiences and raise awareness of what it means to live with dementia

Alison Ward

University of Northampton, United Kingdom

Abstract:

Introduction: There is a growing need to include people with dementia in research so that they can share their experiences of what it means to live with dementia. This can help to raise awareness and improve understanding of dementia. Finding ways to capture the stories of people with dementia is important to make sure they are done in an inclusive and collaborative way. This presentation explores the dynamics of story to understand what constitutes story in research and how participants use this method to express themselves.

Method: A multi-method approach used photo-elicitation, poetry and storytelling techniques with people with dementia who undertake lifelong learning at a school in Denmark. The project aimed to understand their experiences of attending this service through these creative methods. Participants (n=10) took their own photographs of the school and of their home lives and these were discussed over four weekly sessions. Participants created a poem and storyboard about being at the school and told stories about their home life and what it meant to live with dementia.

Results: The findings show how the participants were able to use humour, body language and gesture, narrative scaffolding and listening techniques to share their stories and make sense of their world. The non-linear nature of stories and how these weave through conversations was also reported, showing how dementia can affect memory and language. The ways in which the participants interacted with each other was also observed, often showing patience when words were lost or stories repeated. The findings also explore how people with dementia can disengage from sharing their stories if the wrong approach is used, such as how questions are asked or if criticism is expressed by fellow participants/researchers. Different types of stories were identified, those that are personal or shared narratives and those that are often repeated and form part of a person's identity. The participants also shared insights into what it meant to live with dementia, using metaphor to explain their perceptions of a 'dusty place' in their brain, or door steps getting higher as the dementia prevents them from leaving their house.

Conclusions: The use of story can be an engaging way of including people with dementia in research and to learn more about their lived experience. This can help others to understand more about dementia and therefore how to provide appropriate support. The way that the participants interacted also provides learning on how to communicate and use body language, listening skills and patience to engage in a way which encourages a person to share their stories. The use of creative techniques is shown to support people with dementia to share their experiences both verbally and non-verbally and can help to break down barriers through greater understanding of what it means to live with dementia, and of different approaches to communicating with people with dementia.

Oral Presentation Abstracts

ID: 493 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Dementia, Diagnosis, Post-diagnostic support, Co-design, International

From plan to impact to quality improvement: a review of national and international approaches to improve diagnosis and post-diagnostic support for people living with dementia

Marie Poole¹, Jane Wilcock², Greta Rait², Henry Brodaty³, Louise Robinson¹

¹Newcastle University, United Kingdom; ²UCL, United Kingdom; ³UNSW Sydney, Australia

Abstract:

Background

The Alzheimer's Disease International global action plan 'From plan to impact' (ADI, 2018) emphasises that there is still much more to be done globally to promote the prioritisation of improving the lives of people with dementia and their families. Aligning with priority action areas, the COGNISANCE project aims to improve the situation of dementia diagnosis and post-diagnostic support across three continents.

An international research team (Australia, Canada, Netherlands, UK and Poland) are working in partnership with people with dementia, family care partners, healthcare professionals and key national and international dementia organisations: to co-design, deliver and evaluate toolkits and public campaigns to improve the dementia diagnostic process and post-diagnostic support.

We aimed to undertake a scoping review of existing evidence to inform the development of new international dementia toolkits and campaigns. Policy approaches, evidence-based guidelines and national public awareness campaigns from our partner countries and international organisations were reviewed.

Methods

We conducted online searches of documents and websites using key words, and consulted with partner countries, national and international organisations. Applying a scoping review framework methodology (Arksey and O'Malley, 2005) enabled the identification of concepts and details relating to diagnosis, and post diagnostic support.

We conducted a thematic analysis (Braun and Clarke, 2006) of the evidence to elicit core themes, components, and gaps in current approaches to improving diagnosis and post-diagnostic support.

Results

Eleven overarching themes were identified from national public awareness strategies which convey key messages to the general public and policy makers. Challenges to societal attitudes are a central theme. Thirteen themes reflected the focus of national dementia strategies and guidelines concerning diagnosis and post diagnostic support. Examples include factors relating to systems and processes as well as broader society. These key messages - aimed at the general public, practitioners and policy makers – highlight current and previous priorities around diagnosis and post-diagnostic support; and coherence and divergence of messages. A better understanding of these messages influences the content and delivery of future campaigns and toolkits to improve diagnosis and support.

Conclusions

Despite dementia care and its future prevention being a World Health Organisation priority, considerable diversity and inconsistency remains in the key messages emerging from existing national policy, practice and awareness approaches to dementia diagnosis and post diagnostic support. Within

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the new global COGNISANCE project, awareness of existing themes, emergent gaps, and alignment of key areas for different audiences will inform the co-design of our new, international campaigns and toolkits.

Oral Presentation Abstracts

ID: 497 / OS10: Design, architecture and the built environment I

Abstract Topic: Environment and architecture for dementia

Keywords: day centre, engagement, environment, culture

The built environment and its impact on embodied selfhood: social engagement in a day centre for persons with dementia

Nancy Brown¹, Chariklia Tziraki², Dvora Marcus³, Shirin Mordechai⁴, Shlomzion Pomerantz⁵

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Abstract:

Background/Objectives: Considering the current trend of ageing-in-place, this project provides an in-depth description of a multidisciplinary cultural activity that engages different aspects of brain functionality within a specially designed built environment of a dementia day centre. Much of the past research focuses on the support day centres provide the caregiver, yet few studies have examined the benefits to the cognitively impaired elderly themselves. Studies that do exist rely on caregiver surveys, staff assessments, or the responses of cognitively intact participants. Drawing upon Kitwood's description of the culture of dementia, this project's 'culture of dementia' explores what significance a day centre's built environment—physical, cultural, social, and therapeutic—has on 10 clients' embodied selfhood and the implicit and explicit system of relationships and social engagement of these moderate to severely cognitive impaired individuals.

Method: This project is based upon my 15-year experiential perspective of having created a living laboratory in a day centre for older persons with moderate to advanced dementia in Jerusalem, Israel. The weekly "Yiddish Group" consisting of 10 English-speaking clients, whose mother-tongue is Yiddish, participate in an exchange of conversation, singing, translating for others, and sharing culturally-related food. Through this ethnographic study, the data collected through participant observation may show what we observe on a daily basis--that the clients of this group increase the awareness of their surroundings, their engagement with the world, and their social interactions with coherence, purpose, and meaning. These aspects of their existence are fundamental to their being, define them as individuals, and are thus indicative of selfhood.

Results: Central to my analysis is an understanding of what Kontos calls embodied intentionality and relational presence that describes the participants and their bilingual competency. Within this day centre's social and cultural context, their connection to the Yiddish language, their ability to spontaneously engage in Yiddish conversation and singing among themselves, their ability to translate for someone learning Yiddish, and their sharing of culturally-related food sustains their selfhood despite severe cognitive impairment. This invites a rethinking of selfhood as no longer the prerogative of conscious will, but also as emanating from the instinctiveness of the body within the specially designed day centre environment.

Conclusion/Perspective: Within a framework of embodiment characterised by observable coherence, capacity for improvisation, and affective relationality, this not only adds a new dimension to the debate about selfhood and human agency in Alzheimer's disease, but also adds to our understanding of the importance of the day centre, its built environment, and the key role both plays in ageing-in-place.

Oral Presentation Abstracts

ID: 500 / OS01: The global policy environment

Abstract Topic: Dementia and human rights – NEW

Keywords: PPI, research, involvement

Developing person public involvement (PPI) in Irish dementia research: empowering people with dementia and caregivers to exercise their right to be involved in research that impacts them.

Laura O'Philbin, Kevin Quaid

The Alzheimer Society of Ireland

Abstract:

Introduction

In April 2019, the [Alzheimer Society of Ireland (ASI)] established a Dementia Research Advisory Team (DRAT). This is a group of Experts by Experience who influence, advise and work with researchers across Ireland in a Person Public Involvement capacity (PPI). PPI occurs when the public/patients work in partnership with researchers in setting research priorities, planning and managing studies, as well as in interpreting findings and disseminating results. People with dementia and caregivers have the right to be involved in research that pertains to them, and the purpose of the DRAT is to empower them to exercise this right. This work represents a significant step towards a rights-based approach to dementia research.

Methods

Members of the DRAT collectively developed terms of reference detailing their expectations of [ASI], researchers, and their role in all PPI activities. Researchers request PPI support with their work by completing a detailed application form which is shared with members of the DRAT who then decide if they would like to be involved in that specific project. [ASI] supports team members to become active stakeholders in dementia research through individual support and capacity-building workshops on topics around how research works, communicating your message effectively, and the impact of PPI in research.

Positive Impact

Members of the Dementia Research Advisory Team have made positive and significant contributions to a range of research projects ranging from Masters Level to large national projects. There are ten experts by experience in the group, of which five are people living with dementia and five are caregivers. To date, every member has been involved in at least one research project as a PPI contributor. Within the first 12 months of establishing the team, members have taken part in four capacity-building workshops and co-presented at a national and international research conference.

Perspectives

The Dementia Research Advisory Team is the first dementia-specific PPI group in Ireland. Capacity for facilitating PPI within the research community is still developing, but there is clear progress. Practical 'lessons learned' on what did and did not work well will be presented, in addition to how the Dementia Research Advisory Team has navigated challenges and opportunities for involvement of people living with dementia and caregivers in research. The future of PPI in Irish dementia research will also be discussed.

Oral Presentation Abstracts

ID: 511 / OS18: Education, training and formal carers

Abstract Topic: Education and training in hospitals – NEW

Keywords: Dementia, Hospital, Education, Promoting Excellence.

Leadership and innovation in hospital care: the role of the Alzheimer Scotland dementia nurse consultant in the delivery of education and training in hospitals

Ruth Louise Mantle

NHS Highland, United Kingdom

Abstract:

Improving hospital care is a key change area in Scotland's National Dementia Strategy with a commitment to ensure that when admission to hospital is unavoidable for people with dementia, the care experienced is safe, effective, dignified and person-centred. A range of approaches are being taken forward to improve outcomes for people with dementia admitted into hospital including the implementation of the 10 Dementia Care Actions which have been agreed nationally as the core actions necessary to drive forward improvement. Alzheimer Scotland has been instrumental in helping make this happen and in partnership with the Scottish Government, have introduced an Alzheimer Scotland Dementia Nurse post in each of the 14 Health Boards in Scotland as a direct response to help address the care of people with dementia admitted into general hospital. The Alzheimer Scotland Dementia Nurse role is key to the delivery of the National 10 Dementia Care Actions improvement plan which includes developing the workforce in line with the national dementia education programme 'Promoting Excellence' and act as the formal link between each Health Board and the Scottish Government.

Working at a strategic level within each Health Board and supporting the 1000 frontline staff who have graduated to date from the National Dementia Champion Programme, the Alzheimer Scotland Dementia Nurse posts are working as agents of change, rolling out their knowledge and skills to deliver remarkable levels of systemic change and improvements through effective and inspirational leadership. Examples of national and local education, training and development undertaken by the Dementia Nurse Consultant role includes: developing and delivering the national 'Promoting Excellence' knowledge and skills framework for health and social care staff working with people living with dementia, their families and carers; supporting dementia champions with input to the national programme of education as well as local support through networks and local training; Stress and Distress training at expert level; input into a wide range of pre and post registration education in Universities and awareness sessions, education and training to a range of care professions and community groups.

Oral Presentation Abstracts

ID: 521 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: cognitive intervention program, dementia, fitness

Cognitive and fitness community program for people with dementia

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²School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan;

³Department of Long-Term Care, National Taipei University of Nursing and Health Sciences, Taipei, Taiwan

Abstract:

– Introduction

Based on the plan of “Preparedness for delay Disability” activities, we designed a series of cognitive and fitness community program for people with dementia in the community. An occupational therapist led the program and a case manager was the co-leader. The cognitive and fitness community program consisted of 12 courses with 2 hours per course per week. During the 120 minutes, 15 minutes were for initial warm-up, 45 minutes for physical fitness, 15 minutes for a break, and the final 45 minutes for cognitive training. The physical fitness exercises included stretching, upper and lower limb training, and dynamic coordination and dynamic balance tasks. Cognitive training included memory tasks, attention response tests, eye-hand coordination, mathematical calculation, and color discrimination. We used non-drug therapies and shaped new and interesting experiences for people with dementia.

– Methods

We invited 22 people diagnosed with dementia to join the cognitive intervention program every Monday afternoon from June to September 2019. All the participants had a clinical dementia rating score between 0.5 and 1.0.

– Results

Sixteen people with dementia joined the cognitive and fitness community program. The average age was 78.1 years and 56% of the participants were men. The average attendance of the participants at the cognitive and fitness community program was 78%. During the fitness session, five people with dementia needed physical assistance by caregivers and one used a wheelchair and had transfer limitations. At the cognitive session, three people with moderate or severe dementia needed more assistance than the others to complete the tasks. Approximately 60% participants could complete the tasks independently, and the rest of the participants need an occupational therapist to adjust their level of difficulty.

– Perspectives

Anticipated benefits of the cognitive and fitness activities included the ability to improve physical coordination and provide a better coping experience for both the people with dementia and their caregivers.

Oral Presentation Abstracts

ID: 522 / OS33: Psychosocial interventions

Abstract Topic: Psychosocial interventions

Keywords: young-onset, occupation, therapy, community, caregiver

Work as therapy for people with young onset and early stage dementia: impact and implications on community-based clients and caregivers

Dian Karnina, Sion Teng, Mee Choo Soh

Apex Harmony Lodge, Singapore

Abstract:

According to Kitwood (1997), occupation is one of the six aspects critical in delivering person-centered dementia care. By meeting one's need for occupation, meaningful engagement could be created through stimulating tasks and social interaction.

Globally, efforts in providing work-based interventions for dementia clients are still limited, although pilot research in Australia, USA, and UK have seen positive impacts on the PwDs' wellbeing. In Singapore, Apex Harmony Lodge (AHL) started its Therapy through Work (TTW) program for its long-term care facility residents in 2013, and identified higher average wellbeing scores of residents who participated in outside work activities than those who did not (Soh, Goh, Koh, & Fusek, 2017). Responding to the greater need for early dementia care in Singapore, AHL then expanded the TTW program to reach out to clients with young onset and early stage (YES) dementia based in community. This presentation will explore, quantitatively and qualitatively, the impact of work therapy that is specifically curated in regard to the higher abilities of YES PwD.

Since 2018, PwD were engaged at least once a week in simple occupational tasks (e.g. food preparation, towel folding, and hydroponic farming). Impact of the program on their cognition, activities of daily living (ADL)-performing abilities, perceived wellbeing, and mood were quantitatively assessed using MMSE, ADCS-ADL, EQ-5D, and GDS prior to the intervention, and at 6-month intervals. Concurrently, Zarit Burden Interview-4 was also conducted with the caregivers to monitor the program's impact on caregiver burden, if any. Overall PwDs' & caregivers' experiences were also explored through qualitative interviews to obtain an in-depth understanding of the impact and implication of the program beyond the quantitative measures.

Preliminary quantitative analysis of the first group of clients showed no significant decline in the investigated indicators, suggesting possible maintenance of conditions at 6 months after joining the program. No significant increase in caregiver burden level was found either.

For PwD, impacts of TTW YES such as normalizing life, restoring working identity, relationship building, strengthened sense of self, and enjoyment surfaced through qualitative interviews. Impacts for caregivers identified included respite, greater dementia understanding, and assurance stemming from the program's therapeutic benefits.

These preliminary findings suggest potential benefits of community-based TTW YES program – some of which are in line with past research, while others novel. Quantitative data will continue to be gathered in upcoming phases of the program, to explore evidence of impact from a larger and more diverse sample group. Challenges and other implications will be discussed.

Oral Presentation Abstracts

ID: 525 / OS01: The global policy environment

Abstract Topic: Dementia and labour laws – NEW

Keywords: dementia-friendly workplace, right to work, human right

What can we do for the right of work for people with dementia in Taiwan

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Abstract:

Since 2018, Taiwan Alzheimer's Disease Association (TADA) has added human rights advocacy in the mission of TADA and put more effort to improve the human rights of people with dementia. The right to work is one of them. According to our survey, 75% of people with dementia in Taiwan are diagnosed as mild cognitive impairment (MCI). Although their cognitive functions will deteriorate, this does not mean they need to leave their workplace immediately. TADA works hard in all aspects of vocational rehabilitation to help people with dementia to maintain or return to work.

In 2019, TADA started a project funded by the Ministry of Labor to promote dementia-friendly workplace. In this project, we go through two aspects to help people with dementia who are still capable of staying in the workplace or returning to work. First, raise dementia awareness and friendliness among the workplace. Second, adjust the requirement of the subsidy plan by the central government. From our experience, we have found that we have a higher success rate in promoting dementia-friendly workplace if we contact the company's management directly. The decisions and actions of the managers are more useful to influence the attitude of the workers. Companies usually prefer 1 to 1.5 hours lecture with 30 to 50 attendants. Besides, most of them prefer topic like "what is dementia" and "how to prevent" to "company policy." As of August 2019, we had conducted ten training course, and more than 650 participants participated. In self-evaluation form, the average score of respondents was 4.5 out of 5, regardless of the practicality and knowledge gain from the course.

Moreover, it is necessary to make adjustments to the criteria of the subsidy plan by the central government. Lack of understanding of the government sector leads the inability to provide appropriate arrangements for people with dementia. Even though there are laws and subsidies for the employment of people with disabilities, they cannot meet the needs of people with dementia. For example, people who are still able to work are mostly in a very mild stage, but they are not eligible to use government resources. It is because they are not qualified to apply for a disability card, which causes them unable to use the resources in their workplace. Only when they are in the mild or moderate stage, they can apply for a disability card, but it is already a burden for them to work at least 20 hours a week. It is a big issue we are working hard to resolve. We hope the Ministry of Health and Welfare, the Ministry of Labor and relevant departments have an inter-ministerial meeting to protect the rights of both the people with dementia and the employer.

"Work is the performance of ability." Although the government has not adjusted the relevant laws and services for the work rights, we will continue to work for it. We hope that in the future people with dementia have more job opportunities and work in a dementia-friendly workplace.

Oral Presentation Abstracts

ID: 529 / OS29: Informal carers training

Abstract Topic: Informal carers training

Keywords: Training, carers, animation, pilot

Animation – training of the future?

Debbie Lee de Fiddes, Kirsty Bennett

Evoke Collective Australasia, Australia

Abstract:

Background and Objectives of the Study

Training for care staff in the residential aged care sector predominantly focuses on personal care, infection control, food safety¹ or on improving knowledge of dementia and practical strategies to support people with dementia^{2,3}. Additionally, the Australian Skills Quality Authority intends to target international education and the capability of trainers and assessors⁴. Evoke Collective Australasia (specialist expertise in designing and fitting out residences for older people) identified gaps in environment training at residential aged care facilities (RACFs). Yet studies show that appropriate physical environments improve resident wellbeing and function^{5,6}. Environment training which is simple; efficient; readily understandable with minimal impact to daily routine is required. Evoke Collective partnered with Cell-Media (a multimedia company) and Acacia Living Group (a RACF) to:

- A. Devise an environment training framework for RACFs to be developed into animation modules.
- B. Develop and pilot a wayfinding module.
- C. Describe the industry partnership process and articulate key learnings.

Methods

Adopting a three phase sequential approach; the study mapped the training framework and determined the required modules which also met the criteria for animation. In the second phase, a script and animation for one module was developed and piloted with n=20 operational staff at a RACF. Staff were surveyed on level of knowledge before and after watching the animation to gauge if there is any shift in their position as a result of the module. A random selection of staff (n=10) will also be surveyed on the use of animation as a training modality. The final phase documents the process undertaken and identifies the key learnings. Data collection involves process mapping and interviews for phases one and three and surveys for phase two. The interview data will be analysed using inductive content analysis and the survey data will be cross tabulated with frequencies and percentages established.

Results

Phase 1 has been completed with the conceptual framework developed and consensus reached on the required modules. Phase 2 has commenced with the animated module 'Wayfinding – Where is my room?' developed to train care staff. This will be piloted mid-September with the results and module refinements to be completed by end November. Phase 3 (due for completion end January) will describe the process undertaken with the key learnings articulated.

Conclusion

In response to the residential aged care sector requesting alternative and effective ways of providing training to care staff, this study intends to introduce animation technology as a potential informal training medium. Demonstration of the wayfinding module and the explanation of the industry partnership process with the key learnings articulated will aid sector members wishing to undertake similar initiatives.

Oral Presentation Abstracts

ID: 535 / OS17: Diagnosis II

Abstract Topic: Diagnosis

Keywords: biomarker, blood, DNA Methylation, epigenetics, pre-diagnosis

Blood based DNA methylation biomarkers of dementia

Peter Daniel FRANSQUET¹, James PHUNG¹, Paul LACAZE¹, Emily PARKER¹, Jessica LOCKERY¹, Richard SAFFERY², Raj SHAH³, Michael ERNST⁴, Anne MURRAY⁵, Elsdon STOREY¹, Rory WOLFE¹, Chris REID^{1,6}, Mark NELSON^{1,7}, John MCNEIL¹, Robyn WOODS¹, Joanne RYAN^{1,8}

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Abstract:

Introduction: Dementia is a major public health issue. Accurate, timely preclinical detection is key for the optimal targeting of interventions. A non-invasive, easily measurable peripheral biomarker would have greatest utility in population-wide preventive screening. Epigenetics, including DNA methylation (DNAm) has been implicated in dementia, and has the potential to act as an early biomarker of the disease. The aims of this study are to determine whether a unique DNAm signature exists in the peripheral blood of individuals with dementia, and whether a discernible DNAm signature is present prior to diagnosis.

Methods: The ASPirin in Reducing Events in the Elderly (ASPREE) study recruited 19,114 generally healthy individuals aged predominantly 70 years and over from the community (in Australia and the U.S.). At recruitment, all participants were without a dementia diagnosis, and scored >77 on the modified Mini-Mental State (3MS) exam. Cognitive tests were administered at baseline and over follow-up visits, and incident dementia was adjudicated according to DSM-IV criteria.

Of the ~19,000 participants who supplied samples at baseline, we selected 160 participants (n=73 cases, n=87 controls) based on follow up (approx. 3yrs) dementia diagnosis status, as well as baseline cognitive cut-offs. Forty-nine of these participants (n=25 cases, n=24 controls) had also provided samples at the follow-up time point. Cases had reached the adjudicated dementia study endpoint by follow-up, and were matched by age, sex, education and smoking status to a control group who remained free of dementia diagnosis. Using DNA extracted from buffy coat, epigenome wide association study (EWAS) was performed, which included 761,967 sites of methylation measured across the genome.

The primary analysis compared the EWAS profile of cases versus controls using follow up time point samples. The second stage of the analysis compared the EWAS profile of individuals at baseline, when all participants were without dementia diagnosis. We identified 3955 differentially methylated regions (DMRs) across the genome that were significantly different ($p < 0.01$) between dementia cases and controls (adjusted for batch, age and sex), and 1060 DMRs that differed between pre-diagnosis individuals (at baseline) and controls. There were 33 DMRs overlapping between the follow-up and baseline analyses. These DMRs included genes that have been implicated in neurodegenerative

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diseases such as Alzheimer's, macular degeneration and Amyotrophic Lateral Sclerosis, as well as genes associated with neurotransmission, neurotoxicity, and major cellular functions.

Conclusion: DNAm signatures measured in peripheral blood have the potential to act as early disease biomarkers for dementia. Future studies using larger sample sizes are needed to verify these findings, to determine the predictive potential, and explore the functional significance of these DNAm marks in dementia pathophysiology.

Oral Presentation Abstracts

ID: 552 / OS15: Risk Factors II

Abstract Topic: Risk factors

Keywords: sex differences, cognitive performance, childhood socioeconomic position, population-based study

Role of sex in the association between childhood socioeconomic position and cognitive performance in later-life

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Abstract:

Background and objectives of the study: Our objective was to explore the sex differences in the association between childhood socioeconomic position (SEP) and the level of cognitive performance among older adults and the extent to which sex contributes to the differences in cognitive health in later life. The cognitive performance varies across populations, which might be explained by different levels of cognitive reserve. Factors such as educational and occupational attainment, SEP, and lifetime experience play major role in the development of cognitive reserve that allows coping with brain pathology. In particular, socioeconomic circumstances in which a child grows up have long-term effect on health that can reach into old age regardless of other experiences during the life. Previous findings suggest that poor childhood SEP is strongly associated with impaired cognitive functioning in later life. However, evidence on the moderation effect of sex on cognitive performance in older age is rare.

Methods: We conducted a cross-sectional analysis based on data from population-based multi-centric study Survey on Health, Ageing and Retirement in Europe (SHARE). We analyzed data from 84 059 persons at least 50+ years old (55% women; on average 64 years old). Childhood SEP was assessed as a composite variable that consists of two common indicators of household characteristics: crowding and the number of books at home. Cognition was measured using tests on verbal fluency, immediate recall and delayed recall. We used linear regression to examine sex differences in the association between childhood SEP and later-life cognitive performance. Structural equation modelling tested, whether depression, physical health and education are mediators in this association.

Results: Higher childhood SEP was significantly associated with higher cognition in the whole analytical sample (women: $B=0.304$; 95% CI [0.295,0.312] vs. men: $B=0.255$; 95% CI [0.246,0.265]). This association was attenuated after adjustment for socioeconomic and health-related risk factors but remained statistically significant in both women and men (women: $B=0.161$; 95% CI [0.152,0.169] vs. men: $B=0.138$; 95% CI [0.129,0.148]). There was an interaction between childhood SEP and sex ($p<0.001$). The sex difference was statistically significant in all models in the whole analytical sample. The strongest mediator of the association of childhood SEP with cognition was education. The mediation effect was stronger for women than for men.

Conclusions: There are considerable sex differences in cognitive performance among older adults. This discrepancy might be explained by stronger consequences of childhood adversity on the formation of cognitive reserve in women than in men. Strategies based on prevention of childhood poverty or improving education might protect women's later-life cognitive health.

Oral Presentation Abstracts

ID: 558 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: primary care, systematic review, post diagnostic care

Effective and implementable models of post diagnostic primary care-led dementia care: an evidence synthesis

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¹University College London, United Kingdom; ²Newcastle University, United Kingdom

Abstract:

Introduction: The World Alzheimer Report 2016 recommends a global shift towards primary care led post diagnostic dementia care. However, currently there are few recommendations as to the optimal way in which this could be delivered. We aimed to: 1) assess the effectiveness of current models of post-diagnostic primary dementia care, 2) identify how intervention components and contextual factors might affect implementation of these and 3) identify effective models of care and components of these from primary and community management of other long term conditions in older people.

Methods: We conducted three reviews: 1) a systematic review and meta-analysis of trials and economic evaluations of models of post diagnostic dementia care where primary care had substantial involvement in care plan decision-making, 2) a mixed-methods systematic review of evaluations of primary care led services guided by Proctor et al's (2011) implementation framework, and 3) a scoping overview of systematic reviews of primary and community-based models of care for long term conditions, multimorbidity and frailty in older people. Review results were presented at project Patient and Public Advisory Board (PPAB) meetings.

Results: We found limited evidence for primary care led models of post diagnostic dementia care (n=10 studies), although case management partnership models offered the most promise. Our implementation review (n=54 studies) found that although a range of models were acceptable to people with dementia, caregivers and primary care physicians, feasibility was influenced by good primary care leadership, resources, building primary care capacity for dementia care and interprofessional collaboration. Care quality was similar across models, but increased when adding in a case manager role. Our PPAB feedback criticised the limited range of models available with rigorous evidence. The results of the scoping review are ongoing.

Conclusions: A case manager collaborating closely with a primary care provider who can add capacity to primary care appears to be the most optimal model of post-diagnostic dementia care at present; however, most other care models lack rigorous evidence.

This research was supported by funding from Alzheimer's Society (grant number 331).

Oral Presentation Abstracts

ID: 563 / OS26: Diverse populations

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Dementia, culture, black-elders, BME, equality

Dementia in minority ethnic populations: what and whom are we researching?

Moise Roche, Paul Higgs, Claudia Cooper

University College London, United Kingdom

Abstract:

Introduction: Black families around the world are disproportionately affected by dementia. In the UK where the black population is rapidly growing older, the risk of developing dementia is also increasing, which is poised to raise a major ethnogeriatric imperative for health and social care providers.

Background: Black elders also appear to dismiss the warning signs of dementia until they can no longer cope, often with detrimental outcomes to receiving timely treatments and accessing services and support. Counterintuitively, they live in their own homes for longer than their white counterparts, with a lesser likelihood of moving to a care home. We do not know how black families conceptualise dementia; whether they acknowledge the risk of developing the condition; and how they evaluate the prospect of a diagnosis and the support and treatment available. In our previous work, black adults told us “*we don’t do dementia in our communities*”, “*this is an old white people’s disease, it’s not seen as black people have dementia*”.

Objectives: Thus, for the first objective of our ongoing research, we will explore the psychosocial dimensions and cultural factors that shape how people of black ethnicity conceptualise, respond, and manage dementia. Our second objective will be to use the findings of our investigation to describe a culturally-informed dementia care pathway that better meets the needs of black families with dementia. We hope our model will provide a framework for developing more culturally appropriate dementia services for other minority ethnic populations.

Methods: To gain an overall perspective of the dementia journey and the experiences of black families, we are interviewing people with dementia, family carers, and professionals from 3rd sector, NHS and social care; in community and care home settings. A thematic analytic framework will be used for emerging themes, concepts and beliefs that motivate black families’ choices of dementia care pathway.

Conclusion: We expect our findings will improve the experiences and the outcomes for the black individuals with dementia and their family carers by facilitating timely and appropriate access to diagnosis, support, and treatment, as well as ensuring equality of service provision for all.

Oral Presentation Abstracts

ID: 582 / OS28: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: isolation, loneliness, person, family, friends, community

Diagnosis Alzheimer. The beginning of social isolation, loneliness and depression

Tania Martinez San Martin

None, Spain

Abstract:

Why? Some figures and situation contributes to these feelings. I´ve experienced myself when my father has younger onset dementia, FTP, 10 years ago at the age of 60.

The doctor.-The first sensation of loneliness and isolation comes with the diagnosis from your doctor. Your hope is to obtain some cure for the things you have been feeling for some period of time, and if there is no cure for your symptoms, at less you hope a protocol to do in order to live a better life. In this case, there is no cure, but neither approved protocols to guide you to live with the diagnosis you have just received. Some pills prescriptions and that´s it. In most of the cases, the doctor who tells you the diagnosis doesn´t know exactly what is dementia disease and how to deal with it. There is not enough information in primary community of doctors. The no protocol about Alzheimer´s disease finish right here and with that, the loneliness path begins here too. Normal reactions are isolation, depression, loneliness and a great sense of being lost. It would be necessary a geriatrist or a expert doctor that coul accompany the person with dementia and his caregiver. Most of the doctors prescribes medicines forgetting the person behind. No cure, no hope

The research.-Althoug today my father is gone, when I look for information I have the same feelings today. The information is not update, there were no specific guidelines, and there were no standardized methods of care . There is still few people speak clearly of a subject that remains taboo in the community.

No information about the feelings that the person with the diagnosis have, the challenge path that has to go through, about the isolation, the anxiety a person, a human being has to live. One human being that want to be loved and want to be part of the community, no matter what Feeling with anxiety, with depression about the future is normal.

The family.- There are two forms family isolate the person with dementia: Talk about the person in third person when he or she is still present. It´s true that not all the stages are the same but always you can include the person with dementia in the conversation. They are human being. They want to be part of the family. They need to feel human contact around them

The other form of isolate people with dementia is to pretend to deny the diagnosis. And here is when the stress, the anxiety appears.

Friends.- All people around my father was gone. When my father past away some of them come to us to say how sorry they feel about being apart. They admitted not to know how to handle the disease.

Community. When somebody explain to you how to feel and how to react people with dementia, it´s easy to identify. If our Banks, groceries people were more friendly, this will let this people remain doing their normal life in the first stages of the disease.

Oral Presentation Abstracts

ID: 587 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: Fiji, Pacific Islands, attitudes and beliefs, ageing, dementia

Understandings and experiences of dementia in Fiji

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¹College of Medicine and Dentistry, James Cook University, Townsville, QLD, Australia; ²College of Medicine, Nursing and Health Sciences, Fiji National University, Suva, Fiji

Abstract:

Introduction

Fiji is a Melanesian Pacific Island country located in the South Pacific Ocean, with a population of just over 900,000 people. The proportion of older people (over the age of 60 years) in Fiji is expected to double to 12.6% by 2025. Traditionally, in the Pacific Islands care for parents in older age is the responsibility of children. Factors such as rural-urban drift, increasingly nuclear family units and emigration may reduce the capacity for children to care for their parents in older age.

Specialised services for older people, the disabled and chronically ill are limited in Fiji, and care for dementia usually occurs at the psychiatric hospital. Decentralisation of mental health services has occurred more recently with the opening of stress management wards (mental health units) at divisional hospitals and mental health clinics at various locations. Following global trends, population ageing could have implications in terms of increased dementia prevalence with unknown, though probably significant, impacts on the wellbeing and livelihoods of people living with dementia and their families.

Currently, little is known about the extent of dementia in Fiji, or how dementia is understood and experienced by the Fijian people. Preliminary findings from a study exploring dementia in Fiji will be presented, with a focus on attitudes, awareness and stigma.

Methods

A transformational grounded theory paradigm informed the study design and methods. Qualitative methods were employed to explore the views of people with dementia, family caregivers, service providers and community group leaders on dementia in two towns in Fiji. Interviews and focus groups were audio recorded and transcribed. As data collection and analysis is currently ongoing, initial analysis of data has consisted of open coding.

Results

At the time of this abstract submission, 25 participants (16 health service providers, 2 community group leaders, 6 family members and 1 person with dementia) were interviewed about their views and experiences of dementia. Preliminary findings suggest that dementia is unknown as a defined health condition amongst the lay community. Dementia is commonly viewed as part of the ageing process and sociocultural understandings of dementia also exist. Stigma is strongly associated with the use of mental health care services in Fiji. Seeking help from health services for dementia related concerns is uncommon and may occur only at later stages of the condition. Care for older people with dementia occurs within family and community networks. Service providers are aware of dementia as a health condition but have little experience in caring for people with dementia and supporting caregivers.

Conclusions

Understanding how ageing, health and illness are conceptualised and enacted in Fiji can inform

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Oral Presentation Abstracts

contextually appropriate strategies for awareness raising, destigmatisation of dementia, and the place for health services in dementia care.

Oral Presentation Abstracts

ID: 590 / OS15: Risk Factors II

Abstract Topic: Risk factors

Keywords: dietary salt, cognition, sodium, dementia

Association of dietary salt intake and cognition in middle-aged and older adults: a systematic review

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Background

Dementia is an incurable condition that is characterised by multiple cognitive deficits and loss of independence. There is no effective cure for dementia. Pharmacological treatments have only shown short term effects. Therefore the prevention of cognitive decline and dementia risk reduction are important public health priorities. High intake of dietary salt has been associated with several adverse outcomes of which blood pressure has been the most documented. Whether salt reduction may reduce risk of cognitive decline is less established. Cognitive decline has been hypothesised to be linked to several differing aetiological pathways including altered vascular regulation. Hence, a reduction in salt intake (and therefore sodium intake) may represent an effective strategy to improve cognitive function. This systematic review aims to assess the current evidence of the association of dietary sodium intake and the risk of cognitive decline or dementia.

Methodology

Four databases (PubMed, EMBASE, CINAHL and Psycinfo) were searched from inception to February 2019, to identify studies assessing the association of dietary salt and cognition in middle aged or older adults (50 years and older). Both observational studies and trials were included. No restriction was placed on participants' cognitive status. Data extraction of eligible studies included information on study design, population characteristics, salt reduction strategy (trials) or assessment of dietary salt intake (observational studies), measurement of cognitive function or dementia and summary of main results. Study quality assessment was performed using the quality assessment tool from the National Heart, Lung, and Blood Institute.

Results

Thirteen studies fulfilled the inclusion criteria including: one clinical trial, five cohort studies and seven cross-sectional studies. Results from the clinical trial showed that lower sodium intake is associated with better cognitive scores. Observational studies overall reported mixed associations between sodium levels and cognition, suggesting a possibility that both low and very high levels of sodium intake may be associated with poor cognitive function. In a subgroup analysis including studies rated as good quality, a higher sodium intake was consistently found to be associated with cognitive decline and poor cognitive function.

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Conclusion

Overall, the strength of the evidence is modest. Lack of clear findings is largely due to differences in study design, dietary and cognition assessment methods, and statistical approaches used across studies. We recommend that more robust longitudinal studies be initiated, employing accurate measurements of dietary salt intake, cognitive function and dementia risk to explain if an excessive salt consumption is linked to increased risk of cognitive decline and dementia.

Oral Presentation Abstracts

ID: 591 / OS30: Innovation, entrepreneurship and technology

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: dementia action plan, technology, LINE app, google map

Utilizing the electronic technology to reach the goals of the dementia action plan

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Abstract:

Introduction

To lower the impact of dementia, WHO issues the “Global action plan on the public health response to dementia 2017–2025”. Based on the action plan issued by WHO, the Taiwanese government launches the “National program and action plan on the dementia prevention and care (2018-2025)”, aimed at raising the public awareness of dementia, facilitating the diagnosis, and enhancing the medical and social support of the people living with dementia and their caregivers.

Methods

We have been utilizing the electronic technology to try to reach the goals of the Taiwanese version of the action plan with the residents of Zhongzheng District, Taipei for our practice. First, we uploaded the films of introduction of dementia into the website (https://elearning.taipei/mpage/home/view_type_list), easily accessed by the publics, to raise the awareness and increase the level of recognition of dementia. Second, 91.3% of the Taiwanese use the LINE app. We collected the information about the prevention, diagnosis, medical and non-medical treatment, social support, and law problems of dementia. Then, we set up a program about the information in the LINE app (<https://line.me/R/ti/p/%40taipei>), which can automatically find the answers when people asking questions about dementia in the LINE app. The last, we combined with the google map to launch the map regarding the dementia-friendly organizations and shops (<https://dementiafc.tpech.gov.tw/Nursing/Map>), increasing the access of these institutions by the people living with dementia and their caregivers, whom enhancing the social support of.

Results

There were 3,193 people completing the introduction films, and we recruited 156 dementia-friendly institutions labeled in the map. Furthermore, there were more than 3,000 (by March, 2018) uses of the program set up in the LINE app.

Conclusions

The results indicate that the electronic technology can help us reach the goals. We will continue to conduct these electronic strategies and may implement them in other districts of Taipei.

Oral Presentation Abstracts

ID: 594 / OS18: Education, training and formal carers

Abstract Topic: Formal carers education and training

Keywords: Education, knowledge, nurses, care assistants, motivation

Building knowledge and understanding of dementia in aged care personnel: the understanding dementia massive open online course

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Abstract:

Introduction: Providing accessible and evidence-based education to improve the knowledge and understanding of dementia in care personnel is a key target of the Global action plan on dementia. Since 2013, the free Understanding Dementia Massive Open Online Course (UDMOOC) has delivered evidence-based education about dementia to the broadest possible cohort, amongst whom residential aged care staff are highly represented. This study investigated motivation to participate, engagement, and effectiveness of the UDMOOC as a means to meet the knowledge needs of both nurses and care assistants working in this sector.

Methods: Indices of engagement over three modules (1: The Brain, 2: The Diseases, 3: The Person) were examined for 4305 participants in the UDMOOC who consented to participate in research and identified as nurses or care assistants working in residential aged care. Motivation to undertake the course was determined quantitatively by survey responses and qualitatively by structural topic modelling of responses to an open-ended question. Knowledge of dementia was assessed pre and post UDMOOC participation using the Dementia Knowledge Assessment Scale (DKAS) with a maximum possible score of 50.

Results: Probability of course completion was significantly higher for nurses (0.68 +/- 0.018) than care assistants (0.64 +/- 0.015). Baseline DKAS scores were also significantly higher for nurses than care assistants (37.9 +/- 7.33 vs 33.5 +/- 8.14). Lower pre UDMOOC DKAS scores were associated with reduced probability of completion of the first UDMOOC module (The Brain) and the entire course, particularly for care assistants. Both groups showed significantly improved post course DKAS scores (44.2 +/- 5.03 vs 40.6 +/- 7.36) across all subscales, with care assistants showing a greater magnitude of improvement. Analysis of 3587 responses revealed the predominant motivating factors for both nurses and care assistants were: to acquire *new* knowledge in order to deliver the best possible care; to address *deficits* in their existing training; and to *develop* new skills and deliver *person-centred* care. Care assistants particularly reported on the need to build on their *existing* practical dementia care skills in order to provide better care.

Conclusion: Both care assistants and nurses in residential aged care recognise the need to address deficiencies in their training which impact on their capacity to deliver appropriate care to residents living with dementia. The UDMOOC demonstrably improves knowledge of dementia in both groups, even for those with limited initial knowledge. This free online course is an effective way to provide accessible and evidence-based information about dementia and dementia care to the care workforce.

Oral Presentation Abstracts

ID: 598 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: evaluation, translation, quality improvement, guidelines

What works?: a process evaluation of translation of dementia care guidelines into practice

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Abstract:

Background

The quality of post-diagnostic dementia care in Australia is dependent on the clinician involved and how well they integrate evidence into their routine practice. Guidelines to promote independence and quality of life, in Australia in 2016, provided an opportunity to improve clinical practice nationally. This research evaluated a large translational project to identify how light touch on-line quality improvement collaboratives influenced the implementation of three dementia care guidelines in Australia.

Methods

A multi-method process evaluation identified what worked in the quality improvement collaboratives, how acceptable was the addition of quality improvement to clinician roles, and what value did the involvement of experts by experience of dementia add to the approach.

30 clinicians and 7 experts by experience of dementia were invited to participate in pre and post intervention interviews to explore the influence of collaboration on improved practice. Tools were used to assess knowledge gained by clinicians, mapping of organisational context, adherence to guidelines and the experience of the experts by experience of dementia. Themes from interviews were analysed with outcomes data and costs, to identify how effective learning new skills in quality improvement, and collaboration with peers and experts by lived experience of dementia were in implementing dementia care guidelines.

Results

The 30 participating clinicians included physicians, nurses, occupational therapists, physiotherapists, social workers and dieticians who were leaders within their service. Organisational mapping identified barriers to best practice including restrictive policies and a lack of consumer and clinician consultation in organisational decision making. Experts by experience of dementia identified the clarity of roles, the support provided and the benefit to them of contributing to improved care. Participation in the QIC has facilitated the development of strategies which are generated by the clinician and therefore most likely to be appropriate to their context. Most clinicians used their quality improvement strategies to improve dementia care in their practice. A cost-benefit analysis will be conducted to identify opportunities to expand the quality improvement collaborative approach.

Conclusion

Collaboration with peers, researchers, clinical experts and experts by lived experience of dementia enabled clinicians to improve adherence to clinical guidelines. The cost of developing the quality improvement collaborative was modest in relation to the improvement in skills of participants and outcomes for people living with dementia. The potential exists for this type of light touch on-line collaborative to scale up to improve adherence to dementia care guidelines in Australia and elsewhere and provide cost-benefits in health and dementia care.

Oral Presentation Abstracts

ID: 607 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Young onset dementia

Keywords: younger onset dementia; strategic plan; innovation; service provision; residential care; day programme; cognitive stimulation therapy (CST)

The younger onset dementia aotearoa trust (YODAT): strategic management plan 2020

B Sally Rimkeit, Brigid Ryan, Joanne Loveridge, Fred Browning, Yvonne Browning

Younger Onset Dementia Aotearoa Trust (YODAT)

Abstract:

YODAT Vision Statement: ***Purposeful living with younger onset dementia.***

YODAT was founded in New Zealand in 2015 to improve the lives of younger people living with dementia and their families and support persons.

People are said to have 'younger onset dementia' when experiencing symptoms of dementia aged 65 or younger. As a direct outcome of their relative youth, people with younger onset dementia are generally physically fitter and less frail than those with older onset dementia. They also may still be working, or even raising families. There are few specialist support services available for people with younger onset dementia, and people often default to services designed for elders with dementia who may be frail.

Research has shown that the lived experience of those with younger onset dementia, potentially facing life in senior living residences, may be one of distress with fear of loss of belonging, loss of autonomy and loss of meaningful activity. Difficulty in timely diagnosis, combined with lack of access to age-appropriate care and unfamiliar, institutional environments all compromise quality of life.

The outcomes that YODAT is seeking to deliver on are:

- That people living with younger onset dementia retain a sense of belonging within their families and communities.
- That people living with younger onset dementia retain appropriate levels of autonomy by having opportunities for choice and control allowing them to express and develop their own individuality.
- That people living with younger onset dementia receive age appropriate therapies that encourage physical fitness, emotional expression and assist to retain self-esteem by enabling them to continue with tasks which are meaningful to them.
- That people living with younger onset dementia, their families and support people have access to advice and advocacy that will help them to deal with challenges that may arise.

YODAT will use the following strategies to achieve these outcomes:

1. Services

- Design, develop and operate services that provide age appropriate day programmes and residential facilities.
- YODAT has operated a Cognitive Stimulation Therapy-based day programme in Wellington since 2018. We hope to roll this out across the country through 2020.
- We are looking at funding models for establishing a place of residence.

2. Connectedness

- Facilitate support programmes that provide education and information for people living with younger onset dementia, their families and support people.
- Provide opportunities for interaction with others living with younger onset dementia.

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- Enable people living with younger onset dementia to remain integrated into their community.

3. Advocacy

- Access to relevant and specialised health care services.
- Prompt and timely diagnosis.
- Advancement of research funding.
- Reduction in stigma.
- Support structures within the workplace.
- Maintain citizenship as outlined in the United Nations Convention on the Rights of Persons with Disabilities.

Oral Presentation Abstracts

ID: 610 / OS13: Dementia and public policy I

Abstract Topic: Dementia policies and public policy

Keywords: dementia national plan, alzheimer, Indonesia

Evaluating the 7 action steps of Indonesia's dementia national strategy and the role of Alzheimer's Indonesia organization

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Abstract:

Introduction

In 2016, Indonesia launched a national strategy for dementia. Here we evaluate the implementation of its action steps during the three years after the launching and the role of Alzheimer Indonesia (ALZI).

Methods

As part of the STRiDE project, we searched for evidence on the progress in implementation the actions announced in the National Strategy by carrying out a desk review of academic and grey literature (regulations, reports, news article from Google search and Ministry of Health website) and focus group discussions with stakeholders

Results

In early 2019, the Ministry of Health issued a regulation to include cognitive examination among health services provided for older adults. However, this regulation has not been fully implemented. Dementia awareness and friendliness has braised through campaigns using various means of communications (including print materials, LED videos on billboards across Jakarta, and social media). Responding to concerns about non-communicable diseases (NCD)-related dementia risk factors, including hypertension, diabetes, obesity, stroke, smoking, and physical inactivity, a Healthy Living Community Movement (GERMAS) program has been established in Indonesia since 2016.

In principle, the national health insurance covers dementia diagnosis treatment in referral hospital's memory clinics, but there are a small number of referrals so far, suggesting a low level of implementation. Similar obstacles can also be found in the financing of long-term care. Nonetheless, there has been an increase in the community support for dementia through the voluntary sector. ALZI has expanded into 21 chapters all across Indonesia and have an extensive online support program through Webinars, WhatsApp groups, and other online channels.

Despite studies in 2 provinces, there is no system in place to monitor the prevalence of dementia and no national prevalence estimates. In 2018, Indonesia has joined the STRiDE research project, with the goal of strengthening the scientific evidence to support dementia policies.

Conclusion

Better coordination and multidisciplinary approach across various programs and sectors are essential to implement the national strategy's action steps. There is a necessity to increase the number of chapters and educational activities and cooperation with private sectors through the availability of Dementia Day Care, Counselling, Dementia Care Skills Training.

Oral Presentation Abstracts

ID: 613 / OS22: Diagnostic tools

Abstract Topic: Diagnostic tools

Keywords: Everyday Ability Scale for India (EASI), Dementia, Screening, Community setting

Diagnostic accuracy of everyday ability scale for India (EASI) for dementia in a rural population, South India

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¹Health Action by People, India; ²Newcastle University Institute for Ageing, UK

Abstract:

Background: Everyday Ability Scale for India (EASI) is a validated tool to assess the activities of daily living. This screening tool which measures the functional ability has been documented as a successful alternative to measure the cognitive status of individuals, particularly with lower educational status.

Aim: To find the diagnostic accuracy of EASI for dementia in comparison with the DSM V diagnosis, in a rural setting

Methods: The study was conducted among rural residents aged above 65 years in Kerala, South India. Trained health volunteers screened 364 systematically sampled elder individuals using EASI. In the next phase, excluding the lost to follow up, 311 subjects were interviewed by a health care team comprising of neurologists, public health experts and neuropsychologists. The major neurocognitive disorder was diagnosed according to DSM V criteria. The sensitivity, specificity of EASI was estimated to detect the major neurocognitive disorder. Data analysis was done using SPSS.

Results: The mean (SD) age of the study participants was 71.8 (6.5) years. Females comprised 59% of the population (n=189). Among 311 participants, 21 (6.8%) had dementia according to DSM V criteria. A total of 84 individuals were screened positively with EASI (scores more than or equal to 3). Out of the 21 individuals with dementia, EASI was positive for 17 individuals. The sensitivity of EASI was 80.95% and the specificity was 64.7%.

Conclusion: EASI is a sensitive tool to detect dementia in the community.

Disclaimer: This study is a part of the Dementia Prevention and Enhanced Care (DePEC) project, funded by NIHR, Global Health Research Group. The lead PI of the project is Prof. Louise Robinson.

Oral Presentation Abstracts

ID: 616 / OS32: End of life and palliative care

Abstract Topic: End of life and palliative care

Keywords: severe dementia, end of life, life extending intervention, goal of care, mixed methods

What causes misalignment between caregivers' overall goal of care and their preference for potentially life extending interventions for persons with severe dementia?

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Abstract:

Introduction: When making difficult decisions regarding persons with severe dementia (PWSDs)' care options at the end of life (EOL), physicians frequently elicit specific intervention preferences for potentially life extending treatments from their caregivers. However, these specific intervention preferences may not always align with caregivers' overall goal of care for PWSDs. We aimed to explore the factors that influence misalignment between caregivers' overall goal for EOL care and their preference for potentially life extending interventions for PWSDs.

Methods: We conducted semi-structured in-depth interviews with 26 caregivers of community-dwelling PWSDs with FAST staging 7 and above. We used purposive sampling to reflect the ethnic distribution in Singapore and also a variety of dyadic relationships. Caregivers were asked about their overall goal for PWSDs' EOL care and their preferences for intravenous (IV) antibiotics, tube feeding and cardiopulmonary resuscitation (CPR). After verbatim transcription of interviews, we used principles of reflexive thematic analysis to code and analyse the data.

Results: Most caregivers were aged 60-69 years (50%), females (77%), Chinese (69%), and were children of PWSDs (65%) with a mean caregiving duration of 8 years. No life extension was the overall goal of care for majority (77%) of the caregivers. Yet, 80% of them preferred IV antibiotics, 60% preferred tube feeding and 45% preferred CPR. Caregivers preferred these interventions because they 1) felt it was unethical not to provide intervention, 2) desired not to see life end, 3) perceived an absence of choice, 4) deferred to healthcare provider's recommendation, 5) perceived intervention as not burdensome, 6) perceived intervention as alleviating suffering or pain, 7) perceived an option to withdraw intervention if it increased PWSD suffering, 8) experienced difficulty in deciding for PWSD and faced 9) family conflict. Thematic analysis revealed that misalignment between overall goal for care and preference for potentially life extending interventions was due to 1) lack of clarity on whether treatments are lifesaving or life prolonging, 2) overall goals for care being based on the totality of suffering but specific treatment preferences being based on the immediacy of suffering and 3) fear of regret over making the wrong decision.

Conclusion: Findings highlight that when discussing specific intervention preferences with caregivers of PWSDs, physicians should elicit their overall goal for EOL care concurrently in order to ensure a congruent outcome and avoidance of misalignment. Results also suggest that caregivers need informational and decisional support to make treatment choices that are aligned with their overall goal of care for PWSDs at EOL.

Oral Presentation Abstracts

ID: 618 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: mild cognitive impairment, social cognition, empathy, theory of mind, emotion recognition

Social cognitive performance in older adults with and without mild cognitive impairment

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Abstract:

Background: Social cognition encompasses a range of perceptive skills needed to navigate social environments, such as theory of mind (ToM), affective empathy (AE), and facial emotion recognition (FER). Deficits in these domains have been observed in persons with dementia and mild cognitive impairment (MCI). It is worth studying multiple domains of social cognition together in order to better understand its role in the prodromal stages of neurocognitive disorders.

Methods: Nondemented participants in Wave 6 of the Sydney Memory and Ageing Study (MAS) were interviewed (2017 – 2019). During interviews, participants underwent cognitive assessments via the Mini-Mental-State Examination (MMSE) and the Addenbrooke Cognitive Examination version 3 (ACE-3), social cognitive assessments via the Reading the Mind in the Eyes Test (RMET), Emotion Recognition Task (ERT), and the informant-rated Interpersonal Reactivity Index (IRI). Additionally, other measures used to assess mood (Geriatric Depression Scale; GDS) and social network (Lubben Social Network Scale; LSNS) were done. Participants scoring less than 27/30 for the MMSE and/or less than 74/100 ACE-3 were classified as having MCI, and were compared with participants with no cognitive impairments (NCI).

Results: 337 participants, of which 54 (16%) were classified as MCI. MCI participants were older [mean (SD) age: 88.55 (4.36) vs. 86.72 (3.91) years; $p=0.004$] and less educated [mean (SD) education: 10.61 (2.80) vs. 11.98 (3.45) years; $p=0.014$]. MCI participants also scored lower in the RMET, and in the ERT for identification of angry, disgusted, fearful, happy, and surprised faces. There were no differences for ERT for sad faces, or any IRI subdomains. In multivariable regression controlling for age, education, gender, language background, depressive symptoms, and extent of social networks, MCI status predicted poorer performance in the RMET [$\beta = -1.98$ (95% CI: -3.42 – -0.53); $p=0.008$] and ERT Anger [$\beta = -9.27$ (95% CI: -16.92 – -1.63); $p=0.018$], Disgust [$\beta = -11.23$ (95% CI: -18.93 – -3.53); $p=0.004$], Happiness [$\beta = -1.98$ (95% CI: -3.42 – -0.53); $p=0.08$], and Surprise [$\beta = -1.98$ (95% CI: -3.42 – -0.53); $p=0.08$].

Conclusions: MCI was associated with poorer performance in ToM and FER for anger, disgust, happiness, and surprise, but not with FER for sadness or fear, or AE. MCI participants performed poorer in psychometric social cognitive measures, but not in observer-rated measures. Impaired FER for happiness in MCI is of note, as prior FER studies in healthy ageing cohorts largely find no deficits for happiness. MCI is likely associated with very mild deficits in social cognition that might be undetectable by observers or in ecological environments. Further work assessing cognitive trajectories and development of dementia in MCI individuals with social cognitive deficits is currently underway

Oral Presentation Abstracts

ID: 620 / OS13: Dementia and public policy I

Abstract Topic: Dementia policies and public policy

Keywords: public policy, empowerment, research, dementia friendliness

Dementia policy in the Netherlands 2021 – 2030

Jacqueline Hoogendam

Ministry of Health, Welfare and Sport, Netherlands, The

Abstract:

Facts & figures

In The Netherlands 254,000 - 270,000 people live with dementia. If we don't act now, this number will be around 375,000 in 2030.

The costs of professional dementia care was estimated at € 6.6 billion in 2015. If we cannot change the growth of the number of people with dementia, these costs will have risen to € 12 billion in 2030.

Dementia policy

After three consecutive dementia plans (2004 - 2020), The Netherlands Government is now working on its fourth plan (2021 - 2030). This plan will have two main focal points:

1. today: the person with dementia as a worthy member of society
2. tomorrow: a world without dementia

Today: a worthy member of society

We need a paradigm shift in dementia support and care. No longer a focus on compensation for disabilities, but on the possibilities a person with dementia has. People with dementia can have meaningful activities, for instance do (volunteer) work according to their interests and possibilities or during day care. We will investigate the possibilities for people with young onset dementia to continue to have a paid job.

The environment and housing situation can have a big influence on the independence of a person with dementia. What can we do to adapt the environment and housing to stimulate this independence?

Society has an important role in the life of a person with dementia. The Netherlands has a successful dementia friends program, addressing both the general public and workers in specific businesses (shops, banks, taxi and bus drivers, hairdressers, information desks etc). Dementia Friendly Together 2.0 will not only address individual dementia friends, but aims to create communities of dementia friends who contribute to the quality of life for both a person with dementia and his/her informal carers together as well.

Tomorrow: a world without dementia

We need research to find ways to effectively prevent dementia and to find a cure or a disease modifying treatment. From 2013 - 2020 The Netherlands' Government invested € 64 million in dementia research. Both in the national research programme 'Memorabel' and through participation in the global Joint Programme on Neurodegenerative Diseases, especially Alzheimers' (JPND). The Government aims to double its financial investment in dementia research on a national and an international level.

Presentation

During the presentation on behalf of The Netherlands' Government you will get more in depth information on the most recent developments in setting up the fourth Netherlands' Governmental dementia plan: specific goals, financial means and way of execution (public or ppp).

Oral Presentation Abstracts

ID: 624 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: Dementia, hearing impairment, LMIC, South Asia, feasibility trial

Sense-cog Asia: a feasibility study of a hearing intervention in dementia

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Abstract:

Background: There is limited formal care available for dementia in South Asian countries. In contrast, hearing services are more accepted, and improving hearing function in older people represents a potentially reversible cause of cognitive impairment or may optimize remaining cognitive and functional ability and improve quality of life.

Objective: To evaluate the feasibility of conducting a low-cost, non-invasive, supportive interventional study of hearing support for people with dementia in South Asia.

Method: This was an open label trial of feasibility, tolerability and acceptability of an 8-week hearing support intervention ('Asian Supportive Hearing Intervention for Dementia'; ASHID) for people with mild-to-moderate stage dementia and their care partners in three South Asian countries: Bangladesh, India and Pakistan. The intervention was delivered by a trained 'Hearing Support Practitioner' (HSP), addressing: assessment, fitting of hearing aids, education about hearing and cognitive dysfunction, communication skills, and sign-posting to additional services. The primary outcome was feasibility and acceptability of the study procedures and the intervention. Exploratory outcomes of quality of life, cognition, behaviour and functional ability were also assessed in both members of the dyad.

Results: The study logistics and procedures were feasible, and recruitment, retention and data quality were within *a priori* acceptable limits. Capacity and capability for applied dementia research was developed in seven sites in the three South Asian countries, in preparation for a full randomised controlled trial. Participant dyads reported positive outcomes following the intervention.

Conclusion: This is the first study of hearing remediation for people with dementia in South Asia and represents an important example of a non-pharmacological intervention to improve dementia outcomes. Findings will support a follow-up randomised controlled trial of the intervention.

*Chaudhry N; Goswami SP; Hafiz MM; Husain N; Krishna M; Sakel M; Sandeep M; Shivashankar N; Sivakumar PT; Sumathi V; Tofique S; Thirumorthy A; Vaitheswaran S; Varghese M; and Yamini BK.

Oral Presentation Abstracts

ID: 629 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia awareness, Attitudes, Stigma, Caregiver, Religion, Low- and Middle-Income Country

Understanding, beliefs and treatment of dementia in Pakistan: a case study of the disease in low- and middle-income countries

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Abstract:

Background

Despite being a global health priority, progress towards understanding and treatment of dementia in low- & middle-income countries is slow (ADI, 2015; WHO, 2017). This issue is of great importance given their rapidly ageing populations placing further stress upon their health and social care system and informal care.

There is also lack relevant social science research in these countries, especially in Pakistan. Despite the rising number of older persons in Pakistan and their low socio-economic status, there is very little research on related issues, especially the rising public health concern of dementia (Zaidi et al. 2019a). In particular, research needs to be undertaken to advocate for policies and programs to offer support to people living with dementia (Zaidi et al. 2019b).

The current study has aimed to fill this gap. The study is novel in identifying the interaction between dementia symptoms and Islamic context (Willis et al. 2018), and how this causes distress among people living with dementia (Balouch et al. 2019; Farina et al 2019).

Methods

The study interviewed a total of 40 dementia patients and caregivers in the two most populous cities: Karachi and Lahore. Focus group discussions involved a further 40 participants, divided between men and women. Eight clinicians and academics took part in the key informant interviews.

Three research instruments have been prepared, including the guidelines for individual interviews for persons with mild dementia. Interviews were conducted in Urdu, translated to English and transcripts were analysed thematically using an induction led approach.

Results

One of the key findings is the lack of awareness of dementia and its symptoms. Concerning stigma, there was a diversity of experiences: discussions in the FGD reported a potentially stigmatising attitude whereas in the individual interviews for people with dementia many noted support in view of dementia persons' age and debility. Caregivers spoke of feeling isolated, with more women than men expressing concerns about how they must neglect other duties such as childcare, household tasks and their jobs. Religion stands out as an important theme particularly the failure to perform the five daily prayers leading to a strong sense of guilt as well as a risk of societal disapproval leading to further isolation.

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Conclusions

Important policy recommendations stemming from this research include developing a national campaign to raise awareness of dementia, highlighting symptoms and their progression, and how to seek help and diagnosis. A strong communication strategy is required from experts, religious and community leaders to raise awareness about the disease as well as to enhance the acceptability of seeking help from outside home and to learn to exercise exemptions from prayers.

A greater emphasis on research and evidence informed policymaking is essential, with knowledge translation from the research in Pakistan and from different regions of the world.

Oral Presentation Abstracts

ID: 630 / OS31: Dementia and the equitable society II

Abstract Topic: Dementia and equitable society – NEW

Keywords: access to care, conceptualization, measurement, dementia services

Quantifying access to dementia care: a review on concept and measurement of service accessibility

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Abstract:

Background and Objective

As the number of people with dementia (PwD) keeps growing, how to enable them to live well with dementia with appropriate care services has become a global concern. Facing the challenges that less than half of dementia cases in high income countries and less than 10% cases in low and middle income countries are diagnosed, and the coverage of post-diagnostic services remains low, evidence is needed on how to increase access to dementia care. However, there is a lack of satisfactory operationalization of service accessibility, and existing research often resort to simplified or proxy measurements, such as actual service utilization or coverage. This review study aims to analyse existing concepts and measurements on service access, to provide the theoretical basis for future studies in measuring access to dementia services.

Methods

This study is a synthesis review on existing literature on the conceptualization and measurement of access to health and social care services. Both empirical studies and review articles have been included.

Results

Access to care has been defined as the ways or opportunities of reaching and using health and social care services. It can be quantified by accessibility, the degree of fit between resources and attributes of care system and people's need, ability and willingness to use services. Conceptually, access can comprise 3 dimensions with 6 subdomains: 1) availability; 2) approachability, including geographic accessibility, accommodation, and affordability; 3) appropriateness, including acceptability and timeliness.

A total of 5 methods for measuring access were identified from 35 studies: 1) realized access – utilization of services; 2) potential access – coverage of insurance/services; 3) overall perceived accessibility, difficulty or inability; 4) multi-dimensional perceived accessibility; 5) combination of former categories.

Conclusion

Despite existing definition and conceptualization of access to care, commonly used operationalizations of access in research studies used measurements that captured only proxies or a limited number of dimensions of the concept. In dementia, use of these common measurements may not reflect important issues in access to care, such as lack of informal support, difficulties in mobility, low motivation, and how well does the service fit with users' needs, ability and attitude. Future studies using a multi-dimensional comprehensive instrument to measure access are needed. This will allow understanding of the current access to care, identify major barriers and inequitable factors affecting access, to inform distribution of resources to improve access to dementia care.

Oral Presentation Abstracts

ID: 636 / OS33: Psychosocial interventions

Abstract Topic: Psychosocial interventions

Keywords: young onset dementia, dramatherapy, grieving, metaphor, expression

The indescribable pain : using metaphor to help people with young onset dementia to grieve their loss in dramatherapy

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Abstract:

It is estimated that there are more than 12,000 young people with dementia in Taiwan. People with early dementia encounter a huge change of life, mourning and grieving often occur in response to changes. However, most of the activities of dementia focus on boosting emotions and encouraging interactions instead of helping them to express feelings and accompanying them to go through grieving process.

Dramatherapy is a form of psychological therapy in which all of the performance arts are utilised within therapeutic relationships. Through utilising these media as a metaphor and container, people with early dementia are able to express their indescribable pain within safer distance. Furthermore, using metaphor instead of talking helps them to visualize, concretize and embody their feelings and reconnect with their inner-self without boundaries, and helping them to go through grieving process to accept their body and change of life.

This research had a qualitative design based on seven case studies. These seven cases were closed dramatherapy group took place in Home for Young Onset Dementia of Taiwan Alzheimer Disease Association(TADA) from 2017-2019. It was a 12-week program. Each session lasted 2 hours and took place once per week with participants of mixed genders.

This research had a qualitative design based on seven cases with mixed genders. Data collected within this research consist of client's medical records, therapy notes, supervision notes and hand over notes from TADA. Therapy notes were written after sessions. Data were analysed by inductive analysis with an interpretive approach.

Findings revealed that members in the group showed more willingness to express their feelings about their loss and pain through stories and visual materials. The group also showed significant support and empathy which made them feel "being recognized". Furthermore, more positive emotions appeared after the group discussed the "pain of loss". The members in the group were more willing to accept their condition. Feedback from caregivers point out that members were more stable, calm and humorous after each session.

Overall, the results highlight the significant benefits on expressions, emotions and interactions, which enable the clients to mourn their loss and finally embrace their next stage of life.

Oral Presentation Abstracts

ID: 638 / OS22: Diagnostic tools

Abstract Topic: Diagnostic tools

Keywords: Psychometric tests, Normative, Cognitive control, Assessment battery, Neurocognitive disorders

Towards novel tools for discriminating healthy adults from people with neurocognitive disorders: a pilot study utilizing the remedex for Alzheimer (r4alz) battery

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Background: The early diagnosis of neurocognitive disorders before the onset of the symptoms of the clinical diagnosis is the ultimate goal of the scientific community. REMEDEX for Alzheimer (R4Alz) is a battery, designed for assessing cognitive control abilities in people with minor and major neurocognitive disorders. The battery utilizes the "REMEDEX" system, capable of measuring reflexes using visual and auditory triggers. The battery comprises three (3) tasks for assessing working memory capacity, attention control and inhibitory control, plus cognitive flexibility.

Objectives: To investigate (a) whether the R4Alz battery's tasks differentiate healthy adults controls (HAc) aged 20-85 years old from people with Subjective Cognitive Decline (SCD) and Mild Cognitive Impairment (MCI), (b) whether the battery is free of age, gender and educational level effects, and (c) the criterion-related validity of the R4Alz in all groups.

Methods: The R4Alz battery administered in 100 Greek adults, categorized in healthy adult controls (HAc) ($n = 39$), community-dwelling older adults with SCD ($n = 25$) and patients with MCI ($n = 36$). Statistical analysis comprised Analysis of Variance (ANOVA) and Multivariate Analysis of Covariance (MANCOVA) with age and demographics as covariates when was necessary. The Scheffe post hoc test, applied in batteries' tasks, as well. Pearson's Correlation was also used for the investigation of the criterion-related validity.

Results: The updating of working memory task discriminates the three groups and is free of gender ($p = 0.184$), age ($p = 0.280$) and education ($p = 0.367$) effects. The attention control task also discriminates the three diagnostic groups, while is independent from gender ($p = 0.465$) and education ($p = 0.061$). The inhibition control task is also gender ($p = 0.697$), age ($p = 0.604$) and education ($p = 0.111$) independent and can discriminate HAc from MCI and SCD from MCI. Criterion-related validity in all groups was supported by significant correlations. The updating of working memory task was correlated with the n-back test, where the attention control task was correlated with the Paper and pencil Dual test and the Test of Everyday Attention (TEA). Finally the inhibition control task of the R4Alz battery was correlated with the Color-Word Interference Test of D-KEFS.

Conclusion: The preliminary data of this study indicates that the R4Alz battery is a novel technological approach regarding the psychometric assessment of people with minor and major cognitive deficits, since it is free of demographic effects and it can help with discriminating HAc from SCI and MCI and SCI from MCI.

Oral Presentation Abstracts

ID: 639 / OS33: Psychosocial interventions

Abstract Topic: Psychosocial interventions

Keywords: dementia, Brazil, Cognitive stimulation therapy, implementation

CST- International: development of an implementation plan for Brazil, India and Tanzania

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Abstract:

Background: This work forms part of the CST-International research programme. Dementia is largely untreated in low- and middle-income countries (LMICs) due to limited awareness, resources or care pathways. Medication is commonly not viable, relying on ongoing support of care specialist medical professionals. CST is a group intervention with a robust, global evidence-base for improved cognition and quality of life. Crucially, it is culturally adaptable and can be delivered by health workers with no specialist equipment at low cost.

Aims: To develop, test, refine and disseminate implementation strategies in three diverse countries; Brazil (upper middle income), India (lower middle income) and Tanzania (low income). Each have translated and adapted the United Kingdom (UK) CST manual and begun or completed feasibility/pilot work, with positive outcomes. Secondary aim: to increase awareness and skills in the detection and management of dementia for health workers and families.

Methods: Phase 1: investigate barriers to and facilitators of implementation using meetings, qualitative interviews and consensus conferences with stakeholders. Phase 2: develop generic and country-specific implementation strategies. Phase 3: test this strategy through establishing cascade training models and eight CST groups / 50 people with dementia in each country; offer families a brief dementia awareness course. We will examine feasibility (adherence, attendance, acceptability and attrition), agreed parameters of success (numbers of trained facilitators, numbers of groups run), outcomes (cognition, quality of life, behaviour, carer burden) and costs/affordability of models. Phase 4: refine and disseminate implementation strategies.

Results/Discussion: Results from phases 1 and 2 will be presented. We will increase understanding of successful implementation of an effective and cost-effective intervention in LMIC settings, aiming to establish a system of ongoing CST groups, cascade training models and changes in policy and care pathways. Ultimately, this work could lead to improved cognition and quality of life for the current generation of people with dementia, reduce costs of care; and create a more skilled workforce and educated communities. This talk will consider how the methodology might be extended to other countries globally.

Oral Presentation Abstracts

ID: 640 / OS32: End of life and palliative care

Abstract Topic: End of life and palliative care

Keywords: ACP, Knowledge, Self-efficacy, Long-term care facilities, Nurses, Nursing homes

Uptake of, knowledge about and self-efficacy in advance care planning does not differ among types of nursing home staff and is lowest in dementia

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Abstract:

Introduction Given the large population of residents living with dementia in nursing homes, the need for advance care planning (ACP) is high in these settings. To involve and train nursing home care staff and to delineate accurate roles and responsibilities, we need to know if and to what extent staff differs in the ACP practices they undertake, their knowledge and self-efficacy, in general and in dementia specifically.

Methods We performed a survey study as part of the baseline measurement of a cluster randomized controlled trial in a purposively recruited sample of 14 large nursing homes (NCT03521206). Eligible nurses, care assistants and allied care staff was asked to complete a self-administered survey, including 6 items related to ACP practices (ACP conversation, documentation, advance directive (AD), estimating someone's capability, ACP in dementia, and with family), 11 knowledge items and 12 ACP roles to evaluate self-efficacy.

Results A total of 196 nurses, 319 care assistants and 169 allied staff participated (67% response). Function was not significantly associated with carrying out any of the ACP practices. The odds of starting an ACP conversation and documenting ACP was 4 times higher ($p < .001$) in nurses, compared to care assistants. Engagement in ACP conversations with residents living with dementia ranged from 13.3% in nurses to 8.4% in care assistants. Nurses scored on average 0.13 (95%CI 0.08-0.17; $p < .001$) and allied staff 0.07 (0.03-0.12; $p < .001$) higher than care assistants on knowledge (with scores ranging from 0 to 1, with 1 indicating better knowledge). Only 15% of nurses and 9% of care assistants knew that in Belgium residents living with dementia can change their AD. Overall self-efficacy did not differ between types. Staff however reported lowest self-efficacy in conducting ACP conversations with residents living with dementia; 5 in all groups (on a score from 0 to 10, with 10 indicating most confidence). Follow-up results of the trial study regarding these constructs will be available by March 2020.

Conclusions Carrying out ACP did not differ between nurses, care assistants and allied staff, and might even depend on other elements than function. Staff differed only to a little extent with regards to their knowledge and no differences were found regarding overall (low) self-efficacy. Staff's engagement in ACP practices, their knowledge and self-efficacy were always lowest when it involved items related to ACP in dementia. Nursing home staff should receive appropriate education and function might not be the only leading criterion to delineate ACP roles in nursing homes. Considering increasing time restraints of nurses, interventions that focus primarily on this group are no longer scalable or

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sustainable, and involving other types of professionals might provide a potential solution to correspond to the high need for ACP in the nursing home population.

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ID: 644 / OS30: Innovation, technology and entrepreneurship

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: rare dementia, robot, emotion recognition, LAMIC, India

Recognition of facial expression of emotions by persons with rarer types of dementia in India

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¹Schizophrenia Research Foundation (SCARF), India; ²Imperial College London, UK

Abstract:

Background: Impairment in the ability to identify facial expression of emotions has been extensively reported in dementia in Alzheimer's disease and frontotemporal dementia. With this in mind, the Hybrid Face robot capable of six emotive responses and two facial expressions has been developed in collaboration with Imperial College London, UK to provide social engagement to persons with dementia in India. The literature on the recognition of emotions by persons with rarer types of dementia such as Lewy body dementia and dementia in Parkinson's is conflicting, insufficient and hardly researched in India. This study seeks to understand the recognition of the hybrid face robot's emotive responses by persons with rarer types of dementia in India which will set the ground for further development of this intervention.

Methods: This study aims to extend the existing literature by evaluating the recognition of emotions in three groups of participants: persons with frontotemporal dementia, Lewy body dementia and dementia in Parkinson's disease. The participants were asked to identify the emotive responses of the Hybrid Face Robot. Additionally, the participants were shown photographic representations of human facial expressions and asked to identify them.

Results: Our results identified the differences in impairment of recognition of emotions in persons with frontotemporal dementia, Lewy body dementia and dementia in Parkinson's disease. Furthermore, it described the participants' degree of difficulty in identifying the different emotions. The differences in recognition of the hybrid face robot's emotive responses compared with photographs of human facial expressions were also analyzed. The results will highlight areas that require modification to further develop this intervention.

Conclusions: This study ascertained whether persons with rarer types dementias have pervasive difficulty in recognizing a wide range of emotive responses and if the emotive component of the Hybrid face robot can successfully be used to provide social engagement to persons with rarer types of dementia.

Oral Presentation Abstracts

ID: 650 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, witchcraft, madness, spirituality, prayer camp.

Exploring the experiences of living with dementia in Ghana

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Abstract:

Background: With demographic transition occurring worldwide, the sub-Saharan African (SSA) countries have the youngest population but the fastest growing rates of older people in the world. Undoubtedly, this will lead to more chronic illnesses including dementia in the sub-region. Dementia and cognitive impairments are therefore set to be one of the biggest public health challenges in SSA in the 21st century. However, there is paucity of information on dementia studies in the sub-region and the few studies that have been conducted there have mainly focused on incidence and prevalence with no investigation carried out on the lived experience of the illness in SSA.

Using hermeneutic phenomenological approach, this study aims at exploring the experiences of people living with dementia and the cultural perception of the illness in the SSA country of Ghana.

Method: The study used semi-structured interviews with people with dementia and their family carers and focus group discussions with healthcare professionals and prayer camp staff with experience of working with people with dementia.

Preliminary findings: Early analysis of the data suggests that there is no local name for dementia in Ghana and that dementia is a taboo subject that attracts widespread stigma in the country. The findings also point to a number of misconceptions about the causality of dementia including witchcraft, madness, menopause, curses and evil spirits.

Conclusion: There is a general lack of awareness and knowledge of dementia in Ghana. There is widespread presence and use of prayer camps for the treatment and practices of dementia as opposed to more conventional psychiatric services for dementia care and treatment. There is a need to work to raise the awareness of dementia to reduce the misconception and stigma associated with dementia in Ghana.

Oral Presentation Abstracts

ID: 651 / OS06: Other syndromes and new and future treatments

Abstract Topic: Other syndromes and dementia – NEW

Keywords: HIV-Associated Neurocognitive Disorders, sub-Saharan Africa, combination antiretroviral therapy, Frascati criteria

HIV-associated neurocognitive disorders (HAND) in a cART-treated cohort of adults aged 50 and over in Kilimanjaro, Tanzania: the first longitudinal follow up study of HAND in an older population in sub-Saharan Africa

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Abstract:

Background

HIV-associated neurocognitive disorders (HAND) are highly prevalent in older people living with HIV in high-income countries (HICs). In sub-Saharan Africa (SSA), life expectancy is increasing due to availability of combination antiretroviral therapy (cART) and age-associated complications such as HAND may be increasing in prevalence but current data are extremely limited. We conducted the first prevalence and one year incidence study of HAND by consensus criteria in a cohort of 253 cART treated individuals under long-term follow up in a Government clinic, suggesting a prevalence of 47% and one year incidence of 58%. This follow-up represents the first longitudinal study of HAND in older cART-treated adults in sub-Saharan Africa 2016-2019 with the aim of reporting prevalence and persistence of cognitive impairment.

Method

We investigated prevalence and incidence of HAND diagnosis and subtypes (asymptomatic neurocognitive impairment (ANI), minor neurocognitive disorder (MND) and HIV-associated dementia (HAD) over 40 months in 253 HIV positive adults aged ≥ 50 attending a government clinic. HAND diagnoses were reviewed every 12 months by a consensus panel using Frascati criteria, based on detailed, locally-normed neuropsychological battery, neuropsychiatric clinical assessment and collateral history.

Results

At baseline (2016) HAND prevalence (by consensus Frascati criteria) was 47% (n=253, 71% female, 95.5% cART-treated) and of 185 followed-up at one year (2017) prevalence was 49% (one-year incidence from those at risk 37%). Provisional follow-up data indicates HAND prevalence of 63% in 2018 (n=133) and 54% in 2019 (n=128). Milder forms of HAND predominated with ANI the most frequently diagnosed. The severest form of HAND, HIV associated dementia (HAD) made up < 5 % of the cohort, across the four year follow-up. The patient cohort had well managed HIV disease, with an average mean CD4 count > 450 cells/ μ and suppressed viral load in > 60% across the four year follow-up.

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Conclusion

This is the first follow up study of prevalence and incidence of HAND, in older cART-treated people living with HIV in SSA. Prevalence and incidence were high and our findings suggest cART and regular clinic follow up are insufficient to prevent occurrence or progression of HAND in this setting. If replicated in other SSA settings, HAND is likely to be a major cause of cognitive impairment in older people in SSA, despite cART treatment.

Further work must focus on identifying those most at risk, preventative strategies, and factors associated with clinical improvement and HAND reversibility.

Oral Presentation Abstracts

ID: 652 / OP3: Diagnosis

Abstract Topic: Diagnosis

Keywords: Dementia, Diagnosis, Profile, Memory

Profiles of the different diagnostic outcomes at the NHSCT memory service

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Abstract:

Background The Northern Health and Social Care Trust (NHSCT), Northern Ireland, established a Memory Service in 2013 to offer timely differential diagnosis and improve quality of care in dementia. Timely diagnosis offers advantages for the person which include; better adjustment, slowing of progression and planning ahead. There are also significant savings to the health economy. Increasing awareness about dementia has increased the number of people who seek assessment for dementia. This is a positive development as it will increase the number of people who receive a timely diagnosis but it also increases the number of people who attend for assessment who do not have dementia.

Method Since 2013 there have been over 6000 referrals to the NHSCT Memory Service. come from GPs or hospital liaison. An anonymised database was set up to record information on the profile of people referred to the service. This includes demographic information, details about their social, medical and psychiatric history, performance on the Addenbrooks Cognitive Examination-III (ACE-III), Bristol Activities of Daily Living, Zarit Caregiver Burden Scale and the outcome of the assessment.

Results 59.3% of people attending for assessment receive a diagnosis of dementia. Of these 43.5% are diagnosed with probable Alzheimer's disease, 16% vascular dementia, 1.1% Lewy body dementia, 0.6% frontotemporal dementia and 33.3% mixed dementia. 26.4% attend with Mild Cognitive Impairment (MCI). 40% of people with MCI are subsequently diagnosed with dementia. Analysis of data from the different assessment outcomes highlights the different profiles of specific dementias, MCI, MCI who subsequently develop a dementia and mental health presentations.

Conclusions Greater understanding of the profiles of the different outcomes has significant benefits. 40.7% of people attending the Memory Service did not have dementia. Sharing information about the profile of people who are likely to have a dementia with referral agents will help them to make more informed decisions about who to refer to specialist Memory Services. This has benefits for the person by avoiding the unnecessary stress of a referral for assessment of dementia. It also offers savings to the health economy by reducing inappropriate referrals. Greater understanding of the cognitive profile and relative strengths and weakness of the different types of dementia enables appropriate advice to be provided and the opportunity for the development of compensation strategies. Greater understanding of MCI and MCI which is likely to develop into dementia offers the opportunity to provide early intervention and also informs decisions about who should be offered follow up assessment. This data has facilitated better planning of services to accommodate the number of people presenting to the Memory Service who are likely to have dementia.

Oral Presentation Abstracts

ID: 665 / OS34: Registries II

Abstract Topic: Global Dementia Observatory (GDO) – NEW

Keywords: dementia, Global Dementia Observatory, strategy, public policy

A comprehensive review on the Korean dementia actions using the Global Dementia Observatory framework

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Abstract:

As announcing the 「Global Action Plan on the Public Health Response to dementia 2017-2025」 by World Health Organization (WHO) in May 2017, the WHO is developing seven practical tools to move forward and to support Member States. Especially the Global Dementia Observatory (GDO) is a representative frame to compare national dementia strategies and services among different countries. GDO framework includes 3 domain (policy, service delivery, information & research) and 7 areas (dementia as public health priority, dementia awareness and friendliness, dementia risk reduction, dementia diagnosis, treatment, care and support, support for dementia carers, information systems for dementia, and dementia research and innovation) and 35 main indicators. We firstly reviewed the current status of the national dementia actions in South Korea using the GDO framework. Then we compared the national dementia actions of South Korea with that of 21 pilot countries. As a result, South Korea have been relatively well undertaking in most areas (except the dementia research and innovation) compared to the advanced countries among the pilot. For example, South Korea has been fulfilling 1) the 3rd National Dementia Plan (NDP) and the National Dementia Initiatives under the Dementia Management Act (DeMA) for dementia as public health priority, 2) the National Walkathon for Overcoming Dementia, the Dementia Awareness Day, dementia partners, dementia-friendly initiative for dementia awareness and friendliness, 3) development of prevention programs such as Dugeum-dugeun brain Fitness, Practice Codes by Life Cycle, and the Dementia Prevention Exercise, 4) establishment of the Korean National Dementia Management Delivery System as dementia diagnosis, treatment, care and support, 5) dementia training and education, psycho-social support, respite services, and financial benefits as support for dementia carers, and 6) development and utilization of the Korean Dementia Registry and Management System (K-DReaMs). However, it is necessary to enhance a legal system for right of people with dementia (PWD) and their family caregivers. Also, we need to strengthen dementia research area, especially on comprehensive and integrated research management, such as managing research funds, sharing the research results, participating PWD and caregivers in clinical researches etc. To progress the WHO dementia action plan and develop the GDO better, we suggest several improvement points; 1) systematization and balance of the GDO indicators (which can reflect various countries' health and welfare systems), 2) solution to share the best practices of each areas and indicators in the advanced countries, and 3) clarifying indicators' definition enable to apply unambiguously.

Oral Presentation Abstracts

ID: 666 / OS07: Models of care

Abstract Topic: Models of care

Keywords: service delivery, dementia day care, rights, quality of life, models of care

Evaluating & planning of future day care for people with dementia

Bernadette Rock

The Alzheimer Society of Ireland, Ireland

Abstract:

Background and objectives

This presentation explores how The Alzheimer Society of Ireland (ASI) strives to implement a rights-based and person-centred approach to service delivery for people with dementia. ASI operates 54 day care centres nationally. Day care is vital to supporting the person with dementia to continue living at home and enabling family members to take time out from caregiving which could otherwise extend around the clock and adversely affect their health.

Little is known in Ireland about the merits and demerits of day care from the perspectives of persons with dementia and informal caregivers. The person with dementia deserves affordable, accessible, equitable and a high quality day care service. This evaluation involves exploring day care services from the point of views of people with dementia and informal caregivers. It uncovers the lived experiences of people with dementia in relation to day care services, and seeks to ascertain their needs and preferences in relation to delivery of care.

Methods

This evaluation adopts a mixed methods approach and includes five key elements:

- Focus groups with people with dementia in day care centres,
- Interviews with family carers of people with dementia attending day care centres,
- Surveys of ASI day centre staff,
- Survey of people with dementia and carers who, for whatever reason, do not access ASI day care.

Additionally, in-depth desk research is currently being carried out to pool knowledge about best practices in other jurisdictions in relation to day care services. Exploring international practices will be crucial in identifying new innovations in day care services and delivery.

Results / Positive impact

This evaluation is in the process of being undertaken, and is due to be completed in November 2019. Currently being gathered and analysed. Specifically, this evaluation will inform the following:

- Inform service provision: Identify aspects of day care services that are most and least helpful, and what services users want but cannot access, and how ASI can develop an effective person-centred model of care.
- Inform future development and improvement of day care services and access; Identify barriers to service use and how to address these.
- Influence advocacy work that champions the rights of people living with dementia and their communities to quality support and services.

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Oral Presentation Abstracts

Conclusions / Perspectives

This evaluation supports the implementation of proposed actions within Area Action 4, “*develop a pathway of efficient, coordinated care for people with dementia that is embedded in the health and social care system .. to provide integrated, person-centred care as and when it is required.*” This evaluation will also ensure that people with dementia have access to appropriate services throughout their journey in line with ASI’s vision of “[A]n Ireland where people on the journey of dementia are valued and supported”.

Oral Presentation Abstracts

ID: 672 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: Mild Cognitive Impairment, Early Detection, Technology, Internet of Things

Early detection of mild cognitive impairment (mci) among community living seniors: feasibility of an in-home sensor monitoring system to detect changes in behaviour patterns

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¹Sengkang General Hospital, Singhealth Duke-NUS Academic Medical Centre, Singapore; ²National University Hospital; ³Singapore Management University; ⁴Duke-Nus Medical School; ⁵Yong Loo Lin School of Medicine, National University of Singapore

Abstract:

Introduction: Dementia is a global epidemic with one new case diagnosed every three seconds. A window of opportunity is the pre-dementia stage known as Mild cognitive impairment (MCI). Up to half of those with MCI convert to dementia at the end of 3 years. Multi-domain, multi-component interventions can delay further cognitive decline. Delaying dementia onset by just five years can halve global dementia prevalence with accompanying economic and societal impact. Individuals often present to services late in the course of their disease and more needs to be done for early detection.

Method: To determine the feasibility and acceptability of deploying different sensors in the homes of seniors to monitor behaviour change patterns, we recruited 59 community living elderly (aged ≥ 65 years who live alone) with and without MCI and observed them over 2 months. Frequency of forgetfulness was monitored by tagging personal items and tracking missed doses of medication. Activities such as step count, time spent away from home, television use, sleep duration and quality was tracked with passive infrared motion sensors, smart plugs, bed sensors and a wearable activity band. Psychometric measures of cognition, depression, sleep and social connectedness were also administered.

Results: Out of 59 participants, 49 were followed for 2 months. Of the 49, 28 were diagnosed with MCI and 21 with normal cognition (HC). Frequencies of various forgetting incidents and activity patterns were computed and compared between MCI and HC, which was determined at baseline. As expected, the MCI group had lower mini mental state examination (MMSE) scores than the HC group. They also tended to have poorer sleep quality with higher scores on the Pittsburg Sleep Quality Index (PSQI). With the sensor derived data, we found that MCI participants were less active than their HC counterparts; had more sleep interruptions and forgot their medications more frequently compared to the HC group. It was acceptable to older adults with over 60% of study participants giving positive feedback and some requesting for the system to be permanently installed.

Conclusion: We demonstrated it was both feasible and acceptable to set up these sensors to unobtrusively collect data. We now plan to deploy a similar system in the homes of elderly to look at behaviour change patterns over 3 years. We hypothesize that there are behaviour change trajectories that signal those who are likely to decline over a short term, allowing for earlier intervention. It is a global and national priority to prevent or delay the onset of dementia. With our ageing population, we can no longer rely on next-of-kin to be our eyes and ears in the community to monitor for changes in our seniors' wellbeing. In line with Singapore's push to be a tech-enabled Smart Nation, we need to evaluate if the technology can be optimized to yield more clinically impactful information with public health significance.

Oral Presentation Abstracts

ID: 673 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: CREATIVE ARTS, PERSON-CENTRED CARE, DEMENTIA CARE MAPPING, WELL-BEING PROFILE, SOCIETAL ATTITUDES

Arts and dementia programme evaluation : the impact on well-being indicators, caregiver outcomes and attitudes towards dementia

DONALD YEO, THERESA LEE, HWAN JING KOH, SZE CHI WONG, WAN JIE KATE TAN
ALZHEIMER'S DISEASE ASSOCIATION, Singapore;

Abstract:

Non-pharmacological arts-based community programmes have the potential to enhance personhood, social inclusion and positive well-being of persons with dementia and their family caregivers. This presentation highlights some of the findings of an evidence-based research study evaluating the impact of the Arts and Dementia programme, initiated and developed by the Alzheimer's Disease Association (ADA) in Singapore. This programme has shown positive outcomes on persons with dementia, their family caregivers, and positive shifts in societal attitudes towards dementia. Each activity in this programme builds on social confidence, and supports the creativity and imaginative skills of the persons with dementia, including those without prior experience in engaging the arts. The programme provides temporary but meaningful respite for dementia care partners, with longer-term benefits such as reducing perceived burden in dementia caregiving. Caregivers are often surprised and relieved knowing that their loved ones are contented and engaged during the programme. Through creating friendships and strengthening social connections, such purposeful interactions shift the focus to abilities rather than deficits, fostering more positive attitudes towards dementia among ADA staff, volunteers and community artists who facilitated the art-making and art-appreciation activities. We will also discuss several possible directions for future programmes and evaluation studies to explore.

Oral Presentation Abstracts

ID: 676 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: frailty, dementia, MCI, CNCDs, LMIC

Prevalence and incidence of mild cognitive impairment and dementia in elderly people with frailty in Latin America, china and India.

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Abstract:

Background : There have been few cross-national studies of the prevalence of the frailty phenotype and dementia conducted among low or middle income countries. We aimed to study the prevalence and incidence of MCI and dementia and the association with frailty in rural and urban sites in Latin America, India and China.

Method: Cross-sectional population-based catchment area surveys conducted in eight urban and four rural catchment areas in eight countries; Cuba, Dominican Republic, Puerto Rico, Venezuela, Peru, Mexico, China and India. The protocols for the one phase surveys, comprising; a clinical interview; a health, medical history, healthcare utilisation and lifestyle interview; a cognitive assessment; a physical examination; and an informant interview. Dementia diagnosis was determined after clinical interview, cognitive test battery, physical and neurological examination and informant interview according to a) the education- and culture-fair 10/66 dementia diagnostic algorithm. We assessed weight loss, exhaustion, slow walking speed and low energy consumption, but not hand grip strength.

Incidence wave studies in urban sites in Cuba, Dominican Republic, Puerto Rico and Venezuela, and rural and urban sites in Peru, Mexico and China, with ascertainment of 10/66 incident cases three to five years after cohort inception in frailty participants.

Results: We surveyed 17,031 adults aged 65 years and over. Overall frailty prevalence was 15.2% (95% CI 14.6-15.7%). Prevalence was low in rural (5.4%) and urban China (9.1%) and varied between 12.6% and 21.5% in other sites. A similar pattern of variation was apparent after direct standardisation for age and sex. Prevalence of frailty was 16.4% in females and 13.1% in men. There was a clear trend in all sites for prevalence to increase with age; from 9.5% (65-69 years), 11.9% (70-74 years), 16.5% (75-79 years), and 25.5% (80 years and over). The prevalence of dementia was higher in frailty people. The prevalence of MCI 4.47(3.19- 6.23) and 10/66 dementia 27.65 (24.5-31.01)

Controlling for age, gender and education, frailty was positively associated with older age, female sex, lower socioeconomic status, physical impairments, stroke, depression, dementia, disability and dependence, and high healthcare costs. The prevalence of dementia was double in older frailty compared to that in non-frailty (adjusted PR=2.00, 95%CI 1.84–2.16). In the follow up frailty was also

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associated with an increased risk of the development of mild cognitive impairment and dementia (hazard ratio [HR] 1.83, 95% CI 1.29–2.06).

Conclusions: The high prevalence in older adults of frailty, dependency and dementia—all of which are associated with higher mortality—indicates a need for special attention to this age group as a risk group and implement and evaluate package of care for frail or dependent older people (among whom there will be a high prevalence of cognitive impairment, including dementia)

Oral Presentation Abstracts

ID: 677 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: Dementia / Research/ Developing Countries/ Findings

Past present and future of the 10/66 dementia research gro

Daisy Miguelina Acosta Valerio

10/66 Dementia Reseach, Dominican Republic

Abstract:

The 10/66 population-based study is a longitudinal study of adults aged 65 and over, living in 11 defined catchment areas in eight low and middle-income countries (China, Cuba, Dominican Republic, India, Mexico, Peru, Puerto Rico, Venezuela). The surveys, which commenced in 2003, use the same cross-culturally validated assessments. This includes measures of cognitive function, mental disorders, physical health, anthropometry, socio-demographics, health and lifestyle risk factors, disability/dependence, health service utilisation, care arrangements, caregiver strain and biological measures. A second follow up was carried out between 2007 and 2010 and a third wave of assessment using an extended form of the basic 10/66 survey will start in 2016. This will be both a new prevalence sweep, with a re-door-knocking of the original catchment areas to generate a new representative prevalence sample of all older adults, and a final follow-up of the original baseline cohort. The original sample consisted of 15901 individuals.

Morbidity in the baseline surveys of the cohort has been described in detail, with publications on the prevalence of dementia, mild cognitive impairment, mental disorder, sleep disorder, hypertension, stroke, anaemia and dependence. More recently, we have been focusing on determinants of longitudinal outcomes, specifically incident dementia, mortality, and dependence.

The data set is openly available and data access forms can be found on our website, together with a full list of findings and publications (<http://www.alz.co.uk/1066>).

During the presentation, the Main findings from each phase of our study will be discussed.

Oral Presentation Abstracts

ID: 684 / OS16: Dignity and spirituality

Abstract Topic: Dementia and dignity

Keywords: implementation, decision aid, autonomy, community care, communication

Implementing a risk negotiation conversation tool into practice: experiences of a community aged care organisation

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¹Bolton Clarke, Australia; ²Centre for Health Communication and Participation, LaTrobe University, Australia; ³Austin Health Department of Medicine, University of Melbourne, Australia; ⁴School of Public Health & Preventive Medicine, Monash University, Australia

Abstract:

Introduction:

Achieving quality health and aged care for people with dementia and their informal carers requires structured implementation of evidence-based interventions into practice in a timely and practical manner. Using a systematic process, such as with an implementation framework, leads to a greater likelihood of successful uptake of the target intervention. We describe the implementation of a risk negotiation conversation tool 'Enabling Choices' for people with dementia, using an implementation framework specifically designed for a large Australian health and aged care service provider. The implementation framework included 6 steps: (1) Why change? (2) What do we know? (3) Who will benefit? (4) Who will bring about change? (5) What strategies will be used? and (6) With what effect? In each step the current socio-cultural-political context and current academic landscape was considered.

Method:

Implementation into practice is occurring in 3 stages: (1) older people, front line care staff, management and researchers work together to identify and prioritise pressing issues related to the negotiation of risk in daily activities for people with dementia; (2) co-design the 'Enabling Choices' online conversation tool for use by community aged care staff; and (3) field test and iterative feedback with up to 10 community aged care staff and 41 people living with dementia +/- their carers.

Results:

Implementation challenges and learnings include: (1) understanding and communicating *why* change is needed (particularly in the changing aged care landscape in Australia of consumer directed care); (2) *what* the conversation tool looks like and what we want the target audience to do with it (e.g. encouraging staff and clients of its benefits); (3) *who* will benefit from the tool and what the *barriers* to use are (e.g. ensuring the tool is in line with new person-centred Aged Care Quality Standards); (4) *who* will bring about the change and what *strategies* can be used to ensure uptake into practice (e.g. engaging regularly with implementers and recipients of the tool to ensure it meets their needs and wishes); and (5) are we making any *difference* (e.g. dignity and autonomy for people living with dementia, improved carer wellbeing and satisfaction with work role for community aged care workers)?

Conclusion:

Effectively communicating the value proposition of the 'Enabling Choices' tool to older people living with dementia, their carers and the aged care workforce is essential for successful implementation. Working collaboratively with all parties ensured that the tool was feasible and acceptable, ready for scale up throughout a Nationally-based large aged care provider.

Oral Presentation Abstracts

ID: 693 / OS02: Attitudes and awareness I

Abstract Topic: Attitudes, awareness and stigma

Keywords: Stigma, Attitudes, National, Survey, Dementia

The first national survey of attitudes of stigma against dementia in Singapore

Rosie Ching

Singapore Management University, Singapore

Abstract:

Singapore's first nation-wide survey on dementia has gained in excess of 5670 respondents across population demographics of age, race and gender, in quantifying the national landscape with statistics relating to persons with dementia, their primary or secondary caregivers and the general public with no connections to dementia. In collaboration with Alzheimer's Disease Association (ADA), Singapore Management University (SMU) statistics faculty Rosie Ching crafted the extensive survey exceeding 138 variables and together with her 99 introductory statistics students, actively conducted the survey at dementia daycare homes, door-to-door at apartment blocks, malls, markets, hawker centres, train stations, with the online link strictly restricted to only family and close friends. In the subsequent statistical analysis of attitudes and perceptions, 86% of respondents overall rate themselves with low knowledge of the disease. Nearly 3 in 4 persons with dementia indicate feelings of rejection and loneliness, with more than half saying that others act as though they are less competent due to their condition. Although they perceive themselves negatively in rejection, shame and competence, they are further outstripped in magnitude of negativity and stigma by the general public with no dementia connections. While the more remote the connection with dementia, the lower the awareness and consequently the greater the stigma, persons with dementia, however, buck this trend, coming a very close second in stigmatic attitude against themselves, on par with that of the general public. This finding deepens the worry that with significant prevailing stigma associated with dementia, the less likely that those in need of help or support will seek it, especially with Singapore the oldest society in ASEAN, and predicted by the UN to have the world's oldest population by 2100.

Oral Presentation Abstracts

ID: 702 / OS08: Community partnerships / Public-Private-People partnerships

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Public, private, community, partnerships

Kerala state initiative on dementia - a pioneering successful model

Meera Pattabiraman

Alzheimer's and Related Disorders Society of India, India

Abstract:

With an estimated 5.1 million persons with dementia in India and lots of language and cultural diversity, dementia is a difficult and complex issue. While efforts are on to make the central government come up with a national plan for dementia, what is equally important is for the state governments to have their own state plans for providing care services for dementia. In India, health is a state subject and so ARDSI has been advocating with state governments as well.

We have had success in the state of Kerala, where the Kerala State Initiative on Dementia was launched in 2014. The project covers all important aspects of dementia – creating massive awareness, setting up of day care and residential care facilities in all districts, starting of memory clinics attached to government hospitals, training of health care and social workers and a creating a dementia friendly environment with large numbers of dementia friends.

The initiative has been progressive and dynamic, with creation of large amount of Information, Education and Communication materials in the local language for dissemination, setting up standard operating procedures for different types of services, state-wide campaigns, mobilizing professional support and ensuring feasibility for expansion through reconnaissance visits in all 14 districts of Kerala.

This has been functioning successfully for the past 5 years as an ideal model through public private partnership for the welfare of persons with dementia. It is a collaborative project between the Department of Social Justice and Empowerment Kerala, Kerala Social Security Mission and Alzheimer's and Related Disorders Society of India (ARDSI). Efforts are on to replicate this model in other states like Karnataka, Maharashtra and West Bengal.

Oral Presentation Abstracts

ID: 703 / OS21: STRiDE

Abstract Topic: Diagnostic tools

Keywords: dementia, STRiDE toolkit, cognitive debriefing, interviews, cross-cultural

The cross-cultural adaptation of the STRiDE toolkit: towards the generation of prevalence, impact and dementia care cost estimates in South Africa

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¹Alan J Flisher Centre for Public Mental Health, University of Cape Town, South Africa; ²Centre for Dementia Studies, Trafford Centre, Brighton & Sussex Medical School, University of Sussex

Abstract:

Background: Dementia is expected to increase dramatically in the coming decades due to rising life expectancies, particularly in low-and middle income countries (LMICs). Increasing numbers of dementia are being observed within a context of ill-equipped healthcare systems, with very little data available in South Africa on prevalence. The “*Strengthening responses to dementia in developing countries*” (STRiDE) project, in part, sets to address this gap by generating new evidence of prevalence of dementia. To achieve this, we aim to cross-culturally adapt the English version of the STRiDE toolkit for use in South Africa (Northern Sotho, isiXhosa and Afrikaans). The toolkit consists of 20 measures that measure cognition, quality of life, functioning and disability, well-being and health status, socio-demographics, support received and costs of care, a physical assessment, injury, and also stigma, knowledge and awareness.

Methods: Ten older adults (65 years and older) and ten carers will be recruited per target language (N=30), and will be recruited within two provinces: The Limpopo province with Northern Sotho-language, and the Western Cape province with English, Afrikaans and isiXhosa as target languages. Recruitment will be supported by Alzheimer’s South Africa (ASA), a South African partner on the project, and queries around clarity and appropriateness of items from the STRiDE toolkit will be addressed via semi-structured debriefing interviews, noting participants’ comments and responses.

Results: This presentation will discuss the considerations around data collection of prevalence and cost of care for dementia in South Africa, and present perspectives on the appropriateness of the STRiDE toolkit (including individual items and response scales) in South Africa.

Conclusion: These findings will provide the country with a culturally-appropriate toolkit to go on to generate new evidence on the prevalence, impact and cost of dementia care and support in South Africa.

Oral Presentation Abstracts

ID: 705 / OS21: STRiDE

Abstract Topic: Dementia policies and public policy

Keywords: Dementia healthcare in Brazil, views, healthcare provision.

How can we improve the healthcare provided for people with dementia in brazil? Views from policymakers, people living with dementia and their carers

Fabiana Araujo Figueiredo Da Mata¹, Déborah Oliveira¹, Elaine Mateus², Klara Lorenz³, Adelina Comas-Herrera³, Cleusa P Ferri¹

¹Federal University of Sao Paulo, Brazil; ²FEBRAZ - Brazilian Federation of Alzheimer's Associations, Brazil; ³London School of Economics, United Kingdom

Abstract:

Background and objectives: Health and social care in Brazil are provided by public (universal) and private sectors. Older people usually receive assistance regarding many health conditions including dementia. However, little is known about the existence of dementia-specific care strategies as well as people's views regarding the access to proper diagnosis, treatment and support. This study aimed to investigate the care currently being offered to people living with dementia in Brazil and to explore ways of how the provision of such care could be improved.

Methods: This study was undertaken as part of STRiDE, an international collaborative research programme aimed at strengthening responses to dementia in low- and middle-income countries. Ten semi-structured interviews were conducted with policymakers, people living with dementia and family carers. The interviews lasted around 60 minutes each and were conducted either by telephone or in-person, in Sao Jose dos Campos, São Paulo. Participants were identified in the community through supporting groups, schools, community centres, healthcare services and the Brazilian Federation of Alzheimer's Associations (FEBRAZ). All the interviews were transcribed verbatim and were analysed using thematic analysis in NVivo®.

Results/Positive impact: Findings from the interviews will be presented at the conference according to the following themes: 1) identified challenges and restrictions to meet future demands regarding treatment and support of dementia, 2) options for implementing an evidence-based care pathway for dementia, 3) financing of care, treatment and support for dementia, and 4) "desires and ideals" to improve care in dementia. Aspects identified in the three interviewed groups – policymakers, people living with dementia and carers – will be highlighted and condensed into each of the themes. Therefore, the study will present the views of different groups towards changes to conceive a better dementia healthcare provision in Brazil.

Conclusions/Perspectives: The key findings identified in the study may contribute towards 1) disentangling dementia-specific healthcare delivery in Brazil; 2) getting to know the aspirations of the population towards a better system for people living with dementia and their carers; and 3) identifying the main difficulties and challenges that need to be met to improve dementia healthcare provision in Brazil. These findings may also be beneficial for future policymaking and research.

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Oral Presentation Abstracts

ID: 708 / OS08: Community partnerships / Public-Private-People partnerships

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: social security, trial and errors, public and private

Learning from trials and errors

Noriyo Washizu

Alzheimer's Association Japan, Japan

Abstract:

Japan is the most aged society in the world now and the elderly population has already reached 28% in 2018. The number is increasing year by year and will reach 33% by 2030.

Age is not the only cause of dementia but is a major factor. Therefore, the number of people with dementia is increasing and the total number of people living with dementia and mild cognitive impairment has reached 10 million people now.

The government started a prognostic approach for the aging society and dementia in the early '80s and has been developing various methods. Also, the private sector and individuals have been making efforts to seek the best practices. This entire process done by the public and private sectors is series of trial and error. Both the successful and unsuccessful experiences of Japan will serve as useful references for countries in all stages of aging no matter how old one is. In this presentation, the analysis of unsuccessful examples will be examined. In addition, Japan has established a certain level of the social security system but we are still facing the challenges related aging and dementia. To share these challenges will be meaningful for us and other countries, as well.

Oral Presentation Abstracts

ID: 711 / OS27: Risk reduction and prevention

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: Cognition, Dietary Patterns, Nutrition, DASH diet, Mediterranean diet, Older Adults

Association of dietary patterns with cognition in older adults: findings from Sydney memory and aging study

Xi Chen¹, Fiona O'Leary², Zhixin Liu¹, Henry Brodaty¹

¹University of New South Wales, Australia; ²University of Sydney, Australia;

Abstract:

Background

Dietary patterns have been associated with cognitive health in older adults, with positive effects on cognition reported to be diets that are mostly plant-based, rich in poly- and mono-unsaturated fatty acids and lower in consumption of processed foods [1]. However, inconsistencies or gaps in research to date especially for large scale studies warrant further investigation.

Objective

We aim to examine the associations between dietary patterns including Mediterranean diet, Dietary Approach to Stop Hypertension (DASH) diet, and Dietary Patterns derived by Principle Component Analysis (PCA), and cognitive function among older adults.

Methods

Participants from Sydney Memory and Ageing study were 1037 non-demented, community dwelling (n=1037) persons aged 70-90 years at baseline assessment recruited from the electoral roll [2]. The 80-item Cancer Council of Victoria FFQ was used to assess dietary intake including food and alcoholic beverage. Mediterranean diet scores were calculated using the 0-9 scale Trichopoulou method [3] and 0-55 scale Pangiotakoes method [4] separately. DASH diet score was calculated according to quintiles of DASH food group consumption [5]. A healthy prudent dietary pattern and western dietary pattern were derived using PCA. Neuropsychological tests assessed global cognition and 6 cognitive domains [2]. Multivariate linear regression, adjusted for age, gender, education, BMI, metabolic syndrome, cardiovascular risk factors, history of stroke, physical activity, smoking, depression and APOE ε4 genotype, was used to assess the relationship between the dietary patterns and cognition.

Results

No association were found between Mediterranean diet and cognition among older adults, although the total intake of legumes and nuts, as a typical Mediterranean food group, was positively related to better performance in cognitive domains of attention processing speed ($\beta=0.073$; 95% CI:0.007,0.139; $P=0.03$), language ($\beta=0.109$ 95% CI:0.031,0.187; $P=0.006$), verbal memory ($\beta=0.072$; 95% CI:0.004,0.139; $P=0.037$) and global cognition ($\beta=0.118$; 95% CI:0.052, 0.185; $P=0.001$). Higher adherence to a DASH diet was associated with better visual-spatial cognition ($\beta=0.043$; 95% CI: 0.008, 0.077; $P=0.016$). The prudent healthy diet pattern was associated with better cognition among older females in cognitive domains of language ($\beta=0.568$; 95% CI: 0.197, 0.939; $P=0.003$), memory ($\beta=0.463$; 95% CI: -0.174,0.751 ; $P=0.002$), verbal memory ($\beta=0.437$; 95% CI: 0.139,0.735; $P=0.004$) and global memory ($\beta=0.486$; 95% CI: 0.181,0.791; $P=0.002$). A westernised diet was related to poorer performance in executive function among males ($\beta=-0.123$; 95% CI: -0.360,0.113; $P=0.024$).

Conclusion

In this cross-sectional analysis, dietary patterns were variably associated with cognitive function in several domains among older adults. Further longitudinal analysis is needed for further investigation into diet-nutrition in relation to cognitive change in older adults.

Oral Presentation Abstracts

ID: 713 / OS35: Young onset dementia and mild cognitive impairment

Abstract Topic: Young onset dementia

Keywords: EOAD, YOAD, disease variants, biomarker characterisation, cognition, prognosis

Advancing clinical and biomarker research in ad: the lead study

Liana Apostolova¹, Paul Aisen², Ani Eloyan³, Anne Fagan⁴, Tatiana Foroud¹, Constantine Gatsonis³, Clifford Jack⁵, Joel Kramer⁶, Robert Koeppe⁷, Andrew Saykin¹, Arthur Toga², Prashanti Vemuri⁵, Gregory Day⁴, Neill Graff-Radford⁸, Lawrence Honig⁹, David Jones⁵, Joseph Masdeu¹⁰, Mario Mendez¹¹, Chiadi Onyike¹², Emily Rogalski¹³, Steven Salloway¹⁴, David Wolk¹⁵, Thomas Wingo¹⁶, Bradford Dickerson¹⁷, Gil Rabinovici⁶, Maria Carrillo¹⁸

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Abstract:

Background:

Although early-onset (EOAD) and late-onset AD (LOAD) share the same pathologic substrate, there are notable differences in their clinical and biological phenotypes. Compared to LOAD, sporadic EOAD show more rapid cognitive decline, lower prevalence of amnestic versus non-amnestic presentations, greater baseline cortical atrophy/hypometabolism, less medial temporal lobe involvement and more severe AD pathology. Studies suggest high heritability in EOAD in the absence of known mutations or *APOE4*, signifying that this population may be enriched for novel genetic risk factors.

EOAD patients often face significant delays to diagnosis, to access to AD treatments, and to social and financial support services. Despite being highly motivated and having few comorbidities, EOAD patients are commonly excluded from large scale observational biomarker studies (e.g. ADNI and DIAN) and therapeutic trials due to their young age, non- amnestic presentations, and absence of known pathogenic mutations.

Objective:

LEADS goals are 1) improve EOAD diagnosis, 2) develop sensitive composite clinical and biomarker tools that capture disease progression across all disease variants, 3) establish a network of EOAD sites ready to launch interventional studies in this population; and 4) explore possible genetic susceptibility factors through GWAS.

Methods:

The Longitudinal Early-onset AD study (LEADS) is a multi-site, observational clinical and biomarker study of EOAD. We plan to recruit and longitudinally follow 400 amyloid PET-positive EOAD, 200 amyloid-negative cognitively impaired participants (EOnonAD), and 100 age-matched controls (CN). LEADS participants are undergoing clinical and psychometric assessments, MRI, amyloid ([¹⁸F]Florbetaben) and tau ([¹⁸F]AV1451) PET, CSF and blood draw for collection of DNA, RNA, plasma, serum and peripheral blood mononuclear cells (PBMC). Methods are harmonized with ADNI and DIAN. We are comprehensively characterizing cognitive, imaging and biofluid changes over time in EOAD, and planning to compare to a matched sample of LOAD participants identified in ADNI. An exploratory aim will apply next generation sequencing to assess for novel AD genetic risk factors.

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Results:

At the time of abstract submission, 155 research subjects have been consented. Of those 56 EOADs (mean age 58.7, MMSE 21.6), 17 EOonAD (mean age 58.3, MMSE 25.8), and 42 CN (mean age 54.2, MMSE 29.3) have completed screening and baseline assessments. Most cognitively impaired participants present with an amnesic phenotype (82.2%), 6.8% have PPA, 6.8% PCA and 4.1% dysexecutive variant AD. We will present a summary of demographic, clinical and biomarker characteristics of the current sample.

Conclusions:

Successful completion of this project will address several substantial gaps in our understanding of EOAD and AD research in general. LEADS will provide a publicly available natural history dataset and a platform for launch of therapeutic trials in this population.

Oral Presentation Abstracts

ID: 719 / OS32: End of life and palliative care

Abstract Topic: End of life and palliative care

Keywords: end-of-life care, palliative care, advance care planning, hand feeding, surrogate decision maker

Guiding early decision making for palliative approaches and end-of-life care in persons living with dementia

Anne Kenny

Livewell, United States of America

Abstract:

Persons living with dementia (PLWD) must contemplate values and choices about medical care before progressive neurocognitive and functional decline due to their dementia. Advanced care planning (ACP) is a voluntary process of discussion regarding future care preferences so that people receive medical care consistent with their values and goals. End-of-life care for persons living with dementia (PLWD) is often complicated by numerous emergency room visits or hospitalizations, burdensome medical treatments, under-treatment of pain, and unmet patient/family/carer emotional and spiritual needs. Those that state their wishes are less likely to receive burdensome care, and they and their families are more satisfied with the care received.

A recent qualitative review delineates five themes regarding PLWD/carers perspectives regarding end-of-life care in PLWD: avoiding dehumanizing treatment, confronting emotionally difficult conversations, navigating existential tensions, defining personal autonomy, and lacking confidence in the healthcare setting (Sellers et al., 2019). The perspectives of PLWD, as outlined in the literature, will guide the presentation.

The session will be led by a geriatric/palliative care physician, author of *Making Tough Decisions about End-of-Life Care in Dementia*, with 30 years of experience in care for PLWD and personal experience as the carer for a family member living with and dying from dementia.

The session will address:

- Conversations regarding choices and preferences about living with dementia in the face of personal, clinician, and system-related barriers to ACP.
- Recognition of the importance of a surrogate decision-maker to advocate for choices made.
- Guidance on disease progression to inform change in treatment choices or place of residence.
- Shift in treatment choices from life-prolonging to palliative care.
- Discussion on limiting medical care of chronic diseases
- Examination of decisions around hand feeding
- Recognition of timing for hospice care

Resources and recommendations for implementing ACP will be presented.

Oral Presentation Abstracts

ID: 739 / OS18: Education, training and formal carers

Abstract Topic: Formal carers education and training

Keywords: Undergraduate Education, lived experience, healthcare student

Time for dementia: understanding medical student outcomes

Sube Banerjee, Juliet Wright, Yvonne Feeney, Molly Hebditch, Stephanie Daley

Brighton and Sussex Medical School

Abstract:

Background and purpose

Examining the curricula of UK medical schools in 2013, Tullo and Gordon found “widespread deficiencies in education relating to attitudes and behaviours, and a failure to ensure students had adequate exposure to patients with dementia and their carers” and that this risked portrayal of a “narrow, and potentially misleading, view of dementia”.

In response to this challenge, the Brighton and Sussex Medical School have developed the Time for Dementia programme (Banerjee, et al, 2015). The programme takes an innovative approach to dementia education for medical students and other undergraduate health care students by providing longitudinal contact with families affected by dementia. Students visit a family affected by dementia over a two period in order to improve student knowledge, skills and attitudes. Families (person with dementia and their carers) are crucial to the delivery and on-going sustainability of the programme

Methodology

The aim of this study was to evaluate the Time for Dementia programme in terms of process and its impact on medical student attitudes, understanding, knowledge and behaviours towards dementia, using a mixed methods design. We completed a parallel group comparison over two years of two cohorts of medical students at the same stage of training from two medical schools one of which participated in the Time for Dementia programme (the intervention group) and one of which did not (the control group). We measured dementia knowledge, attitudes and empathy at baseline before the programme started and repeated these measures one year after while the programme was active for the intervention group, and two years after when the programme had been completed.

Results

Quantitative outcomes (dementia knowledge, attitudes and empathy) were collected at baseline, 12 and 24 months for the intervention group students (n=274) and for the control group (n=112)

Compared to medical students who did not participate in TfD, quantitative evaluation shows statistically significant improvements in student outcomes including: **Dementia Knowledge** (n=247, coef=1.63, p<0.001) and **Approaches to Dementia Questionnaire** (n=276, coef=2.19, p<0.003) and **Dementia Attitudes Scale** (n=278, coef=6.55, p<0.001).

Conclusions

Our research has demonstrated positive impacts on the medical students that have been through the programme. Our medical students have received an education programme which will equip them to understand the needs of patients with dementia, regardless of the area of medicine which they practice in. They will be the doctors of the future, who will be able to share their dementia knowledge and expertise with future patients, carers and colleagues. Our families are the teachers in Time for Dementia and our medical students the beneficiaries of their wisdom and lived experience.

Oral Presentation Abstracts

ID: 741 / OS05: Informal carers support

Abstract Topic: Informal carers support – pre, during and post

Keywords: informal carer, quality of life, measurement

C-DEMQOL: development of a new measure of carer quality of life

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Abstract:

Introduction

The purpose of the C-DEMQOL study was to develop a new measure of quality of life (QOL) of carers of people with dementia.

Method

The C-DEMQOL measure was developed through a six stage process, which involved input from a lived experience advisory panel of carers at each stage.

The first stage began with identifying aspects of good and poor QOL of family carers of people with dementia through a qualitative study with 38 family carers and 14 support staff (Daley et al, 2018). This identified 12 themes for understanding the issues associated with good and poor QOL across different life domains, which were mapped against the findings of two systematic literature reviews. The first review identified factors associated with carer QOL in dementia [Farina et al, 2017] and the second review identified and critically assessed existing QOL measures (Page et al, 2017).

This combined data was used to create a first draft version of the C-DEMQOL measure, which was piloted with 25 carers. Feedback enabled us to develop a second draft of the measure, which was field tested with a new sample of 122 carers recruited across Sussex and North London. Feedback and statistical results from this field testing were used to develop a third version of the measure.

The third measure was field tested with an independent sample of 300 carers across Sussex and North London. The carers completed C-DEMQOL measure alongside established measures of health status, functioning and service use of the carer and the person with dementia. We completed a comprehensive statistical evaluation to establish the scientific properties of C-DEMQOL.

Results

We found that the C-DEMQOL measure assesses five distinct subdomains of QOL in addition to measuring carers' appraisals of their overall QOL. The five domains are (1) *carer wellbeing* (2) *meeting personal need*, (3) *carer-patient* (4) *confidence in the future* and (5) *feeling supported*

We found that C-DEMQOL demonstrated excellent reliability in measuring carers' overall assessment of their QOL, and high reliability for measuring the five individual domains. Furthermore, the relationships between C-DEMQOL and the established measures revealed strong evidence of validity.

Discussion

The final version of C-DEMQOL contains 30 questions in total, with 6 questions measuring each of the five subdomains.

We conclude that C-DEMQOL is a reliable and valid new measure of the QOL of carers of people with dementia. The measure provides a comprehensive coverage of issues consequential to carer QOL and

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can be used across a variety of caring situations and severity in dementia. We recommend that C-DEMQOL is used both in research studies and in health and social care.

Oral Presentation Abstracts

ID: 743 / OP2: Dementia and the equitable society

Abstract Topic: Dementia and equitable society – NEW

Keywords: Inequalities, intersectionality, quality of life, cost of care

DETERMIND protocol: exploring and addressing inequalities in dementia care

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Abstract:

Background and objective: Emerging evidence highlights major inequalities in the care people with dementia receive post-diagnosis and their subsequent well-being outcomes. This may be driven by multiple factors including: gender, ethnicity, sexual orientation, place of residence, whether care is self-funded or paid for by local authorities, and time of diagnosis. To date however, there is no longitudinal research established to address these critical issues. The DETERMIND (DETERMinants of quality of life, care and costs, and consequences of INequalities in people with Dementia and their carers) project is a 5-year, multimillion pound research programme that seeks to fill this gap in the literature across seven complementary work streams (WSs).

Method: Quantitative and qualitative data from a clinically generalisable cohort will be generated from 2019-2024.

- WS1 will provide the infrastructure and data needed for DETERMIND by recruiting a bespoke cohort of 900 people with dementia and their carers in the 6 months following diagnosis, and following them up annually for 3 years. Quantitative data will be collected on quality of life, cognitive function, use of services, activities of daily living and physical illness.
- WS2 and WS3 will examine the extent of inequalities in access to dementia care, barriers and facilitators to accessing care and impact of unmet need over time, as well as investigating relationships between use and costs of services and outcomes for people with dementia and carers.
- WS4 will explore the experience of people with dementia and their carers as self-funders of care and compare these to people who are funded by the State.
- WS5 will use quantitative methods to develop a mechanistic understanding of the processes involved in, and factors influencing, planning and decision-making by people with dementia and carers.
- WS6 will use a mixed method approach to investigate the impacts of earlier vs later diagnosis on quality of life for people with dementia and their carers.

The data collected through DETERMIND will be translated into real-world strategies and actions that can bring about better systems and services for people with dementia and their carers (WS7).

Findings: We will present the DETERMIND protocol, including the work that has led up to its development and the methods of individual work streams. We will highlight the outcomes and intended impact of this novel research programme.

Conclusion: Despite recognising that current healthcare systems do not provide the best support for all people with dementia, there is a poor understanding of how this can be improved. Partly this can be

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attributed to a lack of high quality, longitudinal data that maps people's journey with dementia, post-diagnosis. DETERMIND will provide a dataset and research addressing these critical questions, and so improve future care for people with dementia and their carers.

Oral Presentation Abstracts

ID: 751 / OS02: Attitudes and awareness I

Abstract Topic: Consumer empowerment

Keywords: Dementia, Declaration, Benchmark, Rights, New Zealand

New Zealand's Dementia Declaration

Alister Robertson

Alzheimers NZ, New Zealand

Abstract:

New Zealanders who are affected by dementia got together and identified what we need to live well. We have written a very straight forward and to-the-point document "Dementia Declaration: Our Lives matter". People with a diagnosis of dementia and families have prepared the Declaration to outline what we need from society to live well. We are hoping our Declaration will become a benchmark against which governments, organizations and individuals can measure themselves when they interact with and make policy for people just like me.

People living with dementia have the same rights, needs and desires as everyone else, but are ignored far too often and have been marginalised and stigmatised, both by society and by the health sector. We hope the Declaration will help to change things for the better. Our Declaration - because it is for all New Zealanders with dementia - is our way of educating society about what we need.

The Declaration is our plea to be treated with respect, kindness, understanding and acceptance. It outlines our baseline requirements for the establishment of a more dementia friendly New Zealand. We wrote the Declaration as a vehicle for change and to make our voices heard. Our voices will help to shape how society responds to our needs, what services and support we want and how we'd still like to have some choices in our lives.

Hopefully the Declaration will lead to positive and progressive change in the way people living with dementia are treated, both by society in general and by the government and health policymakers in particular. The next step is to turn the voices of people with dementia into the actions we truly want to see.

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ID: 753 / OS01: The global policy environment

Abstract Topic: Dementia and the Convention on Human Rights of Persons with Disabilities (CRPD) – NEW

Keywords: dementia, CRPD, disability, rehabilitation, quality of life, stigma

Dementia, disability and the CRPD

Kate Swaffer

University of South Australia, Australia

Abstract:

This presentation will review the current medicalisation of dementia globally for the estimated 50 million people living with dementia, and why there is a need for a new pathway of support that includes rehabilitation. The relevance of the Convention on the Rights of Persons with Disabilities (CRPD) to dementia will be reviewed, which will include an exploration of social attitudes and understanding of disability, disablism and ageism, and the impact of these on the current model of care, which continues to ensure earlier loss of dependence and poor quality of life as well as increasing stigma and discrimination. Since the World Health Organisation Global Action Plan: A public Health Response to Dementia, adopted in May 2017 at the world Health Assembly, it is clear we must think outside the box, beyond the lack of health and social care, which currently is not aligned to human rights or the CRPD. The empowerment and involvement of people living with dementia in the last few years has ensured human rights in dementia have moved away from only rhetoric, but this also means society has a legal and moral obligation to apply the principles of disability, and access to the CRPD in policies, programmes, and post diagnostic support. The application of a social model of disability to dementia which includes rehabilitation will lead to important insights, and help explain some of the barriers people with dementia currently face in terms of poor care. Basing dementia care on disability rights, will not only improve well being for people with dementia and their families by promoting independence and a higher quality of life, it will ensure the currently expected high economic impact on governments and health care systems by dementia will be minimized. People with dementia are currently still being denied access to Universal Health Coverage, adequate post diagnostic support and access to the CRPD. This presentation will close by outlining why reframing dementia as a disability, and ensuring access to the CRPD will support positive change.

Oral Presentation Abstracts

ID: 757 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: dementia, alzheimer disease, vascular dementia, aging

Clinical profile of dementias seen in consultation in Antananarivo

Lovatiana ANDRIAMBOAVONJY, Julien RAZAFIMAHEF, Jenny Larissa RAKOTOMANANA, Alain Djacoba TEHINDRAZANARIVELO
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Abstract:

Introduction : The Malagasy population includes more and more elderly people, given the increase in life expectancy. As dementia is an age-related disease, its prevalence and incidence will be correlated with the increase in the number of elderly people. Within a few years, dementia may therefore become a public health problem in the Malagasy population, whereas no study has yet been carried out on this subject in the context of neurology.

Methods : This study was carried out in Antananarivo, within the CHUJRB, on home consultations, during a mass consultation with the NGO Masoandro Mody Alzheimer Madagascar, and in a centre for the elderly. The study took place from March to September 2018. Using a clinical tool we developed, we categorized dementia as cortical or subcortical dementia. During this same study, we studied the dementia risk factors that our study population had.

Results : The number of patients with cortical dementia was almost equal to the number of people with subcortical dementia. The most common risk factor found in patients was high blood pressure, followed by diabetes and a history of stroke.

Cardiovascular risk factors have been prevalent in our population, which are also risk factors for dementia. Better management of these modifiable factors would reduce the incidence of dementia in the Malagasy population and thus avoid an increase in the public health burden that dementia could cause.

dementia, alzheimer disease, vascular dementia, aging

Oral Presentation Abstracts

ID: 759 / OS03: Risk factors I

Abstract Topic: Risk factors

Keywords: cognitive decline; group-based trajectory model; sex difference; CLHLS; risk factors

Sex difference of cognitive function trajectories and their determinants in older adults: evidence from the Chinese longitudinal healthy longevity survey

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Abstract:

Objectives: To examine sex difference of cognitive trajectories of a nationally representative sample of older people living in China, and to explore potential determinants of these trajectories.

Methods: The study included 1,653 women and 1,575 men, who were cognitively healthy and aged 65 to 108 at the first observation from Chinese Longitudinal Healthy Longevity Survey (CLHLS) based on 2005 - 2014 cohort. Cognitive function was measured using the Chinese version of the MMSE. Group-based trajectory modeling was used to identify potential heterogeneity of longitudinal changes over the 9 years, and to investigate associations between baseline characteristics (age, education, marital status, leisure activity, sleep length, activities of daily living (ADL) impairment, instrumental activities of daily living (IADL) impairment, health status and MMSE score) and trajectory classes.

Results: Two trajectories (labelled as decline and stable) were identified according to the changes in MMSE scores for both male and female. The decline group accounted for a small part of female (13.9%) and male (8.9%) population, and the female showed a steeper decline rate than male. In the multivariable logistic regression analyses, age, education, and marital status were significantly associated with cognitive decline both in the female and male groups compared to the stable ones. For the female subjects, having a lower baseline MMSE score and IADL impairment were also associated with the cognitive decline trajectory. While lower frequency leisure activity and sleeping less than 6 hours or over 8 hours contributed more to the male decline group.

Conclusions: Two cognitive trajectories were identified in old Chinese population for both male and female. The female older adults had an overall more serious cognitive decline than the male. The potential determinants of cognitive decline identified in this study, in particular, modifiable risk factors, could be considered for developing specific intervention strategies aimed to promote healthy brain and prevent cognitive decline in different sexes.

Oral Presentation Abstracts

ID: 761 / OS19: Economics of dementia

Abstract Topic: Economics of dementia

Keywords: dementia, carer, progression, review, bilateral impacts

Making dementia carers count in economic studies: what does the clinical research us?

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Abstract:

Background: People with dementia require high levels of care due to cognitive impairment, behaviour symptoms and limited physical functioning. Most care happens in the community and is provided by informal carers. Without them, the quality of life and health outcomes of people with dementia would be poorer and residential aged care placement would arise sooner in the journey. However, carers are mostly invisible in the research on economic impacts of interventions for people with dementia. When they were represented, it was usually as the “opportunity cost of informal care” rather than as two-way dynamic interactions between people with dementia and carers.

Aim: This scoping review explored how previously published research on co-dependency of dementia dyads and reciprocal effects of dementia progression on psychological, physical and subjective outcomes of carers can inform and be used in the economic evaluation of dementia interventions.

Results: We conducted a scoping study through a comprehensive literature search and finding synthesis to extract the themes and quantitative results. The literature search were conducted in Econlit, Medline (PubMed), and Web of science, between January 2018 and August 2019. Two reviewers independently reviewed titles, abstracts and extracted information from the main texts. We included 48 studies, of which 30 investigated the impact of dementia symptoms and progression on carers' outcomes, eight examined the impact of carers on person with dementia's outcomes and ten explored the correlation of between outcomes of dementia dyads. While there was a sizable literature on the bilateral impacts of dementia progression and symptoms and (informal) carers' health outcomes, quality of life and well-being, most studies relied on small and cross-sectional samples. Additionally, the quantitative methods applied in most studies did not appropriately account for the potential endogeneity; thus the estimated impacts might not be robust.

Conclusion: Family caregiving is a dynamic process, and both care recipient and carer constantly adjust to each other's changes, which impacts on dementia progression, health outcomes and quality of life of both. If this dynamic process is absent in economic studies, trade-offs between carer and people with dementia, both in opportunity costs and health outcomes, are masked. Until we can better measure these impacts and embed them in future economic studies, interventions and care practices for dementia dyads, based on their clinical and cost-effectiveness, may be categorised as cost-effective when they are not (or vice versa), leading to sub-optimal resource allocation.

Oral Presentation Abstracts

ID: 773 / OP3: Diagnosis

Abstract Topic: Diagnosis

Keywords: diagnosis, pseudodementia, depression, apathy

Pseudodementia, pseudopseudodementia and pseudodepression

Henry Brodaty, Michael Connors

UNSW Sydney, Australia

Abstract:

While most older people who develop problems with their memory and thinking that are severe enough to impair their ability to function in everyday life typically, are found to have Alzheimer's disease or other neurodegenerative diseases, some have an undiagnosed and treatable psychiatric disorder masquerading as dementia. These conditions including depression can affect memory and thinking and, when severe, create a clinical picture similar to dementia. This phenomenon, known as "pseudodementia", is encountered in clinical practice. It is important to identify because it may be reversible with appropriate treatment.

There is controversy about what the longer-term prognosis is for people diagnosed with pseudodementia. This has implications for how to manage patients, what advice to give to patients and their family, and how to conceptualise the disorder. Some studies found that people with pseudodementia eventually develop organic dementia, so called pseudo-pseudodementia. To address this, we conducted a systematic review of studies that had been conducted on pseudodementia and which followed up patients over time.

Eighteen studies followed patients from several weeks to 18 years. Overall, patients with pseudodementia were at greater risk of later developing organic dementia. Importantly, not all patients did; many patients remained stable or improved, albeit some still impaired by their psychiatric disorder. Our review showed possible treatment benefits and differences with age; patients diagnosed with pseudodementia at a younger age had better outcomes.

Finally, people with apathy (which is the commonest behavioural symptom in dementia) can be misdiagnosed as having depression, so called pseudo-depression and then often treated for the wrong condition. Patients with apathy do not respond to antidepressants.

Receiving the correct clinical diagnoses are crucial to patients receiving the correct treatment for their condition. A missed diagnosis of a potentially reversible depressive pseudodementia can have tragic consequence for the patient and family.

Recent research has neglected the study of pseudodementia. Our findings reveal a clear need for better diagnostic skills, further research with modern investigative tools, such as neuroimaging and genetic sequencing, and clinical trials to better understand underlying mechanisms and determine effective treatment strategies.

Oral Presentation Abstracts

ID: 774 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: People with Dementia, Thai Registered Nurses, The Lived Experience, Providing Care

The lived experience of registered nurses providing care for people with dementia in Thailand

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⁴College of Nursing and Health Sciences, Barry University, Miami, FL, USA.

Abstract:

Background and objectives of the study: Dementia is one of the most significant public health priorities in the world. Providing nursing care for individuals and families dealing with dementia is complex and requires specialized knowledge and experience not routinely offered in pre-licensure nursing programs in Thailand. Little is known about Thai nurses' experiences of providing nursing care to people with dementia in the hospital ward setting. The purpose of this qualitative, hermeneutic phenomenological study was to explore the lived experience of registered nurses providing care for persons with dementia in general hospital wards in Thailand. This research aimed to give Thai registered nurses a voice to express their individual experience of providing care for persons with dementia in this setting, to provide an inductive interpretation of the lived experience, and to gain the understanding of the essence of the experience of providing care for persons with dementia within the context of general hospital wards.

Methods: This qualitative study was guided by the hermeneutic phenomenological approach of Max van Manen (1990). Purposeful and snowball sampling were used for the recruitment of participants. A semi-structured interview was employed for data collection that was audiotape-recorded, transcribed, translated, and translated back, and member checked for verification with a maximum of 14 elected participants. Data analysis was guided by Miles and Huberman's method (1994) to reduce the data into themes.

Results: Four major related themes were conclusive from the findings of the study: feeling empathy, challenging, supporting: patient and family care needs, and requiring: additional knowledge as a total representation of the Thai registered nurses providing care for people with dementia in the hospital ward setting. Jean Watson's (1979) grand theory of human caring was the theoretical framework applied to the themes for further understanding.

Conclusions: The results of the study emphasized the quintessence of registered nurses' experiences by illuminating the feeling of empathy, challenging, supporting both people with dementia and their families, and requiring additional knowledge. There is a necessity for a comprehensive approach to make it possible to provide appropriate nursing care that can also address the nursing protocols for nursing practice.

Oral Presentation Abstracts

ID: 784 / OS18: Education, training and formal carers

Abstract Topic: Formal carers education and training

Keywords: Workforce, Training, Education, Quality Dementia Care

Strategies for effective training of family and professional care partners

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¹Best Friends Approach; ²Christian Care Communities; ³Prestige Senior Living

Abstract:

While much information is available today about quality dementia care via books, articles and materials developed by Alzheimer's societies, (1) there is a broad consensus that the hands-on workforce in various dementia care settings remains under-supported when it comes to innovative education and training. (2) In the US, many states require only 8 hours of annual training and a survey conducted by the authors revealed that companies struggle to even meet this modest goal and are overly reliant on computer based training with little or no follow up.

This presentation will review principles of adult learning and offer specific suggestions and strategies for designing more effective training for the workforce serving persons with dementia.

Specific topics will include:

Adult learning/education principles including discussion of training of multi-cultural staff.

Key topics for presentation including the basics of dementia, empathy, communication, life-story/social history work, behaviors, and activities and engagement.

Strategies for more effective training including role-plays, group work and activities designed to build empathy and understanding. Best practices from various US and Canadian training programs will be shared including work from the co-presenters work (3), and two US long-term care companies.

Effectiveness – strategies will be shared to long lasting effectiveness and evaluation of training programs to look at whether learning has been impactful and supportive of enhanced person centered/relationship centered care.

While the presentation is focused on professional training, key areas will support enhanced support of family care-partners as well.

Finally case studies will be presented from training programs developed by the presenters and training programs used at Prestige Senior Living in its Expressions Dementia program.

(1) https://alz.org/professionals/professional-providers/dementia_care_practice_recommendations

(2) , Unpublished survey to be shared at conference. One good review article that I still relevant is at <https://www.healthaffairs.org/doi/full/10.1377/hlthaff.2009.0554>

(3) Bell and Troxel, *The Best Friends Approach to Dementia Care*, 2nd ed. (2017). Baltimore: Health Professions Press.

Oral Presentation Abstracts

ID: 785 / OS29: Informal carers training

Abstract Topic: Informal carers training

Keywords: Self stigma, self care, care of caregiver

Self-stigma cause for decreased self-care among caregivers

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Abstract:

Background and objective: Dementia caregivers go through self-stigma. This is due to the fact that most of them do not understand the condition which their loved ones have and this has undesirable impact on their personal relationships with their relatives and also with the person living with dementia. We examined caregiver burnout and its effect on self-stigma and self-care.

Methods: Questionnaires were administered to 50 caregivers during the Support group meeting with the aim of understanding self-stigma and how caregivers promote wellness from all spheres of their lives.

Results: Our findings revealed that the caregivers: (i) 20% of the caregivers Did not think "me time" was important (ii) 20% Had emotional distress; (iii) 10% did not think it proper to request for help; (iv) 20% less hours of sleep; and (v) 30% Most of them confessed that they had self-stigma and did not open up about the condition of their loved ones. These perceptions were linked to self-stigma and thus reduced access to personal care as caregivers

Conclusions: Awareness campaigns will be used to educate caregivers and boost public awareness to the dementia cause. This will ensure that the issue of dementia is tackled with information which will lead to less cases of self-stigma. This will also improve the lives of the caregivers as they will realise the importance of speaking to decrease self-stigma and make time for themselves to improve on self-care. There needs to be a paradigm shift on care of the caregiver so we can have healthier caregivers.

Oral Presentation Abstracts

ID: 788 / OS33: Psychosocial interventions

Abstract Topic: Psychosocial interventions

Keywords: Dementia, Non-pharmacological interventions, Family carer, Third Sector, Implementation

Implementation of an evidence-based intervention for family carers of people living with dementia in the third sector – widening access to start (strategies for relatives)

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¹University College London, United Kingdom; ²University of Exeter, United Kingdom; ³Alzheimer's Society, United Kingdom

Abstract:

Background and objectives of the study: Family members providing care to a relative with dementia often become distressed, anxious or depressed. We developed START (Strategies for RelaTives) for family carers of relatives with dementia to promote helpful coping strategies for the difficulties of caring <https://www.ucl.ac.uk/psychiatry/start>. START is the first intervention of its kind, shown to be effective and cost-effective. Carers in treatment-as-usual group were seven times more likely to have clinically significant depression after two years than carers receiving START, and this has continued at 6 years. START is currently delivered within UK National Health Service (NHS) settings. In this study, our aim is to widen access to START by adapting it for delivery in the UK third/non-profit sector, within existing structures of the Alzheimer's Society—the UK's largest Dementia charity—in the first instance.

Methods: In Phase 1, we used the Consolidated Framework for Implementation Research (CFIR) to guide data collection, through the development of a semi-structured interview guide. We interviewed a range of stakeholders to identify factors affecting the implementation of START within third sector organisations, scope voluntary sector workers' training and support needs, and inform modifications to START intervention materials. In Phase 2, we worked closely with local teams (e.g. leadership, operations, research translation) to recruit, train and supervise Alzheimer's Society Dementia Support Workers (DSWs) to deliver the modified intervention to family carers. In Phase 3, we evaluated the implementation of START, using the i-PARIHS implementation framework. To inform the evaluation, we conducted qualitative interviews with all participants including DSWs, management and family carers, and assessed all carers before and after receiving START, and at one year post-delivery using the HADS, HSQ and CSRI.

Results: We interviewed twenty-six (n=26) Alzheimer's Society stakeholders across a range of localities. We recorded interviews, which were coded independently by four researchers overall. The project group met to agree on the modifications to START intervention materials. We made changes to formatting, wording, pictures and vignettes but core components of the manual and training material remain unchanged. We trained and supervised three (n=3) DSWs to deliver the modified intervention; each DSW successfully delivered the intervention to three carers over a period of eight months running from beginning of December 2018, to end of July 2019.

Conclusions: We will consider how characteristics of the intervention, its recipients (i.e. DSWs), and the local, organisational and external context, as well as the facilitation process led by internal and external facilitators, impacted START implementation and outcomes, and provide a template for the implementation of START in third sector settings.

Oral Presentation Abstracts

ID: 794 / OS25: Dementia and public policy II

Abstract Topic: Dementia policies and public policy

Keywords: Dementia management strategy, informal education, reduction of regional differences, building competences

Knowledge comes first, nationwide caregiver and health professional's education programme

Štefanija Lukič Zlobec, David Krivec, Maša Bastarda, Alenka Virant

Spominčica - Alzheimer Slovenija, Slovenia

Abstract:

Introduction

Dementia management strategy in Slovenia, adopted in May 2016, is based on ten priorities, one among them is continuous education and training to ensure high-quality care. The Action Plan working group was established by the Ministry of health immediately after Strategy adoption. The first result was the Public call worth 700.000 EUR for co-financing Dementia management education programmes in July 2017.

Methods

The call was divided into two sections: Programme A, education for GP's and health professionals and Programme B, education for caregivers. The priority area of the call was the reduction of regional differences in accessibility to education, competences and knowledge level about dementia care and services. Education programmes were carried out locally in all regions involving caregivers and health professionals from the local community. The Ministry co-financed 7 education programmes, two Programmes A for healthcare professionals and 5 Programmes B for formal and informal carers. All education courses were free of charge.

Positive impact

Spominčica lead one the programme "For dementia friendly community - De*Spot", a consortium of seven partners (Psychiatric Clinic Ormož, Department of Neurology - Ljubljana Medical Faculty, Community healthcare centre Izola, Home for retired persons Nova Gorica, Hmelina nursing home and Home Care Institute Ljubljana) and was partner in two other programmes. In the De*Spot programme, 30 intense education courses were carried out in different cities. At the courses, 46 professionals gave lecture to 2191 carers from different institutions like Community healthcare centres, Centres for social work, nursing homes, local communities, Public Administration offices, volunteer organizations and NGO's. The education courses were supported by a strong media campaign through national and local media and web platforms.

Perspectives

The programmes ended in November 2018. The Ministry of Health assessed the results of the programmes. Education courses should be carried out permanently, the impact was multiplied by the media campaign and resulted in awareness raising among professionals and also the general public. A new working group has been formed at the Ministry for Health, which is preparing Dementia management strategy in Slovenia 2020 - 2030. The public consultation about the new strategy is scheduled for early spring 2020. Similar programmes are planned to be carried out continuously to support the implementation of the Dementia strategy.

Oral Presentation Abstracts

ID: 796 / OS29: Informal carers training

Abstract Topic: Informal carers training

Keywords: autonomy, competences, training, co-creation, independent living

Ad-autonomy - training program for maintaining the autonomy of persons with dementia

David Krivec, Alenka Virant, Polona Kečkeš, Štefanija Lukič Zlobec

Spominčica - Alzheimer Slovenija, Slovenia

Abstract:

Background and objectives of the study

The main objective of AD-AUTONOMY is to improve the quality of life of persons with dementia, their caregivers or carers through an innovative training program. The program aims to increase competences of caregivers and persons with dementia, raise awareness on the importance of maintaining autonomy and motivate them to increase the autonomy of persons with dementia for decision making and independent living. AD-AUTONOMY project is co-financed by Erasmus+ KA2 with partners from Greece, Spain, Slovenia, Turkey and United Kingdom. The project will end in September 2019 when the final results will be known.

Methods

AD-AUTONOMY represents a unique training program, which is emphasized on direct involvement and training of PwD, their families and professionals. Within the projects, we have defined 9 autonomy dimensions: What is autonomy? Security and Safety, Navigation and orientation, Food & Housekeeping, Personal Hygiene, Finance, Emotional Skills, Meaningful Activities, Health Management. The dimensions and their contents were developed in co-creation sessions with persons with dementia, their caregivers and professionals.

Results

Co-validation sessions, including 30 Persons with Dementia and their families and 10 professionals in 5 different European countries, were carried out to collect the feedback about the usefulness of the contents. Based on the results of co-creative sessions and interactive co-validation workshops we have developed methodological guides, contents and common e-platform with all learning materials for each autonomy dimension. For each dimension different experiential activities and strategies were developed with authentic situations for the training. All activities are supported by tools and techniques, also ICT, for instance, reminders, detectors, checklists, planners, map guides, diaries, ...

Conclusions

Maintaining autonomy of PwD has a greater impact on their social inclusion, promotes active role in the community, explicitly in public places, resulting in a slower progression of the disease. Autonomy itself enhances their identity, self-determination, independence, dignity as long as possible. Therefore, Persons with dementia are more likely to keep their skills for independent living at home. We have already successfully included the developed training in our workshops for persons with dementia and in trainings for their caregivers.

Oral Presentation Abstracts

ID: 799 / OS21: STRiDE

Abstract Topic: Epidemiology

Keywords: Epidemiology, Dementia, Mexico

Overview of the evidence on dementia epidemiology in Mexico

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³Personal Social Services Research Unit, London School of Economics and Political Science, UK

Abstract:

Background and objectives of the study:

One of the most important and immediate challenges of population ageing in Mexico, as in other middle-income countries, is the rapid increase of illnesses that are associated with high care dependency such as dementia. With no long-term care policies in place, there is a great need to develop strategies to provide care, access to services and the necessary care, treatment and support for people with dementia and their carers. In order to understand and implement adequate programs addressing different levels of care, it is important to understand the characteristics of people living with dementia. This work aims to provide an overview of sociodemographic and clinical characteristics of people with dementia reported in epidemiological studies in Mexico. The work forms part of a situational analysis developed as part of the Strengthening responses to dementia in developing countries project (STRiDE Dementia)

Methods:

Review of epidemiological dementia studies to provide an overview of the available evidence of dementia prevalence, as well as a description of sociodemographic characteristics and comorbidities of people living with dementia in Mexico.

Results:

Over the last 15 years, several population-based studies have been conducted in Mexico, providing estimates of the prevalence of dementia. These estimates range from 6.1 to 8.6% in the samples studied. With respect to sociodemographic characteristics, a higher prevalence is reported in older individuals, those with lower educational attainment, as well as among those living with chronic diseases, such as diabetes, cardiovascular illness, and depression. However, there are no routine monitoring systems for case documentation.

Perspectives:

Although information on the epidemiology of dementia is available in Mexico, it must continue to be expanded and updated in order to provide better estimates of its magnitude. Accurate and up-to-date information on dementia and characteristics of people living with dementia provides an important basis for the development of adequate strategies to support the people living with the illness and their families. Routine information systems build an important basis for the development of equitable public policy programmes that appropriately address the needs of different population groups across the country.

Oral Presentation Abstracts

ID: 800 / OS25: Dementia and public policy II

Abstract Topic: Dementia policies and public policy

Keywords: Caribbean, policy, dementia, situational analysis, Jamaica

Where does dementia policy belong? Exploring the Caribbean policy landscape.

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¹Caribbean Institute for Health Research, University of the West Indies, Jamaica; ²Care Policy and Evaluation Centre, Department of Health Policy, London School of Economics and Political Science, UK

Abstract:

Background:

Building capacity for improved dementia care necessitates development and implementation of relevant, realistic policy. Dementia is considered an urgent public health crisis; its socio-economic impact surpasses other chronic illnesses due to the long-term care required and reduced earning potential of families who provide informal care. The effects of this disease therefore warrant robust, effective policy, particularly in developing countries in which most persons with dementia are projected to live within the next 20-30 years. The STRiDE Dementia Project's work package on *research tools to inform and support dementia policy* was designed to explore the policy landscape in each site, including Jamaica.

Methods:

One of the data collection approaches for this work package is a situational analysis. A baseline, desk-research only situation analysis was conducted in the first 3-6 months of the study to get a snapshot of the current dementia care, treatment and support situation in Jamaica. Subsequently, an in-depth situation analysis was conducted. This in-depth situational analysis uses multiple data collection strategies, including online database/literature searches targeting aspects of the local health, economic, social and political landscape; consultations with libraries and librarians, interviews with and data requests from identified stakeholders.

Results:

Preliminary findings indicate that while there are notable opportunities for the inclusion of dementia in existing or forthcoming policies, limited collaboration between sectors, policy makers and academics may have up to now hindered such integration. There remains a great degree of uncertainty about when and how dementia will be included in national policy, despite Jamaica's rapidly ageing society. Regional policy (e.g. Pan American Health Organisation (PAHO) Regional Plan of Action on Dementia in Older Persons) targets increased research, high level dialogue and multisectoral efforts at risk reduction; it also focuses on Latin American countries more than Caribbean ones.

Perspectives:

The development and maintenance of stakeholder relationships across sectors may prove to be a valuable tool in informing and supporting dementia policy in Jamaica. Increased dialogue around dementia among stakeholders can shed light on shared organisational goals and opportunities for collaboration. This has been evident from, for example, stakeholders' willingness to participate in STRiDE Jamaica events, the building of relationships between the research team and relevant government agencies, and the multisectoral nature of the STRiDE Jamaica National Advisory Group. By fostering more high-level dialogue through data collection and stakeholder input, STRiDE may support the integration of dementia in key, relevant, existing health and social policies in Jamaica.

Oral Presentation Abstracts

ID: 802 / OS32: End of life and palliative care

Abstract Topic: End of life and palliative care

Keywords: Home palliative, Home healthcare, Advanced Dementia

Supporting persons with dementia to age and die in place – a case vignette to illustrate a home healthcare model with palliative care for advanced dementia

Cinthia Lim, Jasmine Wong, Kok Chin Yea, Jasmine Sng, Juay Lim

Tsao Foundation, Singapore

Abstract:

Hua Mei Mobile Clinic (HMMC) offers primary healthcare for homebound or frail older persons at their homes, to enable them to live at optimal health and remain in the community for as long as possible. Established in 1993, HMMC was the first medical homecare programme in Singapore. In 2010, HMMC included an End of Life Palliative Care Programme (EoL) to care for elders who requires palliative care due to conditions such as end stage-organ failure and advanced dementia. However, under the EoL programme funding guidelines, patients are required to have a prognosis of 1 year, with which they will need to be discharged to other services. In advanced dementia, this prognostication may not be so straightforward, thus posing limitations in home palliative care models.

To address this issue, elders under the existing home-medical service in HMMC can be converted to EoL programme seamlessly when palliative care is required, and back to home-medical service should their condition improve. This minimizes the need to be discharged from the service should they improve and exceed their 1 year prognosis, thus ensuring continuity of care. HMMC includes regular and acute physician/nursing/social work visits, and a 24-hour emergency hotline with which the caregivers are able to contact medical personnel for after-hours support.

Persons with advanced dementia are predisposed to complications such as recurrent infections, dysphagia with poor oral intake and reduced mobility. These complications can be distressing to the elders and their caregivers, which can result in recurrent admissions to hospitals for treatment. Unfortunately, with every hospitalization, it can result in further decline of the elder's condition and behaviour due to unfamiliar environment, routines and treatment. The availability of a home healthcare team such as HMMC, which encompasses EoL programme, is able to alleviate caregiver burden and reduce unnecessary hospitalization by allowing the most minimally invasive treatment to be carried out at home, as well as regular conversations and discussions on the elder's plan of care throughout the journey. A case study will be used to illustrate how HMMC was able to support a person with dementia and her caregiver through her last days.

Oral Presentation Abstracts

ID: 814 / OS05: Informal carers support

Abstract Topic: Informal carers support – pre, during and post

Keywords: carers support, online technology, rural communities, older people, co-design

Lessons from a pragmatic trial of virtual dementia friendly rural communities in Australia

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Abstract:

Background and objectives of the study – The Virtual Dementia Friendly Rural Communities (Verily Connect) project aimed to trial the use of online strategies to augment support for informal carers of people living with dementia in 12 communities in rural Australia. The strategies included a website (<https://verilyconnect.org.au/>) and mobile application (app), with information about dementia, locally available services and a chat function, and videoconferencing using Zoom. Volunteers were trained and a technology hub was available in all communities to provide face-to-face support for the technical needs of carers.

Methods – This pragmatic stepped wedge cluster randomised trial ran for 8 months from September 2018 until April 2019. A total of 113 carers, service providers, and volunteers participated. Carers completed surveys at baseline, prior to the first cluster implementation, and every 2 months until the end of the project. Semi-structured interviews were completed with carers and service providers. Focus groups were undertaken with volunteers. Process evaluation data were collected throughout project implementation, including contacts with participants and health services. Process data were analysed thematically using the Consolidated Framework for Implementation Research.

Results – Carer profile: 80% of carers were female; their ages ranged from 34 to 79 years; 45% lived in the same house as the person cared for and 45% lived in the same rural community. There were challenges in recruiting and engaging carers. Carers reported low levels of social support according to the Medical Outcomes Study Social Support Survey: lowest possible score=0 and highest=100; in this study the mean score for participants was 43.3 (SD=27.7). Consistent with other studies of carers of people living with dementia, carers in the Verily Connect study reported a high burden of care measured by the Zarit Burden Index (ZBI): lowest possible score=0 and highest=88; in this study the mean ZBI was 62.8 (SD=12). Qualitative data indicated that online strategies can increase the flexibility and availability of support for informal carers. Additional analyses of final outcomes and process evaluation data will be presented.

Conclusions – The study showed that rural carers require more support than is currently offered, and that innovations such as Verily Connect can increase readily accessible help for carers. In Australia, people living in rural areas often need to travel large geographical distance to access appropriate care and support; the online strategies employed by the Verily Connect project reduced the need to travel to access peer-to-peer support and they increased flexibility in receiving such support. Scalability of this type of initiative relies on the auspice of a national organisation.

Oral Presentation Abstracts

ID: 817 / OP3: Diagnosis

Abstract Topic: Diagnosis

Keywords: Behavioural Variant Frontotemporal Dementia (bvFTD), lack of insight, apathy, inertia, exhaustion

Title: nothing about us without us in diagnosis: personal perspectives of bvFTD

Juanita Maree Hughes

Dementia Alliance International, Australia

Abstract:

The rally cry “Nothing about Us without Us”, is common within the disability community and particularly in dementia. I would like to extend this to the diagnosis of behavioural variant frontotemporal dementia (bvFTD). This is from my experience and evidence from a blog: FTD doesn't bring me flowers – living with FTD, <https://ftdnoflowers.blogspot.com> written by a person diagnosed eight years ago with FTD.

The current diagnostic criteria for bvFTD is from the perspective of the carer and the clinician but the perspective of the one diagnosed with this disease is ignored. Why? The consensus understanding is that people with bvFTD lose insight into the disease very early in the process; but is this lack of insight real?

Lack of insight was one of the required criteria in the 1998 Diagnostic Criteria, but the revised 2011 version does not contain this as a criteria. Research studies show that lack of insight is common in all dementias, but especially in bvFTD. However, several studies including a large study of pathologically confirmed cases showed that about 13% of people with bvFTD retain insight into their disease.

This insight is well demonstrated in the pre-mentioned blog: June 16, 2019, post title: FTD IS NEVER ENDING. I was diagnosed very early in my disease course and have retained disease insight, confirmed by several neurologists. So there is no impediment in extending Nothing about Us without Us to bvFTD diagnosis.

The 2011 revised bvFTD diagnostic criteria lists apathy and/or inertia. The second symptom in the DSM-IV Criteria for Major Depressive Disorder (MDD) is Decreased interest or pleasure in most activities, most of each day. I.e. Apathy. Definitions of apathy include such terms as impassiveness and indifference, not caring and unwillingness to change. These terms are quite derogatory so the term apathy should only be used in diagnostic criteria if confirmed by those with bvFTD. Inertia in its Newtonian physics definition: an object will remain at rest or in constant movement in a straight line unless acted upon by an external force; is a much better, non-judgemental replacement, rather than alternative, for apathy.

In my experience and in the blog previously mentioned, a finite amount of energy diminished from what was available pre-disease, is behind what appears to be apathy. My experience is well backed up by the post on Saturday, June 8, 2019, title: EXHAUSTED, which says it all.

Furthermore, this tendency to reuse diagnostic terminology from depression, with minor modifications in meaning, may induce the delay in bvFTD diagnosis. Using terms from depression diagnostic criteria could underlie confusion between the two conditions which affect the frontal lobe of the brain. This could lead to misdiagnosis of early stage bvFTD, particularly as depression is far more common than dementia in the common ages where this younger onset dementia manifests.

Oral Presentation Abstracts

ID: 821 / OS04: Post-diagnostic support

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, caregiver burden, burden clusters, ZBI

Intermediate burden predicts increased risk of caregiver stress at 1-year: longitudinal follow-up of ZBI burden clusters

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Abstract:

Background: There is increasing recognition of the multidimensional (MD) construct of caregiver (CG) burden measured via the Zarit Burden Interview (ZBI), with unique individual factors beyond a single unidimensional (UD) score. In our earlier cross-sectional study (Lau et al., 2015), the MD ZBI was more sensitive than its UD counterpart, and helped identify an intermediate burden group (MD high/UD low) which would otherwise have been missed by the UD score. The prognostic significance of the intermediate vis-à-vis low/high burden groups in terms of longitudinal trends in ZBI score is unclear. We therefore aim to explore whether ZBI clusters predict increased CG burden at 1-year follow-up.

Methods: We studied 165 dyads of persons with dementia (PwD) and their primary family CG attending a tertiary memory clinic. We assessed dementia severity, disease characteristics (cognition, function, mood, Neuropsychiatric Inventory Questionnaire [NPI-Q]) and ZBI scores at baseline (V1) and 1-year follow-up (V2). We adopted the 4-factor ZBI structure of Cheah et al. (2012): F1-role strain, demands of care; F2-role strain, control over the situation; F3-personal strain; F4-worry about caregiving performance. Hierarchical cluster analysis was used to classify CGs into 3 burden clusters: Low, Intermediate or High based on baseline ZBI scores. We compared cluster-specific differences in ZBI total and factor scores at V2. We performed linear regression to determine if burden clusters predicted increased ZBI scores at V2, adjusted for baseline burden and other covariates.

Results: 145 (88%) dyads completed one-year follow up. Intermediate group comprised mostly spousal (53%) and adult child (35%) CGs, caring for PwD who were intermediate between high and low burden clusters in cognition, function and NPI-Q. Compared with low burden, intermediate and high burden clusters endorsed the highest ZBI total scores at V2 (19.1 ± 12.3 vs 33.7 ± 16.4 vs 33.4 ± 17.1 , $p < 0.001$). The intermediate and high burden clusters similarly revealed significantly higher F1-F3 scores for ($p < 0.001$), but not F4. In multivariate analysis, intermediate burden ($\beta = 10.7$, $p = 0.007$), but not high burden ($\beta = 4.29$, $p = 0.293$), predicted higher total ZBI at V2; other significant variables were NPI-Q severity and being either a spousal or child CG. Intermediate burden, but not high burden, similarly predicted F1 ($\beta = 5.52$, $p = 0.004$), and F3 ($\beta = 3.01$, $p = 0.013$) scores at V2.

Conclusion: Intermediate burden predicts increased risk of CG stress among family caregivers on longitudinal follow-up, being predicated mainly upon role and personal strain. These results substantiate the value of adopting a MD approach to understanding CG burden in dementia. Spousal and child CGs caring for PwDs with behavioural issues in the intermediate burden cluster represent an at-risk group predisposed to CG stress and poorer outcomes at longitudinal follow-up, and should be adequately supported at the outset along with high burden groups.

Oral Presentation Abstracts

ID: 831 / OS13: Dementia and public policy I

Abstract Topic: Dementia policies and public policy

Keywords: National plan, dementia, Vietnam, NCD

Toward the development of a dementia plan – the Vietnam situational analysis

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Abstract:

Background: Vietnam has decided to develop an integrated national action plan that integrates dementia into existing non-communicable diseases (NCD) initiatives. Prior to formulating an effective plan, however, reliable information on current situation of dementia care, treatment and support in Vietnam is needed.

Objectives: To better understand the context, barriers and opportunities for improving dementia care, treatment and support in Vietnam and guide the plan development.

Method: A desk review was conducted using the Situational Analysis Desk Review Topic guide developed by the Strengthening responses to dementia in developing countries (STRiDE) project. Key WHO Global Dementia Observatory (GDO) indicators were collected, focusing on Policy, Service Delivery and Epidemiological assessments.

Results: Vietnam has a high level institutional and policy framework on aging, NCD, mental health and disability including the 2009 Law on the Elderly, which provides the legal umbrella for policies on older people. However, no dementia-specific policy exists and policies to promote healthy brain remain weak. Rapid aging significantly contributes to the explosion of NCD including dementia in Vietnam. There are 660000 Vietnamese people estimated to be living with dementia, with resultant dementia related costs of US\$ 960 million. The healthcare system is not yet prepared for the shift to NCD from an acute, communicable disease burden in the past. Health service delivery is hospital-centric, with over-reliance on hospitals and under-utilization of primary care system that in turn is fragmented and poorly prepared to address the rising challenge of dementia. Social care and support specific for dementia is lacking although there is an impressive grassroots organisation of older people with nearly 100,000 branches.

Conclusion: To allow for a more harmonized response across the health sector and more effective use of limited resources, an integrated national action plan for dementia is sensible. However, Vietnam should take into consideration the potential for fragmentation and lack of dedicated resources being allocated to dementia. A new, integrated model of care focusing on a stronger primary healthcare system, community-based social care and a healthy aging approach is needed to improve dementia prevention, care, treatment and support in Vietnam.

Oral Presentation Abstracts

ID: 838 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: Quality Care, Reducing Discrimination, Timely Diagnosis

Designing a new future for dementia in Australia

Maree McCabe

Dementia Australia, Australia

Abstract:

When Dementia Australia was formed in 2017, bringing together our federated structure to create the national peak body, we committed to becoming a bigger, stronger and bolder voice for people living with dementia, their families and carers. To understand how to achieve this we undertook extensive and rigorous consultation with our community to identify the focus areas that will deliver the greatest benefit for those living with dementia, their families and carers. Throughout this planning process we asked two key questions: What are the biggest issues for people living with dementia, their families and carers? How can Dementia Australia have the biggest impact? *Designing a new future 2018-2023* is the result and it highlights the issues that our stakeholders identified as areas of greatest need. The three issues of greatest need were identified as: 1. Improving access to timely diagnosis and ongoing support. 2. Increasing the quality of dementia care. 3. Reducing discrimination. This is a long-term strategy that will be implemented over five years. Our focus to date has been on priority areas 2 and 3. 2. *Quality Care Initiative:* Within the next five years, in consultation with stakeholders, we will create baseline and best practice standards for quality dementia care. We will advocate for the baseline standards, which will include provisions for training, to be implemented into aged care homes and programs across Australia. To date this has resulted in the delivery of a National Quality Care Consumer Summit with more than 30 consultation sessions around the country and a communique that was delivered to government and stakeholders in July 2019; a National Quality Care Stakeholder Roundtable will take place on 12 November 2019; and a National Quality Care Symposium will be held on 24 March 2020. 3. *Reduce discrimination: People living with dementia, their families and carers are free from discrimination.* During the next five years we will tackle discrimination head on so that no-one with dementia feels isolated. Using the theme '*Dementia doesn't discriminate. Do you?*' for our Dementia Action Week 16-22 September 2019, we inspired Australians to complete a short survey to give us a national, informed picture of what discrimination looks like now and what it would take to shift that discrimination. At submission time there were already almost 5,000 respondents with still three weeks until survey closure. In my presentation I will report on the findings in our national strategic planning consultations and our work to date on the two priority areas. Dementia Australia's work will be valuable for other member organisations to enhance and progress with their own strategic planning towards making a difference to the lives of people, of all ages, living with all forms of dementia, and their families and carers.

Oral Presentation Abstracts

ID: 840 / OS21: STRiDE

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, treatment, Kenya, barriers, STRiDE

Barriers to dementia care in rural Kenya

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Abstract:

Background and objective: People tend to be diagnosed late in Kenya, resulting in missed opportunities for better treatment, carer, and support for persons with dementia. This study aimed at exploring the barriers to detection and treatment of dementia in community-based settings in Makueni County (rural Kenya).

Methods: Focus Group Discussions (FGDs) and Key Informant Interviews (KIIs) were conducted among health care workers (2 FGDs), caregivers for persons with dementia (1 FGDs and 7 KIIs) and members of the general public (2 FGDs). Recruitment for health care workers and caregivers was conducted through the County referral hospital while the local administration (chief) was used as a channel to identify participants in the latter group. Ethical approval was sought from the Maseno University Ethical Review Committee (MUERC) in Kenya with all participants consenting to participate in the interview. A thematic process was used to identify barriers associated with accessing dementia care.

Results: The following themes associated with barriers to dementia care were identified; (i) Local interpretation of the term "dementia" resulting to stigma; (ii) Knowledge gaps on dementia care; (iii) Lack of a national plan or policy guidelines on dementia treatment; and (iv) Uncoordinated existing dementia care pathways. Practically, there was evidence that dementia diagnosis occurred at later stages of the disease, as clinicians were unable to identify people with early-stage dementia to participate in the interviews.

Conclusions: The identified barriers make a contribution to missed and delayed diagnosis of dementia. Efforts to develop national dementia plans and policies could provide opportunities for dementia awareness and improve the quality of care for persons with dementia so that caregivers do not shoulder excessive burden, affecting their physical and mental health. Clinicians also need to be well supported through training on creating awareness in communities, making an earlier diagnosis of dementia to increase timely access to treatment and care among populations in low-resource settings. Through the ongoing STRiDE (Strengthening Responses to Dementia in Developing Countries) project the authors will aim to; (i) increase understanding and awareness of dementia among healthcare professionals and community members by empowering individuals with dementia and families to share their experiences and build awareness and engagement; and (ii) provide recommendations for development of a national dementia plan in Kenya.

Oral Presentation Abstracts

ID: 842 / OS15: Risk Factors II

Abstract Topic: Risk factors

Keywords: sleep duration, cognitive impairment, cohort, Chinese

Association between sleep duration and cognitive function among Chinese older adults: results from the Chinese longitudinal healthy longevity survey

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Abstract:

Background: A growing number of cross-sectional studies had examined the association between sleep duration and cognition in older individuals, but longitudinal studies were scarce. Whether sleep duration related to the incidence of cognitive impairment remains unclear. Based on a cohort from Chinese Longitudinal Healthy Longevity Survey (CLHLS), we aimed to evaluate the relationship between sleep duration and the incidence of cognitive impairment among Chinese older adults.

Methods: We conducted a prospective analysis based on CLHLS on 5918 participants, who were aged 65+ years with the Mini-Mental State Examination (MMSE) score ≥ 24 at baseline and with a 3-year later follow-up. Sleep duration was measured by self-reported total hours of sleep, and was classified into three groups: short (≤ 5 hours/day), normal (> 5 , but < 10 hours) and long duration (≥ 10 hours/day). The incidence of cognitive impairment is defined as MMSE score < 24 during follow-up. Logistic regression model was used to examine the association of baseline sleep duration with cognitive impairment after adjusting for age, gender, education, occupation, current marital status, residence, co-residence, economic status, type of dwelling, BMI, exercise situation, smoking status, drinking status, physical illnesses, loneliness and depression.

Results: 1949 participants (52.8%) were men. The average age was 79.40 ± 9.06 (65-114) years old. 562 participants (15.2%) were included in the short duration group, 2522 participants (68.3%) were included in the normal duration group and 608 participants (16.5%) were included in the long duration group. 531 participants (14.4%) had cognitive impairment during follow-up. After adjusting for multiple potential confounders, compared with normal group, long sleep duration was associated with the incidence of cognitive impairment (OR=1.309, 95%CI: 1.019-1.683), especially among men (OR = 1.527, 95%CI: 1.041-2.240), and those aged 75 or over (OR = 1.336, 95%CI: 1.022-1.747). No significant association was observed between short sleep duration and cognitive impairment (OR = 0.860, 95%CI: 0.646-1.145).

Conclusions: Prolonged sleep may induce worse cognitive function in older individuals, and may be a marker of early neurodegeneration as a useful clinical tool to identify those at a higher risk of progressing to cognitive impairment.

Oral Presentation Abstracts

ID: 843 / OS21: STRiDE

Abstract Topic: Dementia policies and public policy

Keywords: Demensia policy, Demensia policy stakeholders, Indonesia

Analysis of dementia policy stakeholders in Indonesia as part of the STRiDE project

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Abstract:

Background and objectives of the study / Introduction

The STRiDE Project aims to strengthen responses to dementia in developing countries, and through new evidence inform the development, or revision, of national dementia policies. To do this STRiDE evidence needs to reach key stakeholders through appropriate channels and in ways that will effectively influence those stakeholders. To facilitate this we are undertaking analysis to determine who are the key stakeholders, how to reach them, and developing Knowledge Exchange, Impact and Engagement (KEIE) activities to realise the potential for impact from the STRiDE project in Indonesia. We are also exploring how policy decisions are made in Indonesia, and what this may mean for impact from the STRiDE Project.

Methods

We are carrying out stakeholder mapping, social network analysis, prioritising stakeholders given the resources available within the project, identifying impact activities that are most appropriate for those stakeholders and implementing those activities. Preliminary stakeholder mapping was carried out to finalise participants of a Theory of Change (ToC) workshop to inform the STRiDE Project in Indonesia and our activities have built on this.

Later in the project, we will be evaluating our KEIE activities, and evaluating the impact (as far as possible) from the project in 2021.

Alongside this, stakeholder interviews will be carried out to understand the types of knowledge used in decision making, and how this may affect our KEIE plans.

Results / Positive impact

By March 2020 we will have developed our KEIE plans (carrying out stakeholder mapping and analyses), and will have completed stakeholder interviews. The team has also carried out a number of KEIE activities to share information about STRiDE and start to develop key networks.

The presentation will talk through the development of our KEIE plans, present initial findings from stakeholder interviews and discuss how these will be taken forward in the remainder of the project to support findings from relevant STRiDE work packages to develop national recommendations. It will also describe some of the KEIE activities carried out so far within Indonesia.

We will also present our preliminary stakeholder mapping for our ToC workshop and how stakeholders contributed to a ToC map and our impact objectives.

Conclusions / Perspectives

Alongside sharing learning on KEIE, and particularly the process for developing their KEIE plan within Indonesia, this presentation will also describe the approach within the STRiDE project of working

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Oral Presentation Abstracts

collaboratively across research and NGO partners, and how working closely in this way has (so far) and will support the STRiDE Project and KEIE activities.

Oral Presentation Abstracts

ID: 844 / OS05: Informal carers support

Abstract Topic: Informal carers support – pre, during and post

Keywords: carer support, primary care, review

Support for carers of people with dementia: a primary care perspective

Constance Dimity Pond, Karen McNeil, Jenny Day

University of Newcastle, Australia

Abstract:

Background and objectives of the study/Introduction

Identification of dementia and the ongoing care and support of the person living with dementia often occurs in the primary care setting. Generally the primary care physician and health care staff working in general practice already know the person living with dementia and the family, so are in a good position to provide support for the carer. The whole primary care team, including physician, practice nurse and allied health professionals can provide elements of support. Our aim was to provide a description of new primary care guidelines detail primary care-based support for carers of people with dementia living in the community. Funding support was received from the Cognitive Decline Partnership Centre (CDPC) in Australia.

Methods

Our team performed a narrative review of literature on being a carer for people living with dementia and identified a number of issues. We also conducted a forum with people who were carers of people living with dementia and obtained their views on what they wished GPs and their primary care team to know about the topic. Taking into account the busy nature of primary care practice, we developed a three-part guideline addressing carer support. The first section summarised the issues from the literature review and carer forum in a series of dot point 'key messages' and illustrated them using a diagram. In the second section, we wrote points which translated the key messages into statements guiding 'what to do in practice' and included quotes from the forum. In the third section we wrote a more formal narrative review, intended to be read by those with a more academic interest in the topic.

Results/Positive impact

Topics covered in the guideline chapter included: assessment of the carer's mental and physical health needs and providing support, information and access to resources/support services. The guidelines are in the late stages of finalisation and will be posted on the CDPC website by the time of the conference.

Conclusions/Perspectives

Caring for carers of people with dementia is an important role for the primary care team. The new guidelines present, in a concise and accessible format, the issues and support options for primary care teams.

Oral Presentation Abstracts

ID: 853 / OS14: Attitudes and awareness II

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, film, stigma, young-generation, medical students

Remember Me Film Festival breakthrough: medical students' perspective on breaking dementia stigma from younger age

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School of Medicine and Health Science, Atma Jaya Catholic University of Indonesia, Indonesia

Abstract:

Introduction

Stigma on dementia can lead to delayed diagnosis as well as inadequate care, treatment, and support. From previous studies, it was found that stigma usually developed during the age of 18 - 22. However, it might even start in the younger age group, especially those with lower education. One of the identified major strategies is increasing awareness about the topic among specific targeted group. However, gaps in knowledge of what method and materials that should be disseminated still limit this proposed strategy. In 2017, Alzheimer Indonesia organisation held Remember Me Film Festival (RMFF) as part of their awareness-raising program. Considering the enthusiasm expressed by medical students toward this event and their existing public health knowledge, this study aims to describe their perspective in breaking dementia stigma using film to educate the public, especially young people.

Methods

This is a triangular study using both qualitative and quantitative methods. Focus group discussion was done to collect qualitative data from 7 medical students in clinical clerkship program who had participated in RMFF. From that, a validated self-administered questionnaire was developed based on the findings from qualitative interpretative thematic approach. This questionnaire was then disseminated to 305 medical students in Jakarta to explore perspective.

Results

FGD participants were 4th and 5th year medical students in clinical clerkship program. Survey respondents were 1st to 5th medical students, with the majority (68%) are females. In terms of their medical study, 51% were in their 1st to 3rd year (pre-clinical program) and 49% of the rest in clinical clerkship. From both FGD and survey, the majority of respondents agreed that availability of dementia information is still lacking. The survey also showed that stigma was still held by many, especially the belief that being forgetful and dementia is normal in old age. As of the non-medics young population's concern, dementia diagnosis was considered less threatening than heart disease, cancer, stroke, and diabetes. Film was also considered a potential and more interesting mean of early dementia education, leveraging on high internet dependency, high usage of social media, and high short-film access in their everyday lives. Targeting young generation using film can also bring more benefits, as awareness can be more massively spread including to the older generation.

Conclusion

Short film appears to be a potential tool and investment to raise awareness of dementia and break the stigma among young generation in this 4.0 industrial era, especially when coupled by factors that fulfilled by the needs of the market.

Oral Presentation Abstracts

ID: 857 / OS17: Diagnosis II

Abstract Topic: Diagnosis

Keywords: dementia; neurocognitive disorder; DSM V

A critical review of DSM-V cognitive impairment and dementia definition and a rational proposal to the found voids.

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Abstract:

The DSM-V diagnosis of Major Neurocognitive Disorder (named dementia before) requires substantial cognitive impairment to interfere with independence in everyday activities. On the other hand the precise definition of Mild Neurocognitive Disorder (named mild cognitive before) states that the individual impairment must represent a decline from a previously higher level. However in the practice of the daily clinic there are medical conditions with different degrees of cognitive and functional impairment that not necessarily are dementia.

In order to correctly classify the different cognitive impairments as dementia or not, we propose a reformulation to the existing classification: a) Major Neurocognitive Disorder - Type I. Cases with impairment of: Executive Functions, Social brain, judgment; b) Major Neurocognitive Disorder - Type II. Cases with impairment of: memory, agnosia, apraxia, viso spatial skills.

Conclusion

SPT is able to generate a good response and effective in managing agitation in persons with dementia. However it was less effective in patients with depressive symptom or aggressive with Pittsburg Agitation Scale rated as 4 on all behavior groups.

Oral Presentation Abstracts

ID: 862 / OS27: Risk reduction and prevention

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: primary prevention, care, risk reduction

Primary prevention workshop "caring my brain" of A.L.M.A. association: fight against Alzheimer's disease, Argentina.

Noemí María Medina

A.L.M.A. Asociación Lucha contra el Mal de Alzheimer, Argentine Republic

Abstract:

A.L.M.A covers activities up to the level of tertiary prevention. With advanced experience, it meets the needs of Cognitive Stimulation and Music Therapy for sick people, Personalized Care for families, Support Groups and Psychotherapeutic Support Workshops for family caregivers, consultations with specialists. Since 2018, it has also developed a program for adults in the area of primary prevention.

Background: The Primary Prevention aims to prevent or delay the onset of the disease. In the genesis of Alzheimer's disease, age and genetic, medical, environmental and behavioral factors are involved, some of them act as risk factors, while others act as protectors; some are not susceptible to manipulation (age, genetic factors, etc.), others on the other hand, do allow it (medical, behavioral factors), thus enabling primary prevention.

Prevention Workshop: It is carried out for 4 months by professionals from various disciplines. For adults who attend twice a week on Tuesdays and Thursdays. The meetings are two hours long. The Workshop integrates activities organized into 4 modules for adults so that participants a) obtain general information about cognitive impairment, risk factors and protective factors. b) Understand that the Primary Prevention aims to prevent or delay the onset of the disease, which is achieved by reducing the exposure or effects of the causative agents and the risk factors and increasing and promoting the protective factors and resistance of the organisms against the pathological process c) Evaluate the benefits of incorporating habits and customs that contribute to care for your brain. d) Acquire a positive attitude to incorporate changes in behavior that contribute to the care of the brain during life. Monthly schedule: Frequency of activities: twice a week Days and times: Tuesday and Thursday from 6 pm to 8 pm. Modules: I) "Music, movement and memory" Harmonizing Dance, on Tuesdays. II) Talks / Interviews of professionals on Healthy Heart, Prevention of cognitive impairment, Nutrition, Art and brain: once a month, Thursday. III) Memory stimulation workshop, twice a month, Thursday. IV) Cinema debate: once a month, Thursday

Summary: A.L.M.A. fulfills its institutional mission to meet the needs of society including the area of primary prevention. The Primary Prevention Workshop "Caring my brain" focuses on activities that allow people to realize the importance of modifying their lifestyle according to the general rule "what is good for the heart is good for the arteries and for the brain."

Oral Presentation Abstracts

ID: 867 / OS31: Dementia and the equitable society II

Abstract Topic: Dementia and equitable society – NEW

Keywords: Unpaid care, low and middle-income countries, qualitative

The costs and consequences of providing unpaid care to people living with dementia in middle-income countries

Sarah Drew, Emily Freeman, Martin Knapp, Adelina Comas-Herrera

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Abstract:

Almost two thirds of people with dementia live in low and middle-income countries. Here, inadequate formal and informal care services, fragmentation of care pathways that do exist, and low rates of diagnosis, mean that care for people living with dementia is primarily provided by unpaid family members. However, there has been little research into the complex realities of providing unpaid care outside high-income countries nor reflection on how the lack of research, the reliance on unpaid care itself or the consequences of providing unpaid care for caregivers might reflect and reproduce inequities at multiple levels.

This study aims to explore the financial, social and health consequences of providing unpaid care for family members living with dementia in India, Jamaica, and Mexico. It uses inductive, iterative qualitative methods to carry out series of interviews with people who care or have cared, without pay, for someone with dementia in each setting. In March 2020 we suspended fieldwork in light of the global COVID-19 pandemic.

We expect that the COVID-19 pandemic will highlight and possibly exacerbate inequities in whether and how providing unpaid care to a family member with dementia presents a burden to caregivers. Data about COVID-19 experiences are likely to help us better understand the broader costs and consequences of providing unpaid care. To this end, we have updated our methodology to include either regular COVID-19 'check in' calls to existing participants or the inclusion of explicit discussion of COVID-19 experiences within remote in depth interviews with new and existing participants. We expect the results of our study to be available towards the end of 2021.

The study forms part of the wider Strengthening responses to dementia in developing countries (STRiDE) Project, a multidisciplinary collaboration across seven countries to support the development and evaluation of National Dementia Plans. The research is done in collaboration with Alzheimer's Associations in each country, ensuring the input of people living with dementia and their caregivers. In addition, National Advisory Groups that include people living with dementia and their carers provide additional oversight to the overall STRiDE project strategy to ensure research conducted within it reflects the priorities of people living with dementia. Findings from the study of unpaid care will contribute to recommendations to support the implementation of National Dementia Plans generated as part of the wider STRiDE Project, and in doing so, help to inform appropriate and equitable dementia policy and practice.

Oral Presentation Abstracts

ID: 868 / OS21: STRiDE

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: Public health priority, dementia, people with dementia, carers, policy

Including people living with dementia in planning for dementia using theory of change workshops in India: a STRiDE initiative

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¹Alzheimer's and Related Disorder Society of India, India; ²National Institute of Mental Health and Neuro Sciences, India; ³London School of Economics and Political Science, UK; ⁴University of Cape Town, South Africa

Abstract:

Background and objectives of the study: While the numbers of people living with dementia is rising in India, the health and social care systems are not sufficiently equipped to deal with its impact. There is a need to develop effective research-based strategies derived from understanding multiple perspectives, to improve lives of people with dementia and carers in India. Generally, voices of people living with dementia are not included in policy discussions in India as it is perceived that they are incapable of contributing due to cognitive impairments and the carers due to poor dementia knowledge. A first step of the STRiDE project, was to organise a Theory of Change (ToC) workshop that aimed to bring together all stakeholders to develop a logical ToC map outlining the impact and pathways to improving quality of life of persons with dementia in India.

Methods: We selected 40 stakeholders for the STRiDE India ToC with expertise and experience in the field of dementia from different regions in India. They included physicians, economists, public health specialists, dementia care providers, policy makers and government officials. For the first time for India, a person with dementia and their family carer actively participated in the workshop. To ensure their confidentiality and well-being, we arranged a psychologist to sit close to them to monitor their reactions and encourage participation. The ToC workshop was conducted over two days, during which participants deliberated on the status of dementia care identified gaps and proposed a logical map for optimum dementia care for the country. The ToC approach involved a process of describing challenges, a logical sequence of key intermediate outcomes and interventions, leading towards a consensus on the eventual impact for dementia care in India.

Positive impact: The ToC was able to define through consensus, the impact that "risk of dementia is reduced, people with dementia are able to live well, and that their family, carers and society are protected from excessive costs and health problems". Two issues relevant to India that emerged were the valuable role of traditional societies in elderly care and the major socio-economic impact of dementia highlighting unpaid dementia care. The key issues highlighted by the ToC map were: dementia awareness, terminology, inclusiveness in society, dementia diagnosis, caregiving services, prevention, management, capacity building, unpaid care, national policy and dementia related research. The Person with dementia and the carer also gave valuable contribution to the discussion.

Conclusions - The STRiDE ToC was instrumental in 1) including perspectives of key stake-holders to identify a road map to improve quality of care for dementia; 2) highlighting the evidence gap related to unpaid care and stigma; and 3) providing a model for the inclusion of people living with dementia and their carers in policy/planning discussions in India.

Oral Presentation Abstracts

ID: 873 / OP2: Dementia and the equitable society

Abstract Topic: Dementia and equitable society – NEW

Keywords: dementia friendly, travel, airports, accessibility, inclusiveness

Enabling adventures with dementia: the journey towards Brisbane Airport becoming “dementia friendly”.

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Abstract:

Introduction: Discussions about dementia in recent years have undergone a paradigm shift from the concept of “being cared for” to “living well”. Whereas at one time receiving a dementia diagnosis was viewed as an end to all activity, it is now known that living life as fully as possible can sustain quality of life and slow the progression of dementia’s effects.

For many people, including those living with a diagnosis of dementia, travel is an important component of a life well lived. However, until recently the issue of travel for people with dementia received little attention. Since 2014, researchers and dementia advocates in various parts of the world, including Australia, Britain, the USA, and Canada, have been working to fill this gap, coming together in 2018 to form the I-D-Air Travel (*International Dementia Air Travel*) Consortium. This paper describes work being undertaken by Australian members of this consortium, specifically reporting on a project that used a knowledge translation framework to collaborate with airport decision makers and staff, as well as people living with dementia and their travel companions, to improve the accessibility of Brisbane International Airport for travellers with dementia.

Methods: Surveys of travellers with dementia (n=7), their travel companions (n=41), airline staff (n=21), and security personnel (n=13) identified airports as the most challenging component of the travel chain for people living with dementia. Interviews with travel companions (n=10) confirmed this finding and provided more detailed insights into the challenges experienced. An environmental audit was subsequently conducted at Brisbane International and Domestic Terminals, using the *Dementia Friendly Communities Environmental Assessment Tool* (DFC-EAT) (Fleming & Bennett, 2017), the results of which informed recommendations to Brisbane Airport Corporation (BAC).

Results: The research team worked with BAC and consumer representatives to develop a *Dementia Friendly Action Plan*; this included changes to the environment (e.g. signage, seating), dementia awareness training for staff, and the development of an airport guide for travellers with dementia. Brisbane Airport was subsequently endorsed by Dementia Australia as Australia’s first “Dementia Friendly Airport” in 2017. This work has been extended to investigate dementia-inclusive travel options and increasing the accessibility of travel hubs in regional Queensland.

Conclusion: People living with dementia are increasingly joining the ranks of “active retirees”, but in order to ensure continuing engagement with the world, we need accessible environments based on inclusive design principles, dementia awareness in the general public, and a willingness to listen to the voices of those living with dementia. If we are to truly increase the self-determination and independence of people living with dementia, we need to ensure that they can participate in a broad range of activities, including air travel.

Oral Presentation Abstracts

ID: 880 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: Dementia prevalence survey, Yangon, Alzheimer association, Myanmar

Prevalence of and risk factors for dementia in botataung township, Yangon region, Myanmar

Le Le Khaing, Soe Min, Aye Chann Maung Maung, Moan Thawdar Myo Thant

Alzheimer Association Myanmar, Myanmar

Abstract:

Background and objectives

Myanmar is now trying to integrate the dementia care and action plans. According to WHO (2012), it is estimated that about 300,000 (three hundred thousand) Myanmar are people living with dementia. It is high time to conduct national dementia survey to detect the prevalence of people living with dementia. As a pilot study, Alzheimer Association Myanmar, one of the initiative NGOs leading the dementia care plan, conduct this prevalence survey in one selected township (Botataung), Yangon Region. The objective is to assess the prevalence of people living with dementia and the risk factors associated with dementia in that township area.

Methods

It was a community-based, cross-sectional descriptive study conducted in ten wards of Botataung Township from 1stOctober, 2018 to March 2019 (11 visits). 529 people of both sex, aged more than 60 years were done for dementia screening with AD8 and Mini-Cog. Along with screening questionnaires for dementia, the assessment questions of the risk factors for dementia were also collected. 9 participants were dropped out because of incomplete data. Data collection and screening was done by trained volunteers of both medical and non-medical backgrounds. The participants who met the scores suggestive of dementia were confirmed the diagnosis of dementia with a validation board (with members of at least two consultants).

Results

Age of the study population ranges between 60 years and 96 years ,and mean age is 71.1 ± 8.37 years. In gender distribution, 64.1 % are females and 35.9 % are males. It is found that 30 participants (5.8%) were diagnosed as people living with dementia and 21 participants (4%) were currently in mild cognitive impairment state. In this survey, 15 participants (14.6% of participants who had diabetic mellitus) are people living with dementia. Calculating with Chi-square test, there is a significant association between diabetic mellitus and risk of dementia ($p = 0.042$). According to adjusted odds ratio calculation (95 % CI), it is found that people with diabetes mellitus are 1.94 times more likely to develop dementia.

Conclusions

In this survey, 9.8 % of study population have cognitive problems. 5.8 % of participants (30 in 520) are diagnosed as dementia. It is much higher than the estimated data of WHO. This study points out the need for nationwide dementia survey to get the prevalence of people living with dementia in Myanmar.

Oral Presentation Abstracts

ID: 882 / OS01: The global policy environment

Abstract Topic: Dementia and NCDs, SDGs, UHC and ageing – NEW

Keywords: policy; sustainability; mental health; human rights; action

Dementia and the global mental health agendas – synergistic opportunities in the SDGs era

Emiliano Albanese

Università della Svizzera Italiana, Switzerland

Abstract:

BACKGROUND / OBJECTIVES

The UN Sustainable Development Goals (SDGs) era provides an excellent opportunity to align the current dementia and the global mental health movement (GMH) agendas. The aim of the presentation is to expose and discuss the communalities, and to highlight some opportunistic synergies between these agendas, which can inform action across all 17 SDGs, and favor multi-sectoral collaborations.

METHODS

We set out to compare the policy statements (including the vision, values, principles, and objectives), of the WHO dementia global action plan on a public health response to dementia (complemented with the WHO Global Dementia Observatory *reference guide*), and the Lancet Commission on global mental health and sustainable development, which provides the latest, state-of-the art policy reference of global mental health.

RESULTS

The vision statements and overall goals of the dementia and global mental health main policy documents do not align, but the two policy documents share most of the values and principles on which they are grounded.

CONCLUSIONS

The current implementation of the WHO global action plan on dementia can benefit substantially from purposely-driven, positive cultural contamination from the global mental health movement. Re-framing the current public health response to dementia within the SDGs can provide concrete opportunities to identify, initiate, and disseminate actions that are explicitly linked to several, multisectoral targets across the SDGs sub-goals and objectives.

Oral Presentation Abstracts

ID: 889 / OS11: Epidemiology

Abstract Topic: Epidemiology

Keywords: population-based study, informed consent, ethics, return of research findings

Preferences regarding the return of research findings in a population-based study on dementia: implications for the informed consent

Marta Fadda, Aliaa Ibnidris, Emiliano Albanese

Università della Svizzera italiana, Switzerland

Abstract:

Background and objectives of the study

Population-based studies are used to describe the distribution and explore the determinants of health characteristics in populations. Large, representative samples are drawn from the target population, and vast amount of information is usually gathered during interviews and assessments, including tests of dementia ascertainment, which may last up to several hours. Therefore, data collection can be extremely taxing not only for the investigators but also for participants. Although sharing the findings of an epidemiological study with participants is certainly morally appropriate, beneficence cannot be automatically assumed. In the piloting phase of a large population-based study on dementia in Southern Switzerland, we set out to conduct a qualitative study to explore the values and preferences regarding the return of research findings among a sample of individuals who gave consent to participate.

Methods

We recruited 20 cognitively healthy men and women, older than 65 years of age, and 20 informants (typically family members) of people with a dementia diagnosis. We conducted 30-minute, unstructured interviews (either in person or by phone) to explore: (1) participants' experience in the study, (2) their motivation for participation, (3) their preferences regarding the return of research findings, including what should be communicated, when, and how; (4) their impressions about the informed consent, including both formatting and content. Interviews were recorded, transcribed verbatim with the help of a digital transcription tool, and analyzed using thematic analysis. Participants' socio-demographic characteristics were self-reported by participants and included gender, age, place of residence and occupation

Results

All participants reported that they decided to join the study out of curiosity, i.e. "wanting to discover something about one's health and cognitive performance, including compared to age-matched counterparts". The large majority of participants expected some kind of information at the end of the study either in person, by phone, email, or regular mail. Moreover, some participants expressed the desire to let the study findings be communicated to their general practitioner.

Conclusions

Participants' reports will be employed to develop a framework that takes their preferences on the return of research findings into account and to integrate them in the informed consent form that will be offered to potential participants of the epidemiological study.

Oral Presentation Abstracts

ID: 892 / OS34: Registries II

Abstract Topic: Global Dementia Observatory (GDO) – NEW

Keywords: Dementia, REDcap, electronic data collection, 10/66 algorithm, population studies

Data collection in large, multisite and multilingual epidemiological studies of dementia using electronic data capturing systems

Aliaa Ibnidris, Giovanni Franscella, Yann Cuttaz, Emiliano Albanese

Università della Svizzera italiana, Switzerland

Abstract:

Background and objectives: The World Health Organization has drawn attention to dementia as a rising public health priority and established a data and knowledge exchange platform: The Global Dementia Observatory (GDO). The platform seeks to support Member States in monitoring the progress in the seven areas, one of which is to establish robust health information systems for dementia. Introducing new tools for data collection and management would contribute greatly to the evolution of dementia information systems. The 10/66 Dementia Research Group addressed the research gap in population-based studies of dementia conducted in LMICs by developing a package of robust measures for older adults as well as a diagnostic algorithm. However, the use of paper-based data collection forms and the lengthy and resource-consuming administration procedure may hamper large scale uses. A short version of the 10/66 diagnostic algorithm was developed and validated to address these issues with the aim of increasing the efficiency and enhancing the practicality of using the 10/66 diagnostic schedule. With the proven validity of the 10/66 short schedule in diagnosing dementia, we hypothesize that, by using REDcap, we retain the functionality of the 10/66 short diagnostic schedule while adding practicality and reducing time and effort in data collection, storage, and management in large scale, multisite and multilingual population studies.

Methods: The short version of the 10/66 diagnostic schedule requires the administration of the Community Screening Instrument for Dementia (CSI-D), the CERAD 10-word list recall task and the EURO-D Depression Scale. The complete set of questionnaires was translated and back-translated from English into French, German and Italian. The questionnaires were then imported into REDcap and piloted in the survey mode for data collection.

Results: Collecting data for the short 10/66 schedule using REDcap with mobile devices such as tablets and smartphones, in the language of choice, showed good acceptability and usability. REDcap provided a user-friendly platform for data collection and offered great flexibility, in particular, due to its offline data capturing feature. This was especially important when an internet connection was not reliable in some of the more remote areas. Data collection, transmission, storage, and management worked seemingly.

Conclusions: REDcap offers a number of advantages; notably, the multi-site and multi-language and offline data capturing options for data collection, which could be ideal for epidemiological studies where subject recruitment is conducted in multiple sites. This could translate to the possibility to collect and compare data on dementia prevalence and impact in different populations.

Oral Presentation Abstracts

ID: 893 / OS20: Dementia friendliness

Abstract Topic: Dementia friendliness

Keywords: Dementia-friendly communities, dementia attitudes, community collaboration, citizen engagement, inclusion

Collaborative citizen engagement to create dementia-friendly communities: assessment to action

Jennifer Carson, Casey Acklin, Zebbedia Gibb, Peter Reed

University of Nevada, Reno, United States of America

Abstract:

Introduction

In 2016, with support from the US Administration for Community Living, the Nevada Aging and Disability Services Division launched Dementia Friendly Nevada (DFN) as a statewide effort to cultivate and strengthen communities in becoming more respectful, educated, supportive and inclusive of people living with dementia and their care partners. Six communities are engaged, including: Elko County, Pahrump, Pyramid Lake Paiute Tribe, Southern Nevada Urban, Washoe County and Winnemucca. Each community convened an action group comprised of volunteers from a range of sectors, including people living with dementia as central participants.

Methods

Using participatory action research to collaboratively plan and document community change, each community conducted a needs assessment and developed specific action goals. Among other key sources of information to determine community strengths and gaps, the needs assessment included a survey incorporating the Dementia Attitudes Scale developed by O'Connor and McFadden (2010). There was a tremendous response to the survey from community members statewide (n=1066), which demonstrated a 71% positive attitude toward dementia with respondents reporting higher levels of knowledge (77%) than level of comfort interacting with people living with dementia (67%). Driven by these results, each community action group determined a need for community-wide education and awareness raising. Five of the six communities adopted the Dementia Friends™ education program; a program offered nationally by Dementia Friends USA, to help community members learn about what it's like to live with dementia and enable them to turn that knowledge into action supporting community members living with dementia.

Results

From 2017 – 2019, these communities achieved widespread dissemination of this program, training 68 Dementia Friends Champions (i.e., trainers), who in turn delivered 55 training sessions to 607 new Dementia Friends (i.e., completers) across Nevada. To evaluate the impact of the program, DFN conducted a pre-post survey (n = 504) to assess program-related knowledge change as well as commitments to take action. Results showed a statistically-significant (p <.001) increase in participant knowledge, with 17% higher scores at the post-assessment. In addition, given ten options for specific actions, responses ranged from 12% of participants committing to “start a dementia friendly effort” to 70% committing to “support dementia friendly efforts”.

Discussion

Overall, the early impact of this ongoing effort to educate the public about dementia across Nevada has been very successful. This presentation will offer attendees detailed insight into assessing their own communities to prioritize action to move toward being more dementia friendly, highlight the role of community education and the Dementia Friends program, and discuss the need for direct inclusion of people living with dementia in all phases of collaborative community change.

Oral Presentation Abstracts

ID: 896 / OS08: Community partnerships / Public-Private-People partnerships

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Dementia, Perception, Witchcraft

Dementia not witch craft: public lecture to create awareness

Temitope Hannah Farombi¹, Fisayo Elugbadebo², Mofoluke Majekodunmi², Oluyinka Ajomale³, Adeyinka Adefolarin⁴

¹Nerulogy Unit, Chief Tony Anenih Geriatric center University College Hospital, Nigeria; ²Psychiatry unit, Chief Tony Anenih Geriatric center University College Hospital, Nigeria; ³Center on ageing, Development and Right of Older adults, Ibadan; ⁴Social Unit, Psychiatry department, University College Hospital, Ibadan

Abstract:

Background: The reported prevalence of Dementia in Nigeria is increasing with studies giving a range from 2.3% - 21.6%. Despite the rise, religious and cultural perceptions limit adequate care for those living with Dementia due to lack of knowledge and understanding of the disease

Aim: To educate the communities on the symptoms and signs of Dementia

Method: An online survey was carried out to assess the perception of families members carried for the elderly with Dementia. Lecture notes were subsequently prepared to address these perceptions. Government officials, community heads, religious leaders and community dwelling adults were invited using radio jingles, personal invitations and advocacy meeting with interest groups. Lecture notes were prepared in simple local dialect to address the knowledge gap and were also interactive.

Impact: A wide acceptance and case identifications of people with symptoms and signs presented were brought to the clinic for diagnosis and treatment

Conclusion: The community perception is driven by lack of knowledge and understanding of Dementia. However with regular community engagement, people will learn to show empathy to people living with Dementia.

Oral Presentation Abstracts

ID: 909 / OS07: Models of care

Abstract Topic: Models of care

Keywords: Dementia, Geriatrics, Acute Patient, Special Care Unit, Cognitive Impairment, Activity of Daily Living

Towards a dementia friendly hospital - treatment of acute patients with dementia as comorbidity in a special care unit, "station silvia": results of a 3-years evaluation study

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¹Malteser Deutschland, Germany; ²Dt. Institut fuer Pflegeforschung/dip

Abstract:

Objectives:

Because of aging population, the prevalence of patients with dementia is increasing in general hospitals all over the world. Patients with dementia face an increased need for hospitalization due to non-dementia related illnesses, especially respiratory and urinary tract infections. They are highly at risk for severe complications during their stay. Significantly associated with dementia are prolonged length of hospital stay and adverse outcomes like delirium, functional and cognitive decline, reduced autonomy, falls, restraint, malnutrition, discharge to nursing homes and increased morbidity and mortality compared to their peers.

To develop a dementia friendly hospital that meets the needs of patients, relatives and staff, and to improve the quality of treatment and care for acutely ill patients with dementia a special care unit (SCU) - "Station Silvia" -, was established at Malteser Krankenhaus St. Hildegardis in Cologne in 2009 as a first step. The care offered is based on the Swedish Silviahemmet philosophy. The specific goal is to prevent delirium and deterioration in the dementia-specific symptoms so that patients do not leave hospital in worse conditions than when they arrived, to preserve cognitive function and to maintain the functional status of patients during their hospital stay.

To investigate the effects of the specialized treatment and environment of the special care unit, a scientific evaluation in three steps was performed between 2013 and 2017.

Methods:

A cohort study with 393 patients and pre- and post-measurement was carried out. The primary endpoints were collected at hospital admittance and discharge, the secondary endpoints were collected continuously during the treatment. For the pre-post-measurement, the Wilcoxon signed-rank test for matched samples respectively the "t-test for connected samples" was used. The secondary endpoints were descriptively evaluated. To this, a suitable set of indicators was established to measure changes in Activities of Daily Living (ADL), mobility, cognition and challenging behaviour. Additionally, intraindividual sequential measurements of the different indicators were performed.

Results:

Activities of Daily Living (ADL) and mobility improved significantly. Systematic evaluation of the prevalence of behavioral and psychological symptoms of dementia (BPSD) and so-called negative events also showed favorable results compared to published data.

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Conclusions:

The results of the study indicate that the specialized treatment and environment of the SCU prevent deterioration of acutely ill patients with dementia. Some indicators even show significant improvement.

The lessons learned with this unit and the results of the study will form the base for the development and certification of a completely sensible hospital in Gorlitz/Germany in 2020.

Oral Presentation Abstracts

ID: 914 / OS16: Dignity and spirituality

Abstract Topic: Dementia and spirituality

Keywords: Dementia friendly church, dementia and spirituality

The development of dementia friendly churches in Taiwan

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¹Taiwan Alzheimer's Disease Association; ²Foundation of Wisdom; ³Bread of Life Christian Church;

⁴Dementia Center, Chang Gung Memorial Hospital

Abstract:

According to report of the trend of Taiwan Christian churches, there were more than four thousand churches in Taiwan in 2017. It is important to raise awareness and friendliness of dementia in churches in order to create dementia friendly society.

We conducted the first seminar of dementia friendly church in 2015. There were more than four hundred Christians participated the seminar. Since then, there were thirteen seminars of dementia friendly church conducted in Taiwan, more than two thousand Christians received the training.

We developed the guideline of dementia friendly church in 2017 and shared the electronic version on the website of Taiwan Alzheimer's Disease Association for all the people who is interested to download. More than one hundred churches applied and became dementia friendly church. We provided a booklet of understanding dementia, the guideline of dementia friendly church and logo of dementia friendly church to them. A google map of dementia friendly churches were created also.

The Ministry of Health and Welfare started to developed community services for people with dementia since 2017. There are more than four hundred support centers for people with dementia and their families in Taiwan. We worked with the Department of Health of Taipei City Government to involve churches in Taipei to develop community services for people with dementia and their carers. More achievement and challenge will be shared in the conference.

Oral Presentation Abstracts

ID: 917 / OS30: Innovation, technology and entrepreneurship

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Social health, dementia friendly, communities, entrepreneurship, innovation

Global innovations in creating dementia friendly social health communities

Janice Chia

Ageing Asia Pte Ltd, Singapore

Abstract:

The top three challenges of ageing globally is Loneliness, Cost of Ageing and Dementia. Firstly, Loneliness - This is a bigger challenge than obesity. Rich or poor, we can be lonely in our old age. As we grow older, our friends and family members start leaving us, also older people are ageing away from their children, some don't have children and we will face the challenge driven by feminisation of ageing when women outlive men, and there are more single women ageing too. Secondly, its expensive to age in poor health. Its not about how long we live, but how healthy we are in the years that we live. We can live to a 100, but we need to in good health to a 100. Thirdly, Dementia. As Dementia becomes as common as having high blood pressure, how can we grow as a society to be more aware and inclusive towards those with mild cognitive impairments and Dementia?

To address these challenges, a five-year case-study developed in Singapore called ASPIRE55. ASPIRE55 is Singapore is Asia's First Virtual Retirement Village focused on Active Ageing. It is a wellbeing community that offers a combination of social, health and care services that are typically available at a traditional retirement village, but enables members to continue living in their existing homes. Using an relationship based approach, the village encourages intergenerational relationships to develop between staff, elders and volunteers. The goal is to support members to age successfully with each other, like a second family. The case-study has 200 clients who undergo a twice weekly structured technology driven small group strength training and falls prevention programme to build strength, enabling them to be strong as they age. Clients are aged over 50, varying from active agers to elders with mild to advance Dementia. Over 100 activities were developed to enable clients of all abilities and ages every opportunity to be socially engaged with purposeful activities.

Apart from clinical outcomes, the most importance implications of this case-study are the social and wellness outcomes when elders with and without Dementia integrate within a supportive second family environment. Some of the key findings that support this relationship-based approach towards creating Dementia friendly communities include:

- Self-motivation to engage in a dedicated strength training programme, twice weekly, 96 times a year, 100% attendance
- Increase willingness to engage in conversations
- Increase laughter and smiles around familiar faces in the community
- Demonstrated improvements in strength and balance observed through 3-monthly reports
- Increase ability and willingness to be physically challenged and shows satisfaction in achievements

Oral Presentation Abstracts

ID: 918 / OS24: Non-pharmacological intervention

Abstract Topic: Non-pharmacological interventions

Keywords: Behaviours, Chair

Novel chair benefits residents with dementia

Debbie Rozario, Karen Janoff, Paula Cooper

Arjo, Sweden

Abstract:

Background and Objectives of the Study /Introduction

For people with dementia, symptoms such as agitation or aggressive behaviours can be difficult to manage and stressful to residents, families and carers. Anecdotal findings suggest a novel chair tailoring a combination of rocking/music/tactile stimulation may improve these behaviours and provide wellness benefits.

A survey was conducted in September 2019 to quantitatively determine the chair's use cases and impact on residents and carers as a non-pharmacological intervention.

Methods

A global on-line survey was conducted with clinicians who utilize the Wellness Nordic Relax® Chair (WNRC) in their daily practice. A sample of facilities that currently own WNRC chairs (as identified by manufacturer/distributor records) was utilised. 512 facilities were asked to participate; 173 completed the survey for a 34% response rate. Questions were provided in 6 languages; Danish, Dutch, French, German, Swedish, and English. Data were translated to English and descriptive statistics performed. Key findings are reported in aggregate.

Results / Positive impact

- The WNRC is used most often today with people diagnosed with moderate or severe dementia living in memory care centres or nursing homes.
- The chair is most commonly used in communal areas such as a dayroom followed by resident's rooms or other private locations.
- Clinicians identified the top 3 primary reasons they use the chair as 1/decrease agitation, shouting, & overall aggressive behavior, 2/improve overall resident well-being/quality of life, and 3/stimulate/obtain cognitive response.
- Strong secondary use cases include reducing the need for antipsychotic medications, improving overall sleep, and providing enjoyment through activity and music.

Conclusions / Perspectives

- This international survey demonstrated strong use cases for residents with dementia living in memory care and nursing homes as well as other post-acute environments.
- Positive primary and secondary resident outcomes were reported; in addition, most respondents believe this chair helps improve the quality of care provided and creates a calmer, more pleasant work environment for carers.
- Nine of every ten respondents would recommend the chair to colleagues providing care to residents with dementia.

Oral Presentation Abstracts

ID: 923 / OS37: COVID-19 and dementia II

Abstract Topic: Young carers – NEW

Keywords: Young Carers, COVID-19, online supports, informal caregivers, needs

Young caregivers: COVID-19 online support created via recommendations of rural and urban communities

Kristine Newman¹, Arthur Ze Yu Wang¹, Heather Chalmers², Yana Berardini (Lakman)², Vivian Stamatopoulos³

¹Ryerson University Canada; ²Brock University, Canada; ³UOIT, Canada

Abstract:

An important facet of meeting the needs of an aging population is addressing dementia and its impact on families. Considering the growing number of cases of early onset dementia and the trend to have children at a later age, there has been a rise in the number of children who must support their parents and grandparents in a variety of capacities including addressing medical, social, emotional, and physical needs. In Canada, over a million young carers provide unpaid support to a loved one who lives with chronic injury, illness, or disability. Despite young carers' contributions to their family and institutions at large (for example, their unpaid work contributes \$25,000 to \$50,000 in annual savings for the family and/or healthcare system), they largely remain invisible because of their absence from key legislation and policies. Young carers often navigate multiple responsibilities on top of caregiving including school and work. If inadequately supported, they can experience short and long-term delays or harm to academic, personal, social, and professional development. COVID-19 has exacerbated existing challenges and fears for young carers and their families. Using a participatory action approach, we aimed to understand young carers' needs and develop a corresponding tool.

In Phase 1, we conducted focus groups with young carers between 12-25 years old to understand how they accessed and used the internet/Wi-Fi, challenges related to caregiving, and potential solutions that would make caregiving easier from their perspective. We then used these findings in Phase 2 to develop an animated YouTube video on emergency planning in providing a timely response to address some of the informational needs that arose due to the impact COVID-19. Interviews and focus groups explore the understandability, usefulness, and impact of the video.

Findings from Phase 1 indicated that, compared to those living in urban communities, young carers in rural areas said Wi-Fi was expensive (data was considered a luxury) and Google was mainly used for entertainment/distraction. Young carers overall had privacy concerns with online resources; used social media such as Facebook, Instagram, and Snapchat to connect with friends and family; and valued connection and visuals in informational resources/supports. For Phase 2, the video connects young carers with the resources they need for emergency planning.

Policies and guidelines need to include and provide consideration specifically for young carers. Resources/services need to be distinct and a system must be in place to help young carers know what is reputable to address the different levels of abilities to filter and approaches in finding information found in this study. Although social media is commonly used, it may not be the best way to disseminate information since it is mainly used to communicate with friends or family.

Oral Presentation Abstracts

ID: 925 / OS36: COVID-19 and dementia

Abstract Topic: COVID-19 and dementia - NEW

Keywords: dementia; COVID-19; care homes

The story of an emerging crisis: understanding the impact of COVID-19 on care home residents living with dementia

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¹De Montfort University, United Kingdom, ²Dementia UK, United Kingdom

Abstract:

Introduction

The impact of the COVID-19 pandemic on care home residents living with dementia has proven to be devastating. In particular for those nearing the end of life, experiences of death and dying have been significantly affected due to increased vulnerability, lack of resources and social isolation.

This review aimed to understand the initial and emerging impact of COVID-19 on care home residents living with dementia during the early months of the pandemic, up to June 2020. And specifically, to understand how this impact was being communicated to members of the public through the media.

Methods

The review was undertaken using blended approaches drawn from qualitative media analysis and tracking discourse. Emerging information relating to the impact of COVID-19 on care home residents living with dementia was mapped as it was published in news and academic articles. Internet and database searches for articles took place at three distinct time points, between April 2020 and June 2020, in order to track the development of the narrative within a specific time frame. A total of 47 articles were selected for the review. The articles primarily related to the USA and Europe, most commonly the UK, followed by France, Italy and Spain, though other countries were also represented in the literature including China and New Zealand. These articles were analysed, coded and synthesised using thematic qualitative methods.

Results

Eighteen themes were identified in the articles which articulate the impact of the COVID-19 pandemic on care home residents living with dementia. The themes include the following: loneliness; safety; data; testing; innovation; policy; clinical implications. There was a particular focus on end of life care. The review outlines these themes in relation to people living with dementia, care home staff, family carers, advance care planning and palliative care, care quality and the ethics of care delivery.

The review also demonstrates how the public narrative around care homes and residents living with dementia changed and evolved in the early months of the COVID-19 pandemic, moving through three salient phases of framing: the dominance of hospital care; the plight of care homes; the death rate in care homes.

Conclusions

This review uses a novel methodological approach to provide initial understandings of the impact of the COVID-19 pandemic on care home residents living with dementia. While future research will be able to analyse these events in greater detail, this rapid qualitative media review presents early, preliminary findings in real time.

Oral Presentation Abstracts

ID: 936 / OS37: COVID-19 and dementia II

Abstract Topic: COVID-19 and dementia - NEW

Keywords: dementia, COVID-19, mental health, social care

Long-term effects of COVID-19 public health measures on UK social support service usage and mental well-being in dementia and ageing

Clarissa Giebel^{1,2}, Kathryn Lord³, Claudia Cooper⁴, Justine Shenton⁵, Jacqueline Cannon⁶, Daniel Pulford⁷, Lisa Shaw¹, Anna Gaughan⁸, Hilary Tetlow⁹, Sarah Butchard¹, Stan Limbert², Steve Callaghan¹⁰, Rosie Whittington^{2,11}, Carol Rogers^{2,12}, Aravind Komuravelli¹³, Manoj Rajagopal⁷, Ruth Eley¹⁴, Caroline Watkins¹⁵, Murna Downs³, Siobhan Reilly³, Kym Ward¹⁶, Rhiannon Corcoran¹, Kate Bennett¹, Mark Gabbay^{1,2}

¹University of Liverpool, UK; ²NIHR ARC NWC, UK; ³University of Bradford, UK; ⁴UCL, UK;

⁵Sefton Older People's Forum, UK; ⁶Lewy Body Society, UK; ⁷Lancashire and South Cumbria NHS

Trust, UK; ⁸TIDE Carers, UK; ⁹SURF Liverpool, UK; ¹⁰EQE Health, UK; ¹¹Me2U Care, UK; ¹²National

Museums Liverpool, UK; ¹³North West Boroughs NHS Trust, UK; ¹⁴Liverpool DAA, UK; ¹⁵UCLAN, UK;

¹⁶The Brain Charity, UK

Abstract:

On the 23rd of March, the UK saw a nationwide lockdown for over 12 weeks. This was likely to have had severe implications on how social support services (i.e. day care centres, paid home care, support groups) could be delivered, with restrictions on face-to-face contact. The aim of this national survey was to explore the impact of COVID-19 public health measures on access to social support services and the effects of closures of services on the mental well-being of older people and those affected by dementia. A longitudinal UK-wide online and telephone survey was conducted with older adults, people with dementia, and carers between April and August 2020. The survey captured demographic and postcode data, social support service usage before and after COVID-19 public health measures, current quality of life, depression, and anxiety. At each of the three time points (Week 1, 6, 12), participants were asked about their social support service usage, anxiety, depression, and mental well-being. With 569 and xx providing complete data at T1 (Week 1) and T2 (Week 2), 377 people participated in all three time points and had complete data (37 PLWD; 147 current carers; 42 former carers; 148 older adults). We found that social support service usage dropped shortly after lockdown measures were imposed at T1, to then increase again by T3. The access to paid care was least affected by COVID-19. Cases of anxiety dropped significantly across the study period, whilst cases of depression rose. Well-being increased significantly for older adults and PLWD from T1 to T3. Access to social support services has been significantly affected by the pandemic, which is starting to recover slowly. With mental well-being differently affected across subgroups, support needs to be put in place to maintain better well-being across those vulnerable groups during the ongoing pandemic. This is particularly important with heightened and long-term public health restrictions in place again in the wake of the second wave.

Oral Presentation Abstracts

ID: 939 / OS36: COVID-19 and dementia

Abstract Topic: COVID-19 and dementia – NEW

Keywords: Dementia, COVID-19, Caregiving stress

Impact of day care service suspension in COVID-19 pandemic on the caregiving stress of caregivers of people with dementia and the functional status of people with dementia

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¹Jockey Club Centre for Positive Ageing, Hong Kong S.A.R. (China); ²Department of Medicine & Therapeutics, Faculty of Medicine, The Chinese University of Hong Kong, Hong Kong S.A.R. (China);

³Jockey Club Cadanza Hub"

Abstract:

Introduction

The Social Welfare Department of HKSAR Government has announced in late January 2020 the suspension of services of the day care centres for the elderly due to the outbreak of COVID-19. This might deprive people with dementia of the routine cognitive and psycho-social intervention; in addition, longer stay-home time of people with dementia and possible deterioration due to inactivity might cause greater caregiving stress. Our study aimed to investigate how the COVID-19 pandemic and the lack of day care support affected the caregiving stress of caregivers of people with dementia as well as the functional status of people with dementia.

Methods

A cross sectional survey was conducted in eleven day care centres serving people with dementia during April and May 2020 to investigate the caregiving difficulties and stress of family caregivers of people with dementia during the pandemic. The target participants were family caregivers of people with dementia who were interviewed through phone or self-completed an online survey about the caregiving challenges they encountered and the caregiving stress during day care service suspension during the COVID-19 pandemic, the observed changes of functional status of their care recipients, and their preference towards day care service during the COVID-19 pandemic. Results were presented in descriptive manner, and regression analyses were conducted to investigate the association between caregiving stress as well as preference of day care service and possible covariates.

Results

N=152 caregivers completed the survey. 76% participants reported greater caregiving stress, the major caregiving challenge was related to infection, and they had difficulty obtaining private time and maintaining psychological and physical health due to increased time with the care recipients. Increase in caregiver's age (AOR = 1.06, 95% CI: 1.02-1.10, p = .006) and observed deterioration of care recipient's mood (AOR = 6.46, 95% CI: 2.77-15.10, p = .000) was significantly associated with the adjusted odds of increased caregiving stress.

70% participants reported that the care recipients had deteriorated mobility and cognition during day care service suspension and 55% caregivers reported that the care recipients had deteriorated mood; in addition, the care recipients had more accidents, such as walking or leaving home, hospital admission, and fall, during day care service suspension.

36% participants thought that day care service should continue during the pandemic, because they worried that the mobility (84%), cognition (76%), and mood (65%) of the care recipients would deteriorate without day care service. They also claimed that day care service was a main source for them to take respite (76%). On the contrary, the participants preferred suspension of day care services for fear of getting infected. While care recipients preferred to go outdoors during pandemic, caregivers preferred day care service (AOR = 14.23, 95% CI: 1.25-161.75, p = .032). Caregivers whose care recipients were older tended to prefer suspension of service (AOR = .95, 95% CI: .90-.99, p = .021).

Conclusions

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This study confirmed that the family caregivers of people with dementia experienced greater caregiving stress after day care service suspension during the COVID-19 pandemic, especially for older caregivers and those taking care of emotionally disturbed people with dementia. Day care service should remain open with stringent infection control to help maintain the functional status of people with dementia and alleviate caregiving stress. In addition, remote intervention such as online cognitive training should be developed so that people with dementia could maintain social stimulation in the era of pandemic.

Oral Presentation Abstracts

ID: 944 / OS36: COVID-19 and dementia

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Online Post-Diagnostic Support Living Well

Getting on with life in the midst of a pandemic – the development and evaluation of the online go programme

Julie Watson¹, Agnes Houston²

¹University of Edinburgh; ²Person Living with Dementia

Abstract:

Background/Objectives

Despite advancements in policy and care, many people with dementia are not accessing existing services and support, a situation drastically exacerbated by the global outbreak of COVID-19. This research aims to address the post-diagnostic support needs of people with dementia not accessing current support and has two main objectives:

To develop and test a seven-week post-diagnostic programme with, by and for people living with dementia to support people to live as well as possible, recognising that what this looks like is unique to each person and their own circumstances.

2. To understand how a post-diagnostic programme can be integrated into existing services, ensuring people hear about it, feel it is relevant, and ensuring that those who attend continue to benefit from what they have gained, once the programme finishes.

Methods

An action research methodology is used, underpinned by theory developed by the authors which underlines the importance of co-operative communication, co-operative care and co-operative action. The research is in three phases. Phase 1 involved eight workshops with people affected by dementia, and interviews with 11 professionals working in dementia care. We used the findings from Phase 1 to develop the seven-week GO programme. In Phase 2 the intention was deliver and evaluate the programme face to face in four geographical areas, alongside further interviews with professionals working in the field to gain insights into how the programme could be integrated and sustained within existing pathways of support, particularly for those not accessing current support. The outbreak of COVID-19 necessitated a pivot to online delivery and an opportunity to adapt and test the GO programme in the online environment. Phase 2 is underway with online programme delivery.

Results

Findings from Phase 1 showed that people affected by dementia emphasise the importance of the values and principles underpinning post-diagnostic support programmes, which recognise the questions, experience, and potential they themselves bring to the table. In developing the programme for online delivery, we have adhered to these values and principles.

Professionals interviewed in Phase 1 had varied views on what post-diagnostic support should entail, pointing to a need for greater clarity and agreement between professionals and people affected by dementia on its content and purpose.

Initial findings from Phase 2 are illuminating the support required and adaptations needed to deliver post-diagnostic support online. It has potential to reach those who were previously struggling to be included in support, such as those with young onset dementia and those experiencing issues with transport. Findings show an even greater need for clarity and agreement about what post-diagnostic support needs to entail amidst concerns for the effects of social isolation on the well-being of people with dementia.

Conclusions

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Online support may be an acceptable and feasible approach to offering post-diagnostic support for some people living with dementia and more needs to be understood about how best to maximise its delivery and benefits. Even in a pandemic, with appropriate support, people with dementia themselves are a resource in post-diagnostic support as they bring knowledge, an ability to learn and an ability to teach and support others.

Oral Presentation Abstracts

ID: 947 / OS25: Dementia and public policy II

Abstract Topic: Dementia policies and public policy

Keywords: Active member in the Qatar National Dementia Plan

Qatar National Dementia Plan -the first in an Arab nation “how did we get there ?”

Dr Irshad Badarudeen, Dr Hanadi Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, Dr Haroon Saleh

Hamad Medical Corporation, Doha, Qatar

Abstract:

Background

Dementia undoubtedly remains one of the greatest 21st Century challenges faced by Health and Social care systems globally. With someone in the world developing dementia every 3 seconds it is projected that there will be 150 million people living with dementia worldwide by 2050. Dementia not only affects the individual with the condition, it invariably has the wider impact on their carers, families and society at large.

In Qatar, based on 2017 UN Population estimates of those over 60 Years of age, there is a chance that over 4400 people currently have dementia .This figure is expected to rise 10 fold with over 41000 people expected to have some form of dementia by the year 2050 in Qatar.

Aim

To set out the vision for future services and deliver dementia care in Qatar for people with dementia, and their families to enable them to live with dignity and autonomy.

Method

The Qatar National Dementia Plan (QNDP) was borne out of the recognition that unless addressed the human and economic costs related to this condition will rise at an accelerated pace in the future, necessitating the need to keep dementia as public health priority in the Country With Healthcare at its heart, recognizing the growing elderly population in our country and its health needs, the concerted effort by the Ministry of Public health and Qatar’s Dementia Stakeholder Group led to the development of the QNDP (2018-2022).

Results and Conclusion

Clinical Leaders and Policy makers worked collaboratively leading to an effective Dementia Plan being launched in record time outlining the seven action areas necessary to improve the quality of care for people with dementia and their families in Qatar.

Oral Presentation Abstracts

ID: 948 / OS38: Design, architecture and the built environment II

Abstract Topic: Environment and architecture for dementia

Keywords: Design, Interior, inclusive, designed

Interior architecture and design for the enhancement of spaces used by those with dementia and Alzheimer

Gilly Susan Craft

Koubou Interiors, United Kingdom

Abstract:

Understanding how we design for impairment such as Dementia and Alzheimers is key.

A space designed well and fit for purpose stimulates and encourages interaction and wellbeing.

A Designer who understands the language of LRV and the need to aid memory in day to day living is paramount in helping owners and managers use this information. For example, how patterns can be perceived by someone with Dementia can be confusing. Fabric with stripes used in curtains can be perceived as bars at the window, specs in a flooring can be perceived as something that has to be picked up. Shiny floors should also be avoided due to the appearance of a 'wet' surface and therefore a slippery surface to the end user. Not every person with Dementia will have the same needs or perceptions and a 'one size fits all' approach should not be used but the tools are out there to create spaces that people want to live in.

Wallcoverings that give an indication as to the activity in the space, can be used to great effect as well as pleasing to the users of the space.

We need to change perceptions and insist on well-designed spaces. It takes imagination and skill, but a lot can be achieved with the right design.

KOUBOU INTERIORS

Specialists in healthcare design, specifically designing for Dementia and Alzheimer care.

www.koubouinteriors.co.uk

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Oral Presentation Abstracts

ID: 950 / OS36: COVID-19 and dementia

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Dementia, COVID-19, national teamwork, learnings

COVID-19 and dementia care and support in new Zealand

Lyneta Russell, Kathy Peri

Alzheimers NZ, New Zealand

Abstract:

To reduce the spread of COVID-19 Aotearoa New Zealand went into lock down in March 2020, much earlier in the pandemic's impact than many other countries. We have not come this far unscathed, but the experience has, to date, been less damaging than in many other international communities. In our presentation we will share how our Alzheimers organisations adapted their services, collaborated with other agencies, and advocated both locally and nationally for those living with dementia, at the same time uniting to support the government and respond in our uniquely New Zealand way. We will discuss the ways in which the "team of 5 million" adopted measures that changed our social behavior and support networks, particularly during levels four (lockdown) and three.

The caring support focus that is central to the services we provide ensured that most people living with dementia continued to receive support during that time. Flexibility and responsiveness, assisted by Government COVID-19 related financial support, enabled Alzheimers organisations to purchase technology that was used to provide telehealth services with innovations such as virtual Cognitive Stimulation Therapy for people with dementia and social connection programs for their care partners. During the lockdown period Alzheimer NZ regularly informed government agencies of the impact for those people living with dementia, provided input into national guidelines, and working groups. We played a critical advocacy role where we felt that the needs of people living with dementia were not being considered.

The impact of the COVID-19 situation on our country cannot be denied and may have a wide and lasting impact. Social groups already marginalised have experienced a greater impact and the stigmas already present in our communities have been emphasised. Research is now identifying the extent of the impact.

However, we will show how the leadership, which focused on manaakitanga (kindness), has lessened the impact. From central government's provision of wage subsidies to NGO organisations like ours and grants to allow initiatives to support people, to local community efforts to identify those groups of people that would require additional support during the pandemic alert levels, to the caring responsiveness of our Alzheimers organisations there was a shared spirit of national teamwork and aroha (love).

The challenge now is for us to learn from the experience so that we are prepared for future events that test our ability to provide services and to strengthen the support for care partners, who are often taken for granted, to ensure they receive good information and respite to continue in their work. But it is also an opportunity for us to consider how the learnings from the experience can be used to stretch our services and our capability and to consider the importance of dementia friendly communities

Oral Presentation Abstracts

ID: 954 / OS38: Design, architecture and the built environment II

Abstract Topic: Environment and architecture for dementia

Keywords: dementia, neighbourhood, design, built environment, dementia-friendly communities

Towards an integrative agenda for research on dementia-friendly and inclusive neighbourhood design

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Simon Fraser University, Canada

Abstract:

The design of the neighbourhood built environment has emerged as a focus area in dementia studies over the last twenty years. Research in this area has focused on relationships between people living with dementia and the neighbourhood built environment and the potential for built environmental interventions to optimize access to and use of public spaces and buildings. Findings have led to the development of dementia-friendly design principles for adoption by communities that seek to integrate environmental design into the creation of dementia-friendly communities (DFCs). However, most of these studies frame dementia-friendly neighbourhood design as a linear process of identifying architectural problems and barriers and solving them through the application of design principles. This approach does not adequately acknowledge and incorporate contextual and socio-spatial variations of neighbourhood environments and the wider range of factors that shape transactions between the environment and people living with dementia. Framing people's relations with the neighbourhood built environment solely based on a compensatory-enablement approach highlights their cognitive deficits and mobility disabilities. This approach does not capture people's lived experiences, social locations, and processes of enacting agency and autonomy in the community. This paper argues for a more holistic orientation towards an inclusive dementia-friendly design of neighbourhoods by drawing upon the integrative framework of social health (Dröes et al., 2017, *Aging Ment Health* 21:4—17). This framework indicates how the built environment interacts with personal, interpersonal, and social factors to influence people's ability to realize their potential and obligations, preserve autonomy by adapting to everyday situations, and participate in meaningful social activities. Complementary perspectives from environmental gerontology are drawn upon to promote a transactional approach to the relations between people living with dementia and the neighbourhood built environment. This approach highlights people's agential capacities, their appraisals of the neighbourhood environment in terms of safety, support, and stimulation, and how these appraisals influence their activity and participation in the neighbourhood. The agenda also weaves in insights from current empirical research focused on processes of placemaking and attachment of people living with dementia to neighbourhoods to understand the role of design not only in terms of enabling functioning but also shaping the affective aspects of people-place relations. The growing emphasis on the perspectives of rights, citizenship, stigma and discrimination, total inclusion, and empowerment in the DFC discourse suggests the need to adopt a more critical approach to the design of the neighbourhood built environment. The proposed research agenda draws from emerging debates on the rights of people living with dementia to not only access urban public spaces, but also to play a key role in helping shape its design (design with, rather than design for), thereby democratizing the design of neighbourhoods. Facilitating collaboration and partnership through participatory design is framed as a way to not only recast people living with dementia as experts by experience and better tailor design to their lived experience but also recognize and support their right to participate in and influence design decisions that are central to their everyday life. Thus, this paper explores how prevailing and emerging perspectives can be integrated to pave the way for a more holistic, integrated, and in-depth exploration of dementia-friendly and inclusive neighbourhood design. Reframing design research by accounting for and integrating subjective and temporal aspects of lived experience and the physical, social, and technological dimensions of the environment could help generate nuanced and holistic responses through neighbourhood design and planning.

Oral Presentation Abstracts

ID: 957 / OS37: COVID-19 and dementia II

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, dementia risk, lockdown, anxiety, alcohol, longitudinal

Are modifiable dementia risk factors exacerbated by COVID-19 containment measures?

Larissa Bartlett, James J R Brady, Maree Farrow, Sarang Kim, Aidan Bindoff, Hannah Fair, James C Vickers, Duncan Sinclair

University of Tasmania, Australia

Abstract:

INTRODUCTION: Containment measures implemented to minimise the spread of COVID-19 are reported to be negatively affecting mental health, diet and alcohol consumption. These factors, as well as poor cardiometabolic health and insufficient physical and cognitive activity, are known to increase the risk of developing dementia. It is feasible COVID-19 containment measures have exacerbated these dementia risk factors amongst people in mid-to-later life.

METHODS: We compared longitudinal data collected before (October 2019) and during (April/May 2020) COVID-19 'lockdown' from 1632 participants who completed self-report online surveys about their dementia risk behaviours and lifestyle factors. Participants were aged 50+, living in Tasmania, Australia, and engaged in a public health program targeting dementia risk reduction. One-third of the sample participated in the Preventing Dementia Massive Open Online Course (PD-MOOC). Changes in smoking, alcohol use, BMI, diet, physical exercise, cognitive and social activity, anxiety and depression, and management of cholesterol, diabetes and blood pressure were assessed, with covariate adjustments for age, sex, work (vs retired) and residential status (alone vs not; remote vs not). Where significant changes were noted, the moderating influence of being in current employment, living with others and completing the PD-MOOC were assessed. Qualitative interview data (n=7) and findings from a separate, concurrent cross-sectional study in the Tasmanian population were used to support interpretation.

RESULTS: While friend networks contracted marginally during the pandemic, no detrimental effects on the assessed modifiable dementia risk factors were noted. Anxiety levels decreased, there was no change in depression scores, and small but significant improvements were observed in physical and cognitive activity, diet and BMI, alcohol consumption and smoking. Physical activity scores for participants in employment at baseline increased more than people who were retired, and cognitive activity increased more among people who were cohabiting (not living alone) or who participated in the PD-MOOC. Improved adherence to the MIND diet was also stronger for PD-MOOC participants. Qualitative data showed participants had more time to engage in the PD-MOOC and used exercise as a way to connect with friends.

CONCLUSIONS: Contrary to expectations, wide-spread negative effects of COVID-19 'lockdown' on modifiable dementia risk factors were not observed in this longitudinal study. Possible explanations include that our relatively healthy, well-educated participants felt well informed and were therefore less anxious about COVID-19, which may have supported their capacity to adapt. The results counter the dominant narratives of universal pandemic-related distress and suggest that engaging at-risk populations in proactive health promotion and education campaigns during 'lockdown' scenarios could be a protective public health strategy.

Oral Presentation Abstracts

ID: 959 / OS38: Design, architecture and the built environment II

Abstract Topic: Environment and architecture for dementia

Keywords: Dementia, Residential care, Built environment, Aged care

The neighbourhood, Canberra: transforming residential care for people living with dementia in Canberra, Australia.

Jane Forbes Thompson¹, Nathan Martin D'Cunha²

¹Member of the Public, ²University of Canberra

Abstract:

The World Alzheimer's Report 2020: Design, Dignity, Dementia: dementia-related design and the built environment is a timely and much needed reminder of the importance of designing well for people living with dementia. For those who need a level of care and support that cannot be provided in their own home, well-designed residential care communities are vital to enable them to continue to live meaningful lives

Australia's Royal Commission into Aged Care Quality and Safety Interim Report (2019) noted serious failings in the provision of quality care to people with dementia in residential aged care. The impact of the built environment was highlighted.

We have an opportunity in Canberra, Australian Capital Territory (ACT), to provide people with dementia an alternative to the traditional model of residential aged care. As a relatively small, young and spacious city, we are ideally placed for innovation in design of residential aged care homes. There are now an estimated 6,130 people with dementia in the ACT. This is projected to increase to 8,450 by 2028 with 20% likely to need residential care. Our current care homes offer various models of care but may be limited in their ability to tailor the built environment and outdoor spaces to the needs of residents with dementia. It is timely to look at best practice alternatives.

We have formed an Association with the objective of creating a thriving village, The Neighbourhood, Canberra, for people with dementia needing 24-hour supportive care. In the village will be a cluster of group homes designed to enable people with dementia to continue to live meaningfully. The village's architecture and design will be based on best-practice principles as outlined in the World Alzheimer's Report 2020. Six residents will live in each home, supported by a multidisciplinary team of dementia care experts with a flexible carer-to-resident ratio. A relationship-centred model of care will ensure that residents are cared for with dignity and compassion. We will engage staff and families of residents to work alongside each other to maximise the support for residents, enhance family carers' well-being and foster community at The Neighbourhood.

The homes will be set on at least one hectare of land and designed around an expansive garden atrium. The village will offer services for residents and connect to the local community through a cafe, shops, child care centre, health facilities and other onsite services. Residents' personal space in each home will be designed to maximise their privacy, mobility and dignity. Each home will have a kitchen and laundry. Residents will participate in all household tasks.

Detailed forecast modelling shows that the operational costs to run The Neighbourhood, are comparable with other facilities in Australia.

We have made significant progress with support from a suburban developer and local government, interest from several aged care providers in forming partnerships, and, a small grant from a local charitable foundation. On completion, we will set a new standard in residential dementia care in the ACT.

Oral Presentation Abstracts

ID: 961 / OS37: COVID-19 and dementia II

Abstract Topic: COVID-19 and dementia - NEW

Keywords: dementia, COVID-19, nursing homes, loneliness, behavior

Consequences of social isolation on nursing home residents during the visitor ban in Dutch nursing homes

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¹Netherlands Institute of Mental Health and Addiction (Trimbos-institute), Netherlands, The; ²Vrije Universiteit Amsterdam, Amsterdam, The Netherlands; ³University of Amsterdam, Amsterdam, The Netherlands

Abstract:

Background:

To prevent the infection of residents in long-term care facilities (LTCF) with COVID-19, on March 20, 2020 the Dutch Ministry of Health, Welfare and Sports implemented a visitor ban in all LTCFs. This study aims to provide insights into loneliness, mood and behavior of nursing homes residents during the visitor ban due to COVID-19.

Methods:

Cross-sectional data were collected online among family members and care workers in Dutch LTCFs between April 30 and May 27, 2020 (six to ten weeks after the visitor-ban initiated). Sub-samples of relatives and care staff related to residents with psychogeriatric problems were used for the analyses. This study is part of the project Corona Times (<https://www.coronatijden.nl/>) and funded by ZonMw.

Results:

1029/1609 participants were family members of residents with cognitive impairment and 326/811 were staff members working in psychogeriatric units. According to staff members and family members, 34-38% of residents were quite or very lonely during the visitor ban. 36-57% of family members reported an increase in frequency of various mood symptoms. More than 30% of staff indicated they observed an increase in severity of behavioral problems in residents on their units for 6 of the 10 studied behavioral symptoms, than before the visitor ban. 53-55% of staff members indicated irritability, anxiety and depression were more severe in residents on their units.

Discussion:

Results of this study show that the visitor ban in Dutch nursing homes during the COVID-19 outbreak has impacted negatively on mood and behavior of nursing home residents, and that the majority of residents were perceived as lonely to some degree. This implicates that policy makers should be very careful with implementing visitor bans when future outbreaks of COVID-19 or other infectious diseases might occur because of the adverse effects it caused for psychogeriatric nursing home residents.

Oral Presentation Abstracts

ID: 963 / OS37: COVID-19 and dementia II

Abstract Topic: COVID-19 and dementia – NEW

Keywords: digital exclusion, everyday life, accessibility, information communication technologies, eHealth

The pressure to participate digitally during the COVID-19 pandemic: an issue of justice

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¹Karolinska Institutet, Sweden; ²Faculty of Health and Society, Malmö University

Abstract:

Background

Since the COVID-19 pandemic, people of all ages and abilities have been forced to move their lives online and so broader sections of society have sympathised with the challenges of digital engagement in everyday life. However, while most people have adjusted with time, those left behind, including some people with dementia are being forgotten and excluded from taking part in this digital society. This presentation will highlight injustices that come with the pressure to digitally participate in everyday life using examples from research.

Methods

356 older adults with and without dementia were recruited for interviews in their own homes in Sweden, the US and UK prior to the pandemic. Information was collected in questionnaires and in-depth discussions about participants' use of everyday technologies (ETs) (e.g. ICTs (information communication technologies) smartphone for receiving a call, messaging, also in the context of eHealth; payment terminal, lift) and the range of places people went to in their everyday life. Data were analysed statistically and using grounded theory.

Results

Computer functions were most challenging to participants, with three being disproportionately more challenging to participants with dementia (i.e. web searching). Other internet-based ICTs (i.e. smartphone internet banking) were relatively less challenging than computer functions, and less relevant among participants with dementia compared to those without. ICTs presented similar challenge when used for eHealth in comparison to general use, but were less relevant. Participants' revealed three levels of complexity with relationships to; 1) their most well-known ICT, 2) significant others, and 3) healthcare contacts affecting their experiences of eHealth. For a minority of participants, going to fewer places was matched by a lower amount of relevant outside home ETs, including ICTs, and living in a neighbourhood that was relatively more deprived.

Conclusion

While many older adults with or without dementia have the resources, capabilities and opportunity to maintain digital everyday lives, many do not. The presence of significant others may be central to technology use for some people with dementia, which places older adults living alone in a more precarious situation. People who went to fewer places before the COVID-19 pandemic may be more at risk since they may also have fewer ICTs available to use at home and less possibility to move their lives online. Finally, the complexity of particularly computer and internet functions means that for people with lower abilities, it may simply be impossible to shop, bank, access healthcare and meet basic everyday needs online. To counter the injustice of complex, digitised systems and services meted upon people with lower abilities; locked-down and restricted societies must urgently become accessible also via simpler means such as well-known ICT.

Oral Presentation Abstracts

ID: 967 / OS38: Design, architecture and the built environment II

Abstract Topic: Environment and architecture for dementia

Keywords: age-in-place, enable, accessible, safe, suburban

Caring home not care home

Helen Beazley

Individual, Australia

Abstract:

Older Australians are not alone in having a preference to live in their own home in the community setting, it is a western world phenomenon (Gitlin, 2017; Sumner, 2010; van Hoof, Kort, van Waarde, & Blom, 2010). Historically, most of published discussion regarding the living environment, design features, and supports to enhance enablement of the person living with dementia have been in the context of residential care settings (Bowes & Dawson, 2019; Calkins, 2018; Gitlin, Leibman & Winter, 2003), However, there is support for general environmental design principles applicable to all residential contexts (Gitlin, Leibman & Winter, 2003).

This presentation discusses findings from observations made in a new home on the Central Coast of NSW, Australia with the homeowner (an occupational therapist and aspiring permaculturalist) and designer having given due consideration to the home permitting the residents to age-in-place (Lee, Yoon, Lim, An & Hwang, 2012; Marquardt, Johnston, Black, Morrison, Rosenblatt, Lyketsos, & Samus, 2011).

It has been the presenter's experience, from both personal and working as a community practitioner experiences that housing design and stocks that permit ageing in place in a suburban street setting are rare. The physical and accessible features of this home are easily observed. In addition, based on family experience consideration has been given to the safety of a person living with dementia being able to be accommodated in the home, be actively engaged within the home and neighbourhood via a proposed productive garden at the street front of the home. It is proposed that this garden will include sensory aspects, be a picking/kitchen garden, and a sharing garden for the neighbourhood. Additionally, there has been due consideration to the energy and environment costs of the construction of the home.

Oral Presentation Abstracts

ID: 975 / OS30: Innovation, technology and entrepreneurship

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Care, Carers, COVID-19, Partnership, Telehealth

Ask us about dementia - a pilot study

Natalie Elliott¹, Rebecca Cicero², Adrian King³, Gemma Johns³

¹Cardiff & Vale University Health Board, Wales, United Kingdom; ²Social Care Wales, United Kingdom; ³TEC Cymru, Aneurin Bevan University Health Board, Wales, United Kingdom"

Abstract:

Background:

The COVID-19 pandemic has placed increased pressures on both care services and family carers. In the community unpaid carers have received less support due to staff shortages and removal day centres and community support groups. Dementia helplines have reported an increase in calls reporting: stress & distress; progression in dementia symptoms; difficulty making contact with local healthcare services. Interventions that include carer support with problem-solving and coping strategies are known increase carer resilience. Recent research shows that one fifth of the health and social care workforce may leave the profession following COVID-19.

Aims:

Provide timely access to expert advice and signposting on dementia care using telehealth
Increase awareness of the Allied Health Professions and improve access to their expertise
Support peer learning between health and social care practitioners

Methods:

Health and Social Care Wales partnered to design and pilot an innovative national dementia support service, Ask us About Dementia, in conjunction with TEC Cymru's Video Consultation programme.

Pilot sites provide a representative sample of potential users: care homes, domiciliary care providers, local carer centres and national dementia helplines.

Health and social care practitioners with expertise in dementia were identified via national professional networks. Policies, procedures and training on the video consulting platform were designed and provided to practitioners.

The calls follow a coaching model. To ensure that safety, risk, safeguarding and matters for escalation were appropriately managed, the programme needed to apply a structure that allowed the caller to identify a course of action, rather than a definitive resolution to the issue. A follow up call is offered should the caller wish to reflect on how they had applied the advice in practice. The national outcomes framework for care and support in Wales is used to evaluate each call.

The technology platform used allows for an immediate, post-call survey. This has been designed to also contribute to a wider, longitudinal study into the use of video consulting in health and care across Wales.

The pilot follows a Quality Improvement approach; regular meetings were established so stakeholders can contribute to continuous improvement.

Results: The service is in early pilot phase. To date, all calls have been resolved and the key area of impact is on physical, mental health and wellbeing.

Practitioners have reported a positive experience with the formation of a national network providing opportunity to learn and share skills.

Conclusions: Whilst at an early stage, Ask Us About Dementia has shown cross organisational and cross disciplinary ambition, design, and working can happen quickly and easily when telehealth is

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applied creatively. Through providing quicker and fluid access to advice carers are already anecdotally identifying and de-escalating potentially unnecessary referrals.

Oral Presentation Abstracts

ID: 977 / OS26: Diverse populations

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, Persons with dementia, carers, caregiving, BAME

Black, Asian and minority ethnic experiences of COVID-19: views from persons with dementia and caregivers

Emily West¹, Pushpa Nair², Nathan Davies², Kate Walters², Elizabeth Sampson¹

¹Marie Curie Palliative Care Research Department, University College London; ²Department of Primary Care and Population Health, University College London

Abstract:

Introduction

COVID-19 has disproportionately affected those of a Black, Asian and minority ethnic (BAME) background in the UK, with members of these populations dying from COVID-19 at twice the rate of the white population as well as contracting COVID-19 at higher rates. COVID-19 has also had a disproportionately high effect on older adults, including those with dementia. This study explores the lived experiences of older adults with dementia and their caregivers.

Methods

Participants were purposively sampled by local/national dementia/carer networks, and were initially approached by that organisation (in line with local organisation policies and guidelines) before being contacted by the research team. Semi-structured interviews were undertaken with 11 caregivers and 7 older adults with dementia. Data was transcribed, anonymised and analysed using thematic analysis methods coding in NVivo.

Results

Culturally-specific issues were faced by almost all respondents – ranging from a lack of availability of culturally-appropriate food delivered by government food parcels, to worries about communities being exposed due to many BAME people working in frontline roles. Broader issues were also widely reported. Social issues such as isolation and its effects, socialising, support networks and faith were widely experienced. More abstract topics, such as adaptation to new circumstances, including help-seeking and both positive and negative COVID-19 impacts were talked about by many respondents. Medical interactions, including care planning and decision-making were key to many interviews – both with caregivers and persons with dementia.

Conclusions

Experiences of care and caregiving among BAME communities during COVID-19 has been varied, though certain culturally-specific challenges have been widely experienced. Greater attention to the diversity of patients and caregivers in policy-making and service provision may help in ensuring better and more appropriate support for persons with dementia and their families.

Oral Presentation Abstracts

ID: 978 / OS37: COVID-19 and dementia II

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, Decision-making, Mixed Methods, Rapid Response, Dementia

Rapid development of a COVID-19 specific decision-aid for people with dementia and their families

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¹Marie Curie Palliative Care Research Department, University College London; ²Department of Primary Care and Population Health, University College London

Abstract:

Introduction

The effects of COVID-19 on health and social care systems have been widespread, and have necessitated a rapid-response approach to care planning and decision-making. In addition to this, COVID-19 has disproportionately affected older adults, including those with dementia. In light of these challenges, a decision-making tool to help families of persons with dementia was developed. The main objective was to develop a decision-aid using a combination of qualitative data and evidence synthesis.

Methods

Qualitative data was gathered through semi-structured interviews with helpline staff from national end-of-life and supportive care organisations. Interview data was presented to two co-design groups of people living with dementia, current and former carers and experts in dementia, general practice and social care to develop the basis of the tool design. We collected individual in-depth comments from additional experts in the field to finalise the tool. Simultaneously, a rapid review of current evidence on making decisions with older people at the end of life was undertaken and contributed to co-design meetings and the development of the tool.

Results

Issues of trust, agency and confusion were key themes from the qualitative data concerning decision-making in the context of COVID-19. The rapid review highlighted the need to consider both process and outcome elements of decision-making. The decision-aid covered care planning, caregiver support systems, access to information and contingency considerations.

Conclusions

Creating a novel decision-making tool for persons with dementia and their families within the context of COVID-19 was feasible using a combination of sources of evidence. Upon publication, the tool was adopted by NHS England and other leading healthcare organisations, supporting this methods suitability for producing tools that are applicable and relevant to clinical practice in fast-paced and rapidly changing contexts.

Oral Presentation Abstracts

ID: 980 / OS38: Design, architecture and the built environment II

Abstract Topic: Environment and architecture for dementia

Keywords: Dementia-friendly design, architecture, nursing homes, COVID-19

Nursing homes, COVID-19, and designing for dementia: finding a balance between quality of life, infection control, and resilience

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¹TrinityHaus Research Centre, Trinity College Dublin; ²Division of Geriatrics, University of California, San Francisco, CA; ³Centre for Aging, Neuroscience and the Humanities, Trinity College Dublin

Abstract:

Background and Introduction: Many nursing home design models have a negative impact on older people, especially those living with dementia, and these flaws have been compounded by COVID-19. The built environment of these settings results in many older residents with high levels of impairment and chronic illness living in close quarters, a situation that can lead to greater infection rates and mortality. In addition to physical health issues, the built environment of long-term care exacerbates psychosocial and mental health challenges of COVID-19 as a result of quarantine, constrained social interaction, restricted visits from family and friends, the cancellation of shared activities, or the wearing of personal protective equipment (PPE) by staff. These interventions are particularly difficult for people with a cognitive impairment such as dementia who may be deprived of familiar faces, their routine, or freedom to move around, a situation that is very challenging for person that walks with purpose, formerly termed 'wandering'.

This paper argues that there is now an urgent need to examine these design models and provide alternative and holistic models that balance infection control and quality of life in residential care settings. This paper also argues that there is a convergence on many fronts between these issues and that certain design models such as small-scale 'households' and approaches that improve quality of life, will also benefit infection control, support greater resilience, and in turn improve overall pandemic preparedness.

Methods: This paper reviews the literature and best practice around dementia-related design for long-term residential care, draws on the collective architectural and clinical expertise and experience of the authors, and presents a range of design approaches and features across key built environment spatial scales. These scales include macro-scale (overall urban setting), meso-scale (neighbourhoods and districts), and micro-scale (site/building design) issues, design approaches, and building features.

Results / Positive impact: This paper illustrates the need for an integrated approach to the design of long-term residential care for older people and those living with dementia. It argues that a holistic approach is requiring that considers macro, meso, and micro issues. It identifies overlaps between design for quality of life, infection control/pandemic preparedness, and overall resilience. Finally, it argues that examining any new approaches to residential care design through the lens of quality of life and resilience will help reduce the fragility of long-term care and protect against ongoing infectious threats such as influenza or COVID-19, or future pandemics. This is of particular importance for residents living with dementia for whom COVID-19 has taken such a high toll.

Oral Presentation Abstracts

ID: 981 / OS36: COVID-19 and dementia

Abstract Topic: COVID-19 and dementia – NEW

Keywords: burden, dementia caregivers, COVID-19, mental health, loneliness

Investigating the burden and needs of informal caregivers of people with dementia during the COVID-19 epidemic in a severely hit region in southern Europe

Martina Lattanzi

USI Lugano, Italy

Abstract:

Background and objectives of the study: Dementia is devastating not only for those who are affected but also for informal caregivers, often family members who bear the burden of care. The COVID-19 pandemic has a disproportionately high impact on vulnerable groups, including both people with dementia and their caregivers. However, evidence is extremely limited on the extent to which isolation, quarantine, social distancing, drastic reductions or abrupt lack of social and healthcare services impact on care and the psychological, mental and physical health of informal caregivers.

Methods: We conducted a large survey in caregivers of people with dementia in Italy (N=425) and southern Switzerland (N=146), two bordering Italian-speaking regions amongst the most severely affected in the world during the first wave of the COVID-19 pandemic between February and June 2020. We collected socio-demographic characteristics of participants, and recorded information about changes in care arrangements during the pandemic period. We assessed strain of caregivers with the Zarit Burden Interview (ZBI), depressive, anxiety and stress symptoms using the eponym scale (i.e. DASS-21 scale), and perceived loneliness with the UCLA 3-Item Loneliness Scale. All measures were previously validated and available in Italian. We present descriptive and analytic statistics stratified by study site (i.e. Italy vs Switzerland).

Results: Of 571 subjects, about 40% had a severe burden levels (ZBI mean score=54.30, SD=18.33) compared to an average 'pre-covid' value mean=33.40 (SD=15.9; Chattat et al., 2011) in the Italian context. We found that while the level of depressive symptoms was moderate (mean=11.80, SD=6.12), anxiety (mean=10.05, SD=6.93), and stress level were relatively mild (mean=12.95, SD=5.53). Data from the UCLA scale showed that 59% of participants experienced feelings of loneliness during this period (mean=6.78, SD=2.06), compared to an average pre-covid value mean=4.4 (SD=1.7; Evans et al., 2018). Most caregivers reported discomfort related to the intensified social isolation and efforts to maintain social distancing. Finally, most caregivers complained for the drastic decrease in health- and social care services and facilities for people with dementia.

Perspectives: The COVID-19 epidemic has aggravated the condition of social isolation and burden of informal caregivers. Community health services should adapt to the needs of informal caregivers and people with dementia, and online trainings and psychosocial interventions for informal caregivers should be made available promptly to respond to the needs of informal caregivers.

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Oral Presentation Abstracts

ID: 990 / OS36: COVID-19 and dementia

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Dementia, Caregiving, COVID-19, pandemic, India

A Qualitative Exploration of the Experiences of Family Caregivers of Persons with Dementia during the COVID-19 Pandemic in India.

Jayeeta Rajagopalan¹, Faheem Arshad¹, H M Rakshith¹, Vasundharaa Nair¹, Saadiya Hurzuk², Harikrishna Annam¹, Feba Varghese¹, Renuka B R¹, Shah Rutul Dhiren¹, Patel Vishal Ganeshbhai¹, Chandrasekhar Kammammettu³, Shashidhar Komaravolu⁴, Priya Treesa Thomas¹, Adelina Comas-Herrera⁵, Suvarna Alladi¹

¹National Institute of Mental Health and Neurosciences, India; ²Alzheimer's and Related Disorders Society of India; ³ASHA Hospital; ⁴Alzheimer's and Related Disorders Society of India Hyderabad Deccan Chapter; ⁵London School of Economics and Political Science (LSE)

Abstract:

Objectives: Family caregivers predominantly provide long-term care for people with dementia in India. Studies have demonstrated the high caregiver burden associated with informal care provision in India. However, limited studies have examined the experience of caregivers during the COVID-19 pandemic in India. The purpose of this study was to explore the experiences of family caregivers of persons with dementia during the early phases of the COVID-19 pandemic in India.

Methods: We recruited 106 caregivers through the Cognitive Disorders Clinic Registry at the National Institute of Mental Health and Neurosciences (NIMHANS) in Bangalore and the Neuropsychiatric Department of ASHA Hospital in partnership with Alzheimer's and Related Disorder's Society of India in Hyderabad. Caregivers were interviewed between May 15th to June 25th 2020 via telephone using a semi-structured interview guide. Notes were taken to record participant responses to all questions and the responses were documented in English by the multilingual research team. The data collected was analysed thematically.

Results: Four major themes and associated sub-themes were identified: 1) Unchanging reality of caregiving; 2) Challenges experienced: a) behaviours; b) access to care; 3) Effect of changes on caregivers; 4) Adapting to the changed scenario: a) infection prevention measures; b) changes in roles and responsibilities; c) post-lockdown strategies.

Conclusions: These findings highlight the vulnerability of persons with dementia and their caregivers, which has been further heightened in some cases due to COVID-19 pandemic. These results can inform future research and also aid policymakers to recognize and address the needs of family caregivers of persons with dementia in India.

Poster Presentation Abstracts

ID: 136

Abstract Topic: Risk factors

Keywords: Oxygen Free Radicals, Alzheimer's disease, Dementia and Noise

Role of oxygen free radicals in Alzheimer's disease following noise exposure: a literature review

Fereshteh Bagheri

Department of Audiology, School of Rehabilitation Sciences, Babol University of Medical Sciences, Mazandaran, Iran

Abstract:

Background: Noise is known as one of the most commonly encountered workplace hazards and identified as one of the top 10 major occupational problems by the National Institute for Occupational Safety and Health (NIOSH) in the United States. Exposure to high level of noise produces surplus oxygen free radicals (OFR) in the brain. Alzheimer's disease is a progressive disorder of the central nervous system and Oxidative stress occurs in the early stage of Alzheimer's disease.

Objectives: The main aim of this study was to review the related literature concerning the relationship between free oxygen radicals and AD after exposure to noise.

Methods: Articles included in this review were identified through searching the databases of PubMed, Medline, Scopus, Google Scholar and Scientific Information Database (SID) using the search terms of Alzheimer's disease, dementia, oxygen free radicals, and noise. The literature search was restricted to the years 1990 to 2019 and English language.

Results: Of 68 primary articles, 23 potentially eligible articles were reviewed. Extra free radicals which could increase the rate of the Fenton reaction in the brain might also be the main causes of Dementia of Alzheimer type.

Conclusions: This review is highly suggestive of determine the high level of noise as a risk factor of AD, perform an annual comprehensive assessment of hearing status and use of hearing protection devices for all workers exposed to loud noise in workplaces.

Poster Presentation Abstracts

ID: 137

Abstract Topic: New and future treatments

Keywords: acupuncture, Chinese medicine, Alzheimer's disease

Acupuncture improved cognitive function and decreases hippocampal il-1 β in a mouse model of Alzheimer's disease via increasing TREM2 and DAP12

Jing Jiang¹, Ning Ding¹, Gang Liu², Shun Wang¹, Huiling Tian¹, Yujie Li¹, Zhigang Li¹

¹Beijing University of Chinese Medicine, China, People's Republic of; ²Beijing Dongcheng District Community Health and Service Center

Abstract:

Objective: To explore the effects and mechanism of acupuncture of Alzheimer's disease and the differences of combined treatment on the expression of IL-1 β , TREM2 and DAP12 in the hippocampus of SAMP8 mice.

Method: 40 SAMP8 mice were divided into four groups (SAMP8; SAMP8+M; SAMP8+A; SAMP8+M+A) randomly, with 10 SAMR1 mice as a control group (SAMR1). In SAMP8+A group, GV20 and *Yintang* (*Ex-HN03*) were chosen as the therapy acupoints. For the SAMP8+M group, donepezil was dosed at 0.65 $\mu\text{g/g}$ per day. In the SAMP8+M+A group, both treatments were provided. Mice in the other two groups (SAMP8 and SAMR1) were subject to restraint under the same conditions, but without needle insertion or drug administration. After 15-days of treatment, Morris water maze was used to examine the learning and memory abilities of SAMP8 mice in each group, immunohistochemistry was used to observe IL-1 β , TREM2 and DAP12 in the hippocampus of the mice in each group, and Western blotting was used to assess levels of IL-1 β , TREM2 and DAP12 in the hippocampus in each group.

Results: Acupuncture improved the learning and memory abilities ($p < 0.05$) and inhibited the expression of IL-1 β and promotes the expression of TREM2 and DAP12 in the hippocampus ($p < 0.05$).

Conclusion: Acupuncture could improve the learning and memory ability of Alzheimer's disease animal model and decrease the expression of IL-1 β via increasing the expression of TREM2 and DAP12, and acupuncture combined with donepezil was more efficacy than either therapy alone.

Poster Presentation Abstracts

ID: 140

Abstract Topic: Dementia friendliness

Keywords: Dementia Friendly Communities, Asset-Based, Inclusive

Building an inclusive dementia-friendly community in Singapore using an asset-based approach

Angeline Lim², Mary-Ann Khoo¹

¹Alzheimer's Disease Association, Singapore; ²Chua Thian Poh Community Leadership Centre, National University of Singapore

Abstract:

There has been a shift toward using an asset-based approach and including the voices of persons with dementia to build dementia-friendly communities recently. In Singapore, several communities have been declared dementia-friendly. However, existing local approaches adopt a technical assistance approach with government and voluntary welfare agencies providing assistance to persons with dementia and their caregivers. While useful, this approach heavily taxes state resources and may not meet the needs and aspirations of persons with dementia and their caregivers. Following the asset-based approach used to build a dementia-friendly Kiama², we attempted to build an inclusive dementia-friendly community (iDFC) in Kebun Baru (KB), a residential district in the north-eastern part of Singapore. KB was chosen for its high population of elderly living in that area. This paper describes the pilot development of an iDFC in Singapore using an asset-based approach.

To understand the needs, assets and aspirations of the community in KB in relation to dementia, a ground-sensing study was conducted via a) a survey of 133 residents to understand their knowledge of dementia and attitudes toward persons with dementia; b) a focus group discussion with 8 caregivers to identify the challenges they face, the assets within the community, and the support they need; and c) walking interviews with a senior with dementia who lives alone, as well as 2 pairs of persons with dementia and their caregivers to understand their lived experience within the neighbourhood. Grassroots leaders were then engaged in dialogues to understand the findings and explore action steps.

Some actions include developing a series of videos involving persons with dementia living in KB to raise dementia awareness and address the stigma; organising talks, pre-dementia screening and activities for persons with dementia; an exhibition to raise dementia awareness; and planning to paint murals at various points within the community as landmarks to assist persons with dementia and the community in wayfinding.

Implementing the asset-based approach to build an iDFC in Singapore proved challenging. Singapore has a tight culture with strong social norms and low tolerance for deviance. It is also known as a nanny state with strong government control and citizens expecting the government to solve their problems. The stigma of dementia also prevents persons with dementia from speaking out. As such, the attempt to include voices of persons with dementia and form an advisory group made up of persons with dementia and their caregivers was challenging. It is important to consider the cultural context when adopting such an approach.

Poster Presentation Abstracts

ID: 143

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: walk test, cueing, physical assessment, walking, mobility

Role of systematic cueing in 2-minute walk test, 6-minute walk test and 10-meter walk test for older adults with dementia

Wayne LS Chan, Tamis W Pin

The Hong Kong Polytechnic University, Hong Kong S.A.R. (China)

Abstract:

Background and Objectives:

Decreased short-term memory, executive function and attention span reduce the ability of older adults living with dementia in following instructions and testing procedures of walk tests. Poor reliability and high drop-out rate have been frequently reported in studies on the walk tests for this population group. Systematic cueing has been shown effective in facilitating older adults with dementia in completing the walk tests. However, the role of systematic cueing in the walk tests for this population group has not been thoroughly investigated. This study aimed at examining the role of systematic cueing in the walk tests for older adults with dementia.

Methods:

Individuals who were aged 65 years or above, diagnosed with Alzheimer's disease or dementia, and able to walk independently for at least 15 meters were recruited from residential care and day care facilities. All the participants completed 2-minute walk test (2MWT), 6-minute walk test (6MWT) and 10-meter walk test (10MeWT) on three separate testing occasions under two independent raters.

A progressive cueing system was used to facilitate the participants to complete the walk tests. The raters provided cues to the participants when they deviated from the testing protocols. The cues were provided in the following escalating sequence: 0) no cue; 1) verbal prompt; 2) modelling/gesturing; 3) one-off physical prompt; 4) intermittent physical prompt; 5) intermittent physical guidance; and 6) complete physical guidance.

Results:

Thirty-nine participants (mean age = 87.1 ± 6.2) completed the walk tests. No significant difference in walking performance was found in the 2MWT ($p = .18$), 6MWT ($p = .13$) and 10MeWT ($p = .23 - .37$) among the participants with different levels of cognitive impairment. The cognitive function of the participants was independently and inversely associated with the level of cueing provided during the walk tests ($p \leq .007$). The level of cueing provided during the 6MWT ($p = .013$) and 10MeWT ($p \leq .040$) was independently and positively associated with the intra-rater and inter-rater differences in the walking performance of the participants.

Conclusions:

Older adults with more severe cognitive impairment required higher level of cueing from the raters to complete the walk tests. The participants who needed higher level of cueing during the walk tests had greater variations of walking performance as measured by the same rater and different raters. Systematic cueing should be implemented as an integral component in the walk tests for older adults with dementia, especially those with significant cognitive impairment, to facilitate the completion of the walk tests across multiple testing occasions. Systematic cueing may also be useful in monitoring the consistency of the walking performances measured on multiple testing occasions in this population group.

Poster Presentation Abstracts

ID: 148

Abstract Topic: Informal carers support – pre, during and post

Keywords: Case Study Design, Chinese Families, Intergenerational Care, Longitudinal, People With Dementia

Under one roof; intergenerational care for people with dementia in Singapore Chinese families - a case study design

May Yeok Koo¹, Helen Pusey², John Keady²

¹Nanyang Polytechnic, Singapore; ²University of Manchester, United Kingdom

Abstract:

The aim of this longitudinal, case study research using a participatory approach was to better understand the everyday caregiving experience of intergenerational Singapore-Chinese families within the context of each family unit living together in Singapore 'under one roof'. Family biographies were co-constructed with five intergenerational families living 'under one roof' during repeated and scheduled visits with each participating family over a period of between six to 15 months. The interviews included the completion of a 23-item structured questionnaire, co-construction of a genogram and ecomap with each family, drawings, audio recordings and digital photographs of the home environment, items and activities.

Results: Narrative analysis of the five intergenerational cases resulted in the emergence of three themes that explained and explored the various dynamics in the data, namely: i) Family values, and its supporting sub-themes of culture; religion; and filial piety; ii) Family support, and its supporting sub-themes of timeliness; internal support network; and external support network; and iii) Family bonds, and its supporting sub-themes of relational; closeness and conflict; and challenges. Data analysis also generated a meta-theme 'Intergenerational Family Connections' which was supported by three properties: i) Strongly held beliefs and practices; ii) Shared space; and iii) Supporting family togetherness.

Conclusion: This study has led to an in-depth understanding of the everyday experience of the intergenerational Singapore-Chinese families of a person with dementia, within the shared context of their family construction. This study makes an original and significant contribution to knowledge through the development of a new theoretical model on intergenerational family connections in dementia care. The findings will better inform formal and informal service providers and policy makers on how best to support and maintain the relational dynamics of intergenerational Singapore-Chinese families who provide care for the person with dementia at home.

Poster Presentation Abstracts

ID: 149

Abstract Topic: Models of care

Keywords: Dementia Care, Intergenerational Family Connections, Theoretical Model

Theoretical model of intergenerational family connections in dementia care

May Yeok Koo¹, Helen Pusey², John Keady²

¹Nanyang Polytechnic, Singapore; ²University of Manchester, United Kingdom

Abstract:

The theoretical model of **Intergenerational Family Connections** is a cohesive and integrated model which explains the relational dynamics that exist in the everyday lives of Singapore-Chinese intergenerational families caring for a person with dementia in the home setting. It is supported by three properties: (i) Culturally grounded and is the significant presence and influence of strongly held beliefs and practices; (ii) Shared space; and (iii) Supporting family togetherness.

The **first property** is culturally grounded and is the significant presence and influence of strongly held beliefs and practices. This was evident across the intergenerational families and it connected together the intergenerational family members and the person with dementia regardless of their professed religion. The **second property** is shared space. This space moves beyond the geographical location of the home and connects intergenerational family members sharing deep emotional bonds and physical contact with each other on a daily basis. These bonding connections were 'reinforced' through the many decades of shared togetherness, learning one another's idiosyncrasies and adapting to one another's needs. The **third property** is supporting family togetherness. For the intergenerational family members, the deep connections were not necessarily bound by blood ties; rather, it was through a loving and giving reciprocal relationship that transpired from the decades spent together and of which the caregiving act was just one other activity in a life-time of togetherness. The reciprocity shown by the intergenerational family members in the study was from their gratefulness and repayment of what the person with dementia had done for them previously, and now, in the present.

In **summary**, the theoretical model of Intergenerational Family Connections highlights the importance of family connections and how these influence the intergenerational family members and person with dementia within the context(s) in which they live and socialise. The model informs health and social care practitioners who are involved with families of the importance of making anticipatory goals and to be aware of the current and future supportive mechanisms that sustain family connections for intergenerational Singapore-Chinese families of people with dementia.

Poster Presentation Abstracts

ID: 150

Abstract Topic: Formal carers education and training

Keywords: Dementia-Inclusive Environment, education

Translating the vision for a smart, elderly- and dementia-inclusive environment in Singapore through education

May Yeok Koo

Nanyang Polytechnic, Singapore

Abstract:

Introduction: The NYP-StarHub Centre for Connected Care (C3) at Nanyang Polytechnic's School of Health and Social Sciences provides an innovative environment for teaching and learning, testing, implementing and developing elderly- and dementia-inclusive solutions and services for the community; especially for the elderly, people with dementia and their intergenerational families. The centre aims to (1) Co-create solutions that support independent and safe living at home or in the community; (2) Provide learners in the disciplines of health and social sciences, technology and design, with a realistic learning environment; and (3) Help learners acquire more in-depth understanding and skills through partnering with developers, tester and users of daily living aids.

Addressing concerns or issues: (1) Ageing population and the prevalence of dementia in Singapore. Between 2020 to 2030, the number of people aged over 65 years and above will triple. Those who are aged 60 years and above will increase two-fold from 19.5% (1.1 million) in 2017 to 40.1% (2.6 million) in 2050 (United Nations, 2017). Of this, 1 in 10 people who are 60 years old and above has dementia (Subramaniam et al 2015). This has significant impact on intergenerational families as most people with dementia are still cared for at home by their families. (2) Education of our nursing students. Lack of awareness about dementia, how to support the person with dementia and their intergenerational families. Lack of systems thinking, that is, there is a need to adopt an interdisciplinary and inter-professional approach in facilitating an elderly- and dementia-friendly Singapore. Preferences to work in acute care versus community and home care. Lack of awareness towards an Elderly- and Dementia-friendly Design for future homes.

Conclusion: We are constantly innovating our pedagogical approaches to align with the current and future health and social care needs of the nation.

Poster Presentation Abstracts

ID: 152

Abstract Topic: Psychosocial interventions

Keywords: Improvisation drama, nursing home, dementia

Improvisation drama for people with dementia

May Wong, Mei Yee Chang

St Joseph's Home, Singapore

Abstract:

This presentation aims to highlight the developmental journey of a pilot group therapy programme using improvisational drama involving residents with dementia in a nursing home. The programme comprises of two parts. The first involves presenting residents with vintage items acting as stimuli to engage their sense of touch, sight, hearing, smell and taste. They are then engaged in reminiscence about the past and are encouraged to share their knowledge and experiences with each other. The second part involves using improvisation to dramatize a fictional scene. The facilitator sets the place, time and characters of a story. Residents will take on roles, provide input to the story, and develop it. The nursing home received funding to pilot this programme in January 2018 with a group of residents with dementia. Due to the successful outcome, the home received funding in 2019 for a second run. For both runs, all residents who participated gave positive feedback. A therapy assistant received training to facilitate this improvisational drama method and the home plans to incorporate improvisational drama as a regular in-house therapy programme to improve the engagement and well-being of residents with dementia. Our presentation will cover the approach the planning team took to create the pilot and its contents for the initial run, how the team improved these aspects for the second run and the plans we have for future runs. We believe improvisational drama is replicable and when introduced to people with dementia, will support their social and psychological well-being.

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Poster Presentation Abstracts

ID: 153

Abstract Topic: Psychosocial interventions

Keywords: Improvisation drama, nursing home, dementia

Improvisation drama: a case study of the social engagement of a resident with dementia

May Wong, Mei Yee Chang, Swee Geok How

St Joseph's Home, Singapore

This poster aims to highlight the improvement in social engagement of a resident with dementia in a nursing home after attending a new group therapy programme using improvisational drama. The programme comprises of two parts. The first involves presenting residents with vintage items acting as stimuli to engage their sense of touch, sight, hearing, smell and taste. They are then engaged in reminiscence about the past and are encouraged to share their knowledge and experiences with each other. The second part involves using improvisation to dramatize a fictional scene. The facilitator sets the place, time and characters of a story. Residents will take on roles, provide input to the story, and develop it. Before participating in this programme, the resident was observed to be in low mood since admission to the nursing home. He regularly refused group therapy sessions. During this programme however, the resident became fully engaged and participative. He actively recalled his past experiences and readily shared his knowledge with other residents. In doing improvisation, he immersed in his role convincingly and interacted with the other characters in a vivid and light-hearted manner. After the therapy programme, the resident continued to participate willingly in other therapy programmes. He even began to lead other residents in group therapy programmes which he had previously refused to take part in. Staff have observed an improvement in his mood and well-being and he now socialises with his fellow residents daily. The nursing home plans to use improvisational drama as a regular in-house therapy programme to connect residents with dementia with other co-residents, community-based senior and youth volunteers as well as with the nursing home's onsite childcare centre children. We believe this approach will help our residents with dementia nurture social connections both within the nursing home and out into its surrounding community, reducing their feelings of isolation and loneliness. This supports the well-being and personhood for our residents with dementia.

Poster Presentation Abstracts

ID: 156

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: carers, caregiver burden, mild cognitive impairment (MCI), Zarit caregiver burden interview

Caregiver burden in mild cognitive impairment in japan

Satoshi Hayashi^{1,2}

¹Okayama University Graduate School of Medicine, Dentistry and Pharmaceutical Sciences;

²Okayama Institute for Medical and Technical Sciences

Abstract:

Background:

Caregivers of patients with mild cognitive impairment (MCI) already experience a need for increased services comparable to that of individuals caring for Alzheimer's disease patients. However, there have been only a few studies on the MCI caregiver burden. In this study, we examined MCI caregiver burden in a larger number of consecutive outpatients in Japan.

Methods:

One hundred and four consecutive caregivers of people with MCI participated in this study. The caregiver burden was evaluated by the short version of the Japanese version of the Zarit Burden Interview (sZBI).

Results:

About 20% of the caregivers reported a clinically significant burden. The multiple linear regression analysis showed that the caregiver burden was significantly associated with neurobehavioral symptoms ($p < 0.001$) and memory problems ($p = 0.022$) of the patient.

Conclusions:

The caregiver burden of MCI patients should be given more attention. The management of neurobehavioral symptoms may be important to reduce the burden on caregivers of MCI patients.

Poster Presentation Abstracts

ID: 158

Abstract Topic: Education and training in hospitals – NEW

Keywords: inpatient dementia teaching restraint free

Development of a 3-tier care model for patients with dementia in an acute hospital

Si Ching Lim

CGH, Singapore

Abstract:

The elderly living with dementia is on the rise in Singapore. The main bulk of the inpatients in an acute hospital will consist of elderly over the age of 65 in the years to come. Currently in the author's hospital, 60% of the total inpatients are aged >65, and half of these patients have cognitive issues. Currently in a teaching hospital in Singapore, the author has developed a 3-tier care model for the elderly patients with dementia, focusing on non-restraint principles and person centred care.

This model of care is the only one of its kind in Singapore. Tier one is for every staff in the general wards, tier 2 involve a consultation service and team to assist with care of patients with challenging behaviour and tier 3 is the provision of dedicated dementia friendly ward. Sharing the journey and outcome of educating the nurses.

The author has also developed a system where patients are screened at entry point at A&E for cognitive issues to put in place measures to reduce elopement. There are care bundles for the confused elderly and the elderly on physical restraints to ensure they receive proper care. There is a delirium pathway and care bundle, all of which are the first in the country.

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Poster Presentation Abstracts

ID: 159

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: person-centred care, robot, dementia care

Person centred care for patients with dementia in a teaching hospital with novel innovation

Si Ching LIM

CGH, Singapore

Abstract:

As the elderly inpatients are the biggest consumers of inpatient services, we aim to provide better care by early diagnosis of delirium and minimising usage of physical restraints. There is a gradual shift away from using physical restraints in managing the elderly with challenging behaviours in order to reduce falls.

In the author's hospital, the care model is gradually shifting towards person centred care, with creating meaningful activities such as art and craft, exercise therapy led by robot and robotic pet therapy. Patients' satisfaction and staff satisfaction are measured with good outcome.

Poster Presentation Abstracts

ID: 164

Abstract Topic: Models of care

Keywords: person centred care, restraint, dementia ward, elderly

The role of dementia ward in an acute hospital

Si Ching LIM

CGH, Singapore

Abstract:

Currently in Singapore, about 50% of the elderly living with dementia are not formally diagnosed. Without a formal diagnosis, the elderly miss out treatment options, referrals to community services, education, support and counselling for their caregivers, in terms of symptoms management with declining cognition and emergence of behavioural symptoms.

In an acute hospital setting, the elderly with dementia are more likely to be restrained due to the emergence of challenging behaviours, coupled with nurses who have no formal training in geriatric care. The main aim for the dementia ward in CGH is to avoid physical and chemical restraints.

The model of care is a shift from the usual task oriented to person centred care (PCC). The environment in the dementia ward is home like, long corridors with wall pictures to encourage mobility, park benches etc. PCC focuses on designing meaningful activities designed for the individuals, music therapy, robotic pets, multisensory room, art and craft, reminiscence therapy, etc.

The model of care including ADLs like feeding routines and choices of meals are all person centred with good feedback from patients and their caregivers. The average LOS is 12days and 2/3 of patients are able to return to their own home.

Poster Presentation Abstracts

ID: 165

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: Dementia, cognitive decline, synergistic effects, exercise, cognitive training

Domain-specific improvements of combined physical activity and cognitive intervention on cognitive and instrumental activities of daily living function in older adults with mild vs. Moderate-to-severe cognitive impairments

Wan-wen Liao¹, Ching-yi Wu^{1,2,3}, I-ching Chuang^{1,2,3}

¹Department of Occupational Therapy and Graduate Institute of Behavioral Sciences, Chang Gung University, Taoyuan City, Taiwan; ²Healthy Aging Research Center, Chang Gung University, Taoyuan City, Taiwan; ³Department of Physical Medicine and Rehabilitation, Linkou Chang Gung Memorial Hospital, Taiwan

Abstract:

Introduction: Combined physical activity and cognitive training has gradually become a popular approach for augmenting cognitive function in older adults with cognitive impairments. Despite its popularity, little is known about the synergistic effects of combined intervention on older adults across different levels of baseline cognitive impairments, as well as, its impact on different cognitive domains and complex instrumental activities of daily living (IADL) function. The purpose of this study was to examine the effects of combined intervention on multiple levels of cognitive and IADL function and determine whether there were domain-specific influence of the combined intervention on older adults with different levels of cognitive impairments.

Methods: 91 older adults (mean age: 74.28± 7.39 years) were enrolled. They received a structured, multi-modal combined intervention for 2 hours per session, 1 session per week for 12 weeks. The combined intervention included 1 hour of physical activity training (e.g. aerobic exercise, muscle strengthening and balance training) following by 1 hour of cognitive training (e.g. attention, memory, language and executive function training). The training was executed according to a standardized curriculum, but allowed discussions and modifications based on the needs of the participants. Outcome measures included the Montreal Cognitive Assessment (MOCA), Word Recall Test (WRT), Stroop Color-Word Test (SCWT), as well as Lawton-Brody IADL Scale. Participants were divided into the mild cognitive impairment (MCI) group (MOCA≥23, n=40) and the moderate-to-severe cognitive impairment (MSCI) group (MOCA< 23, n=51). Outcomes were assessed at pre-and post-intervention.

Results: Significant interaction effects were found in the MOCA ($P=0.002$), WRT ($P=0.003$), SCWT ($P=0.002$) and Lawton-Brody IADL ($P=0.009$). Post-hoc tests showed that the MCI group had significantly greater improvements in the SCWT and WRT than the MSCI group. In contrast, the MSCI group exhibited greater increase in MOCA and Lawton-Brody IADL than the MCI group.

Conclusion: The combined physical activity and cognitive intervention demonstrated domain-specific improvements of cognitive and IADL function based on older adults' baseline global cognitive function. This result provided implications for future research to refine combined intervention protocols according to each individual's initial cognitive ability, which may assist in development of patient-tailored intervention plans.

Poster Presentation Abstracts

ID: 168

Abstract Topic: Formal carers education and training

Keywords: Communication, Formal carers, Virtual reality

The feasibility of using a virtual avatar to improve communication skills among formal carers

Claire Morrisby¹, Marina Ciccarelli¹, Janet Beilby¹, Annette Joosten²

¹Curtin University, Australia; ²Australian Catholic University, Australia

Abstract:

Introduction

Communication may be significantly impacted by dementia; particularly receptive and expressive language, deficits of attention and working memory, and impairments in syntactic, pragmatic, and semantic language. Communication affects the ability of carers to support people with dementia, in casual conversation and during activities of daily living. Difficulties with communication may increase perceived carer burden and/or trigger responsive behaviours such as agitation in people with dementia. In Australia, there is a need for effective training to support carers to communicate with people with dementia. High-fidelity simulation-based training techniques better support the development of strong links between conceptual or theoretical information and application within situational contexts than traditional lecture or computer-based programs. A virtual animation technology, the Curtin University Empathy Simulator (CUES), includes a virtual avatar named Jim, who simulates a person with dementia during real-time conversation in an immersive virtual learning environment to help individuals develop communication skills. CUES has been shown to develop knowledge, increase confidence, and improve communication skills among speech pathology students and community-based carers. This study aimed to determine the feasibility of using CUES combined with face-to-face education in a communication training intervention with formal carers to improve their communication interactions with people with dementia.

Methods

A pre-post study design was used to determine the feasibility of the targeted communication training intervention. Participants (N=25) were recruited from community day respite centres. Each participant was video-recorded while communicating with a person with a diagnosis of dementia, before and after attending one communication training session. The intervention protocol involved an initial interaction with the CUES avatar, participation in formal face-to-face training, followed by a second interaction with CUES. Evaluation measures included an observational checklist, pre-post questionnaire about knowledge, confidence, and satisfaction with communication, and the Dementia Knowledge Assessment Scale.

Results

There was a significant improvement ($p < .001$) in participants' abilities to effectively communicate with a person with dementia and with the CUES virtual avatar. Participants self rated improvements in their knowledge, confidence and satisfaction in communicating with people with dementia.

Conclusions

Communication training involving the CUES virtual avatar and face-to-face education, improved the abilities of formal carers to communicate with people with dementia. This virtual reality technology has the potential to improve carer training through immediate application of theory to practice, in a safe, repeatable environment.

Poster Presentation Abstracts

ID: 169

Abstract Topic: Informal carers training

Keywords: dementia, education, family caregivers, comprehensive, knowledge

Evaluating effectiveness of a new comprehensive, unified, person-centred, dementia education tool in improving dementia knowledge and reducing caregiver stress among family caregivers of dementia patients in a community hospital in Singapore

Amos En Sheng Lee, Amanda Loke, Joel Goh, Matthew Chen, Linus KL Chua
ST LUKE'S HOSPITAL, Singapore

Abstract:

Introduction

Dementia education to family caregivers helps to improve understanding of disease process, improves management of behaviours of concern, and helps to inform about social supports available to aid in the care of a patient with dementia. Differences in methods of education and tools used can yield different outcomes. We seek to evaluate the effectiveness of a new dementia education tool.

Objectives

To evaluate if the use of an enhanced dementia education tool (comprehensive, unified, person-centred, dementia education booklet) can help improve dementia knowledge and reduce caregiver stress among family caregivers of patients enrolled to community hospital based dementia care programme, compared with the use of current education materials.

Methods

This is a prospective, double-blinded, single-centre, randomized control trial with a current recruitment of 14 subjects. Subjects are family caregivers of patients with dementia who were agreeable and keen for education in dementia. Baseline assessments of Dementia Knowledge Assessment Tool version 2 (DKAT2), Neuropsychiatric Inventory (NPI-Q), and Zarit Burden Interview 12-item (ZBI) were done and followup assessments 1 month after discharge or 1 month after outpatient visits were measured.

Interim Results

23 subjects are recruited into the study, of which 14 subjects have data that is complete and analysed, with 7 subjects in the control group and 7 in the intervention group.

Mean improvement in DKAT2 score was 1.43 in the intervention group compared with -0.29 in the control group, the mean difference being 1.72, (95% CI: -0.94 -- 4.37, $p=0.18$). 71% improved in their DKAT2 score in the intervention group compared with 43% in the control group ($p = 0.32$). Mean improvement in ZBI score was 1.29 in the intervention group and -2.57 in the control group, mean difference is 3.86 (-7.05 -- 15.37, $p = 0.47$). 42.9% improved in their ZBI score in the intervention group compared with 28.6% in the control group ($p=0.61$). Mean improvement in NPI-Q distress score was 4.57 in the intervention group compared with -1.14 in the control group, the mean difference being 5.71 (-1.20 – 12.63, $p = 0.09$). 57% in the intervention group improved in their NPI distress scores compared with 14.3% in the control group. ($p=0.11$)

Conclusions

There is promising interim evidence that a comprehensive, unified, person-centred dementia education tool can help improve dementia knowledge and reduce caregiver stress among family caregivers of patients with dementia. We need more subjects in the trial before making definitive conclusions.

Poster Presentation Abstracts

ID: 171

Abstract Topic: Informal carers support – pre, during and post

Keywords: caregiver burden, Zarit Burden Interview, dementia, age, factor analysis

Caregiver burden across different age-groups: differential profile and associated factors

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Abstract:

Background

Demands and stresses change dynamically throughout one's lifetime. The stage of life at which one undertakes informal caregiving can shape subsequent burden and ability to cope. Little existing research has been dedicated to articulating the nuances of caregiver burden at different ages, in spite of the potential such insight could have on implementing efficacious and targeted intervention. To bridge this gap in knowledge, this study examined caregiver burden profiles across different age-groups, and identified factors associated with burden.

Methods

We studied 871 patient-caregiver dyads. Data on caregiver, care-recipient and disease characteristics were obtained. Caregivers were classified by age: younger (≤ 40), intermediate (41-64), and older (> 65). We measured burden using the validated four-factor Zarit Burden Interview (ZBI) of Cheah et al (2012), comprising role strain–demands (F1), role strain–control (F2), personal strain (F3), and worry about performance [F4, comprising “doing more” (item 20) and “doing better” (item 21)]. We compared ZBI total and factor scores across the three age-groups, and performed linear regression models to examine factors associated with ZBI total and factor scores.

Results

Majority of older caregivers were spouses, while adult-children predominated in intermediate/younger age-groups. Intermediate age-group endorsed highest ZBI total and F1-3 scores, whilst lowest burden was endorsed in older caregivers. Younger caregivers had intermediate total and F1-3 scores but were notable in having highest F4 scores. When adjusted for co-variables, age-group was no longer significantly associated with burden. Instead, co-residence, adult child relationship, instrumental and basic activities of daily living, and Neuropsychiatric Inventory Questionnaire (NPI-Q)-severity were significant. NPI-Q severity, in particular, made the largest contribution to total burden (13.6% variance) and F1-3 (9.2 – 14.1% variance). Uniquely, F4 was not associated with functional or caregiver variables, and only weakly with NPI-Q severity (3.2% variance).

Conclusion

Intermediate-age caregivers experience significant role and personal strain, while worry about performance is a notable facet of younger caregiver burden. Behavioural and functional symptoms are modifiable contributors to total burden. As such, directed interventions to alleviate behavioural and functional symptoms may ameliorate caregiver burden, especially in intermediate-age carers. Worry about performance warrants further study to better understand and mitigate the unique strain borne by younger caregivers.

Poster Presentation Abstracts

ID: 172

Abstract Topic: Diagnostic tools

Keywords: holotranscobalamin, Alzheimer, cognitive

Holotranscobalamin as a potential marker in the development of Alzheimer's disease: a systematic review

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Abstract:

Background: Alzheimer's disease (AD) has been a devastating condition for either the patients or their families. Researchers nowadays not only put their focus on the development of the disease-modifying drugs, but also a way for disease prevention. It would be good to define a variety of biomarkers that could allow early detection for people at higher risk for developing AD; one of them is vitamin B₁₂. Metabolic B₁₂ deficiency is common and contributes to cognitive decline and stroke in older people; but it is frequently missed because the measurement is based on total cobalamin serum concentration; meanwhile 20% of circulating cobalamin binds to transcobalamin (holoTC). For this reason, holoTC is referred to as active vitamin B₁₂, yet suggested as an optimal marker for the identification of individuals who suffer cobalamin deficiency and a potential marker in the development of Alzheimer's disease.

Objective: To gather and present supporting data regarding holoTC in elderly people as a laboratory marker that could be utilized as a risk predictor for the incidence of AD.

Methods: The systematic search to identify articles for meta-analysis was taken based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guideline, using the keywords of "holotranscobalamin" AND "Alzheimer" OR "cognitive". The quality of each study was assessed based on The Academy of Nutrition and Dietetics' risk of bias tool called Quality Criteria Checklist (QCC).

Results: There are 1111 articles reviewed in this paper. Six studies are eligible based on the preferred inclusion criteria. Subjects with lower holoTC had an increased risk of AD. Moreover, holoTC level was more strongly associated than total cobalamin with AD and with cognitive function scores in controls. Meta-analysis on this systematic review is unlikely to be done due to high heterogeneity among the involved studies. Cut-off points for holoTC has a wide range of value; so it would be necessary to study and establish difference reference cut-offs according to age and gender.

Conclusion: The association between vitamin B₁₂ status in adult people and AD progression has been supported by numerous studies; but B₁₂ deficiency is still underdiagnosed. Holotranscobalamin is potentially more accurate as a measurement to diagnose functional adequacy of B₁₂ and moreover, cognitive decline. More studies are needed to determine the reference cut-off for holoTC in order to obtain the precise B₁₂ status.

Poster Presentation Abstracts

ID: 176

Abstract Topic: Diagnostic tools

Keywords: Culture, Elders, First Nations, Cognition, Evaluation

Development of culturally appropriate cognitive assessment in a Canadian first nations community

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Abstract:

BACKGROUND: Patient evaluation for neurocognitive disorders frequently takes place in the primary care setting. Appropriate cognitive assessment tools and techniques need to be culturally acceptable and relevant. It is important that an assessment tool helps in distinguishing patients with subjective cognitive complaints from those with mild cognitive impairment and major neurocognitive disorders/dementias. Oral communication is important in native Canadian culture. The purpose of our study is to develop a culturally relevant tool for use among elders among Canadian First Nations.

METHODS: The setting is a First Nations Community in Northern Alberta in Canada. Elders in the Community are assessed in the Health Centre or in their homes within the community. We sought to develop an appropriate and relevant cognitive assessment tool to properly assess and depict cognitive abilities among community elders. The target populations are elders that are older than 60 years old. Our cognitive assessment tool was being piloted among 37 First Nations elders.

RESULTS: We reviewed available literature on First Nations culture and history to gain insights. The literature review highlighted the importance of animals in Aboriginal or First Nations' culture. We have developed a cognitive assessment tool which is culturally relevant. Oral communication is superior to 'paper-and-pencil' tasks in conducting cognitive assessments. Tests of semantic fluency: naming of four-legged animals, birds, fishes and trees; and confrontal naming correlated to the presence of a major neurocognitive disorder. Environmental orientation also showed a strong association with significant major neurocognitive disorder. Time orientation was not considered to be of any importance or significance in the cognitive evaluation.

CONCLUSION: The validity and appropriateness of a cognitive tool is contingent on its ability to correctly identify persons with cognitive deficits. A copy of our cognitive tool is included in this report.

Poster Presentation Abstracts

ID: 180

Abstract Topic: Other syndromes and dementia – NEW

Keywords: dementia with Lewy bodies, α -Synuclein, amyloid β , insulin signaling

Involvement of amyloid β and insulin signaling in the pathogenesis of dementia with Lewy bodies (DLB)

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Abstract:

Introduction

α -Synuclein (α Syn), a neuronal synaptic small protein, has been the center of focus in the pathogenesis of α -synucleinopathies. It is known that α Syn mutations appear to account for some patients. However, it is only a very rare cause of most dementia with Lewy bodies (DLB), suggesting α Syn mutation may not be the main cause of disease. In fact, recent studies have demonstrated that many DLB cases also display Alzheimer's disease (AD) pathology, particularly for the amyloid β ($A\beta$) depositions in the brain. In addition, defective insulin signaling transduction is also associated with α Syn-mediated neurotoxicity. This indicates $A\beta$ may contribute to aggregation and exacerbate neurotoxicity of α Syn. However, details remain unclear in connection between α Syn pathology and $A\beta$.

Methods

To better understand the relationship between $A\beta$ and α Syn in DLB molecular pathogenicity, we established a neuronal cell-based platform in the presence of coexistence both $A\beta$ and α Syn, and analyzed results by a high-content screening (HCS) assay for the multiparametric analysis of cellular events.

Results

Our results showed that $A\beta$ markedly promotes α Syn aggregation and enhances neurotoxicity in a synergistic effect. Moreover, both oxidative stress and mitochondrial dysfunction played a role in α Syn neurotoxicity. However, the administration of glucagon-like peptide-1 (GLP-1) analogue liraglutide effectively attenuated $A\beta$ -associated neuronal insulin resistance, and thereby increased the elimination of intracellular α Syn aggregations by upregulating autophagy.

Conclusions

According to our findings, $A\beta$ -induced insulin signaling impairment could be the causative factor of α Syn neurotoxicity in DLB. In addition, restoration of neuronal insulin sensitivity can be considered as a better way to reduce toxic intracellular protein aggregates. We hope that these new insights can provide a better understanding of α Syn neurotoxicity in preventive or therapeutic strategies of DLB in future.

Poster Presentation Abstracts

ID: 181

Abstract Topic: Diagnostic tools

Keywords: driver's license return, linear discriminant analysis, neuroimaging, cognitive function, elderly

Analysis of cognitive function and neuroimaging related to driver's license return for elderly

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Abstract:

Introduction: Elderly drivers over the age of 75 in Japan are required to get cognitive function tests, and if they do not meet the criteria, medical certificates are required to keep driving. Once diagnosed with dementia, driver's license will be canceled. However, the difference between mild dementia and mild cognitive impairment (MCI) may not be so clear, and an effective diagnostic method is desired. In this study, we analyzed the characteristics of cognitive function and neuroimaging between patients who were recommended to return a driver's license and those who were not. **Methods:** The study includes 65 patients who visited our dementia outpatient department from January 2018 to July 2019, with an average age of 79.2 years (SD 4.1, 53 men, 12 women). Based on the results of a simple cognitive test conducted under the revised Road Traffic Act, cognitive function was evaluated using revised Hasegawa's dementia scale (HDS-R), clinical dementia rating (CDR), functional assessment staging test (FAST), instrumental activities of daily living (IADL), and dementia assessment sheet for community-based integrated care system-21 items (DASC21). MRI / VSRAD for evaluation of brain atrophy and SPECT / ZSAM for evaluation of blood flow reduction were also performed to determine the type and severity of dementia. Based on cognitive function and image results, the attending physician made the decision using the following criteria: 1. Two or more items in the cognitive function test are dementia levels. 2. Restricted driving environment such as family rides, short-distance driving, daytime driving alone is not prepared in borderline cases. 3. Two neuroimaging tests both suggest dementia. 4. Individuals or families wish to give up their driver's license. In addition, we divided into two groups, driver license return (predicted value <0) and renewal group (predicted value > 0), and examined the effective explanatory variables using linear discriminant analysis. **Results:** 1. Clinically diagnosed as followed: Probably Alzheimer disease (AD) 11 cases, possibly AD 14 cases, MCI 37 cases, and others 3 cases. 2. Twenty-nine cases were recommended to return a driver's license, and the other 36 cases were renewed. 3. Cognitive function tests of HDS-R, FAST, CDR, IADL, DASC21 showed significant differences between the return group and the renewal group ($P < 0.05$). 4. The degree of brain atrophy (GMA) in VSRAD was significantly higher in the return group (6.83%) than in the renewal group (5.88%) ($P = 0.069$). 5. The right parietal ZSAM value was significantly higher in the return group (3.02) than in the renewal group (1.90) ($P = 0.066$). 6. As a result of linear discriminant analysis, using GMA(G) and right parietal ZSAM value (RPa) and discriminant = $1.08 - 0.116GMA - 0.1RPa$, the determination of driver's license return was 66% accurately estimated. **Conclusions:** Neuroimaging was considered useful as one of the objective indicators to evaluate driver's license return and renewal.

Poster Presentation Abstracts

ID: 183

Abstract Topic: Attitudes, awareness and stigma

Keywords: perspectives, social service, attitude

Perspectives of staff, in a social service agency, toward persons living with dementia

Lay Lay Pee

GoodLife!, Singapore

Abstract:

Background

In recent years, we saw more and more social agencies extending specialised services to the persons living with mental health conditions. There were 16 Community Mental Health Intervention Teams (COMIT) in 2016 and the number is expected to reach 50 by year 2021. As of today, we have eight Dementia Friendly Pilot Sites in Singapore. With this, it is thus assumed that the staff in Dementia Friendly sites or on the COMIT programs plays an important role in influencing the community to be more dementia friendly. In this paper, I would like to compare if there were any significant differences in perspectives of staff, towards dementia, who are on COMIT programs and those in other fields of community social work.

Methodology

A 51-item questionnaire (using 5 point Likert scale) based on past literatures was administered to 124 staff working within a social service agency. These staff may be working in Family service centres, Child protection unit or the COMIT programs.

Outcome

114 staff responded to the questionnaire. 54 were from COMIT program, 57 from non-COMIT program and 3 did not indicate which program they were from. Profiles of these staff were 20% male, 80% female with an average age of 26 years old. 41% holds a degree in social work, 31% holds a degree in psychology/ counseling/sociology and 28% holds a degree in an unrelated field or did not indicate their field of study.

Independent T tests were conducted on the data collected. A significant p-value of 0.05 or less were found in the following areas:

- Social workers tend to answer more positively on questions pertaining to the strengths or remaining abilities of the persons living with dementia while non social work trained staff tend to give more neutral answers.
- Direct caseworkers on COMIT programs disagreed that persons living with dementia should stay in a nursing home while workers in other programs gave a more neutral answer.
- Staff not trained in dementia care felt that persons living with dementia were respected for their wisdom while staff that were trained gave more neutral answers.
- Social workers on COMIT program felt that doctors will listen to them when they have dementia while those on other programs gave a neutral answer.

4. Conclusion

Most of the staff, regardless of program or field of training, have positive views of the persons living with dementia. Most of them were comfortable working with the persons living with dementia and felt that they should enjoy citizenship rights, however, majority of staff agreed that they will not be taken seriously if they themselves suffers from dementia. Direct caseworkers on the COMIT program provided answers that were more reflective of the current context of care and social situation for the persons living with dementia.

Poster Presentation Abstracts

ID: 184

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia Stigma

Breaking the myth of Alzheimer's in Jordan

Hamza Khaled Nouri

Jordan Alzheimer Association, Jordan, Hashemite Kingdom of

Jordan Alzheimer's Association

Hamzah Nouri is a 21-year-old Amman Baccalaureate School (ABS) graduate who founded the Jordan Alzheimer's Association (JAA) in 2016. The group aims to provide support and care for people living with Alzheimer's disease and their caregivers in Jordan. The organisation registered with the Jordanian government in 2018 and has recently signed a contract with Dementia Friends UK. JAA is the first Alzheimer's organisation in Amman and is working towards becoming a full member of Alzheimer's Disease International (ADI). To date, JAA has organised multiple events globally to raise awareness of the disease. From climbing the tallest mountain in Jordan, Wadi Rum, with renowned national climber Mustafa Salameh to recording a hit song with local talent Zain Awad in Arabic titled "You are not alone", JAA has been busy organising events to promote awareness of Alzheimer's in Jordan. More than one hundred people participated in a walk from Crowne Plaza Hotel (6th Circle) to Rainbow Street, organised by JAA for World Alzheimer's month in September 2018, under the patronage of HRH Princess Alia Al Tabaa. This event attracted regional media coverage and provided a widespread platform to promote awareness in the region. JAA has also been representing Jordan globally in conferences from London and Beirut, creating a global network of contacts and strategic partners.

Abstract:

Caring for persons living with dementia

On a personal note, JAA's founder cares for an aunt living with early onset dementia. She was diagnosed with Alzheimer's roughly 10 years ago, at only 50 years of age. It came as a shock to the entire family, as she was a lively character and full of energy. It started by forgetting small things, such as car keys or her mobile phone. Gradually she started repeating the same questions multiple times, only a few minutes apart. Unfortunately, it started affecting her mood, mobility and speech. Current medications can slow down progression of the disease, however, researchers are still searching for a cure. It is important to seek medical attention early on and know that Alzheimer's disease is *not* a natural part of ageing. It's vital that patients are treated with kindness, patience and the utmost care. There are many steps that can be taken to create a more dementia friendly environment in your home and society. That's why JAA has attended official Dementia Friends Champion training in London and will run regular interactive sessions open to the public to educate people on the disease and how to treat those affected by it. Stay tuned by following JAA on Facebook, Instagram and Twitter to find out about upcoming events and how you can support this exciting initiative.

Poster Presentation Abstracts

ID: 185

Abstract Topic: Dementia friendliness

Keywords: Communication, Friendly

Good Chat Challenge!

Iay Iay Pee, Micki Sim, Jue Ann Ng

GoodLife!, Singapore

Abstract:

Good Chat Challenge is part of a movement under Dementia with Dignity (2D), an initiative under GoodLife!@MontfortCare. Good Chat Challenge is taking place on 14 September 2019 and prior to this, a team of us had been going round neighbourhoods in Yishun and Bedok to conduct workshops on better communications for persons living with dementia. A total of 17 workshops, targeting a total audience of 1000 is expected to be completed by 7 September 2019.

On the day of the public event on 14 September 2019, we will be using an interactive skit to highlight the difficulties encountered by the PLD (persons living with dementia) in the community. We will then challenge the audience to use "Good Chat" to help the PLD overcome these difficulties. In addition, our community partners and 2D will also be running game and interactive booths related to dementia care. Senior citizens and persons living with dementia will also be supporting this event through interactive stage performances.

The finale for the event will be to encourage the audience/partners to pledge their support for the persons living with dementia by using "Good Chats" and to have a temporary "tattoo" on their hand. As the tattoo fades from our hand, it symbolizes the fading memory of a person living with dementia, from a clear to a blurry state. It also symbolizes that although the PLD may lose their memory, their personhood can be supported through positive relationships with people around them. It is just like when the tattoo fades from our hand, our identity as a person remains.

We are looking at a crowd of 1000 to pledge their support towards persons living with dementia and their caregivers.

Poster Presentation Abstracts

ID: 186

Abstract Topic: Non-pharmacological interventions

Keywords: person-centred care, care homes, relationships, interactions

Person-centred care: how is it practiced today?

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¹Dementia Centre for Research Collaboration, University of NSW, Australia; ²Centre for Healthy Brain Ageing; ³Centre for Healthcare Resilience and Implementation Science; ⁴Australian Institute of Health Innovation

Abstract:

Background

The predominant care approach for people experiencing dementia-associated symptoms (DAS) in residential care is physically-based. While evidence is growing for relationally-based approaches, they are not the norm (Lawrence et al 2012, Edvardsson et al 2014). Even care approaches professing person-centredness, can neglect that Kitwood's definition of personhood is 'a standing or status that is bestowed on one human being by others, in the context of relationship and well-being' (Kitwood 1997). This study explored meaningful relationships among people experiencing DAS in residential care as a key expression of person-centredness.

Methods

The relationships of 14 residents with DAS while living in five aged care homes in Sydney, with 139 others involved in their care were explored. The Quality of Interactions Schedule (Proudfoot et al 1993) and Emotional Response in Care (Fleming 2005) instruments revealed the type of, and how much relating occurred between participating residents and those caring for them, during observations of their interactions in five-hour segments totalling 210 hours, on different days between 7 am and 10 pm. The person-centred environment and care assessment tool (PCECAT) (Burke et al 2016) explored care home's understanding and implementation of person-centredness through staff allocations, organisational culture, care processes and architectural design. Social Network Analysis assessed resident relationship structures among consenting family and friends, other residents, staff and visiting service personnel.

Results

Of the 210 hours observed, residents engaged in interaction for 38.9 hours (18.5% of the time) and positive interaction for 32.8 hours (15.6%). Of their 2645 interactions in the 210 hours, 1957 (74%) were positive; 1114 (57%) were with other residents or residents' family and friends; the remainder with staff. Of the 32.8 hours, 21.6 hours (66%) were with other residents or residents' family and friends. Results varied across care homes: for the number of interactions, $M = 391$, $SD = 251$; and for the duration (minutes), $M=394$, $SD = 220$.

Care homes' implementation of person-centredness varied. One care home's total score showed they understood and operationalised it (206 of 212). Another mostly reflected it in physical care (161.5 of 212). Person-centredness was less implemented in the other three homes (score range: 128 - 142.5).

Relationship structure measures identified that care home staff connected with other staff and had few, if any connections with residents' family and friends and visiting personnel such as physiotherapists and hairdressers.

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Conclusion

Person-centredness, exemplified in a relation-based approach to care for people experiencing DAS, is not operationalised in most of this study's care homes.

Poster Presentation Abstracts

ID: 187

Abstract Topic: Well being and quality of life

Keywords: Dementia, Group Music Therapy, Well-being, Quality of Life.

My heart time: benefits of group music therapy for elderly with dementia

Dean Neo, Lynn Koh

Apex Harmony Lodge, Singapore

Abstract:

Background and Objectives of Study / Introduction:

There is a lack of local evidence-based practices which examine effects of music therapy on the well-being and engagement of persons with dementia in residential care facilities. This study aims to contribute to the knowledge base in this area and improve the quality of care for elderly persons with dementia in Singapore. The objectives of the study are:

1. To assess the effects such as meaningful engagement of music-based interventions in a group-setting for People with dementia
2. To propose elements for consideration when planning and facilitating music-based programmes in a group-setting for People with dementia

Methods:

Music therapy sessions focusing on cognitive, psychomotor and social-emotional domains, are carried out on a weekly basis for a group of 6-7 female residents with moderate to severe dementia by a trained music therapist. Quantitative data is collected based on presenting levels of engagement before, during and after music therapy sessions.

The measurement tool is the Music Therapy in Dementia Assessment Scale (MiDAS). This tool was chosen as it measures observable engagement within, during and outside music therapy sessions of individuals with moderate or severe dementia (they may not be able to communicate the quality of their musical experience verbally). The scale is completed by both the music therapist and a staff member who provides direct care for the residents with dementia on the same day as the music therapy sessions. The scale measures key areas of impact of music namely: Levels of interest, levels of response, levels of initiation, levels of involvement and levels of enjoyment. A total of 10 sessions of 30 – 40 minutes each will be conducted from the period between July to September 2019. Data will be collected using the MiDAS each week, and collated for analysis at the end of the 10 weeks.

Results / Positive Impact:

Music therapy sessions have been observed to contribute to the well-being and engagement of People with dementia, hence enhancing the quality of person-centred care provided. Through the validation of individuals' identity and abilities within the group setting, aspects of self, such as self-esteem, relationships between residents, and positive perception of self and others, are also targeted and enhanced.

Conclusions / Perspectives:

As Singapore's aging population continues to grow, there is a greater demand for quality person-centred care to be provided. Music therapy services and interventions, which utilises the medium of music within a safe and supportive space, is potentially able to offer and provide a platform for enhanced well-being and engagement in person-centred care.

Poster Presentation Abstracts

ID: 188

Abstract Topic: Other syndromes and dementia – NEW

Keywords: leukoencephalopathy, polyneuropathy, dementia

A case of neuronal intranuclear inclusion disease

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Abstract:

Introduction

Sporadic adult-onset neuronal intranuclear inclusion disease (NIID) is a rare and insidious neurodegenerative disease that commonly presents with cognitive dysfunction. It is pathologically characterised by eosinophilic hyaline intranuclear inclusions, and can be found in the peripheral, central and/or autonomic nervous system as well as organs. Clinical manifestations can vary widely, and NIID is often misdiagnosed or remains undiagnosed.

Case Description

We describe a 70 year old male patient who first presented with recurrent syncopes with falls in his early 60s. Nerve conduction study showed demyelinating polyneuropathy and he was first treated for chronic inflammatory demyelinating polyneuropathy (CIDP). MRI of the brain then showed periventricular leukoencephalopathy. Subsequently he developed resting tremors with mild bradykinesia and depressive symptoms. He was then treated for multiple systems atrophy (MSA) and major depression.

Syncopal episodes continued throughout his 60s with severe orthostatic hypotension with findings of sudomotor and cardiovascular dysautonomia. This was accompanied with slow cognitive decline amounting to dementia towards his late 60s, with symptoms of visual agnosia and REM sleep behaviour disorder. Diagnosis was subsequently revised to Dementia with Lewy Bodies.

His symptoms reached a pinnacle in his 70s when he was hospitalised for encephalitic-like symptoms with upper limb dyskinetic movements. Investigations were negative for an infectious cause. A repeat MRI of the brain showed confluent leukoencephalopathy on fluid attenuated inversion recovery (FLAIR) images and curvilinear high intensity signal change at the corticomedullary junction in bilateral frontoparietal lobes on diffusion-weighted images (DWI) (Fig. 1) consistent with NIID.

Conclusion

Dementia due to NIID is difficult to diagnose due to its insidious nature and multitude manifestations. NIID should be considered as a unifying diagnosis for cognitive symptoms with polyneuropathy and leukoencephalopathy.

Poster Presentation Abstracts

ID: 190

Abstract Topic: Clinical trials – NEW

Keywords: dementia, sectorisation, hospital, discharge management, Germany, Care Management, intervention

Supporting elderly people with cognitive impairment during and after hospital stays with intersectoral care management [intersec-cm]: a randomized controlled trial

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Abstract:

Background: Sectorization of health care systems causes inefficient treatment, especially for elderly people with cognitive impairments. The transition from hospital care to primary care is insufficiently coordinated, and communication between health care providers is often lacking. Consequences include a further deterioration of health, higher rates of hospital readmission, and institutionalization. Models of collaborative care have shown their efficacy in primary care by improving patient-related outcomes. The main goal of this trial is to test the effectiveness of a collaborative care model for people with cognitive impairment (PCI) and current hospital treatment due to a somatic illness to improve the continuity of treatment and care across the transition between the in-hospital and adjoining primary care sectors. We will describe the study protocol and the intervention.

Method: The ongoing trial is a longitudinal multisite randomized controlled trial with two arms (“care as usual” and “intersectoral care management”). Inclusion criteria at the time of hospital admission due to a somatic illness: age 70+, cognitive impairment (Mini Mental State Examination, MMSE \leq 26), live at home, provide written informed consent. Each participant will have a baseline assessment at the hospital and two follow-up assessments at home (three and twelve months after discharge). The estimated sample size is $n=398$ participants together with (where available) their respective informal caregivers.

In the intersectoral care management group, specialized care managers will develop, implement and monitor individualized treatment and care based on comprehensive assessments of the patients and informal caregivers for unmet needs at the hospital and in their homes. Primary outcomes are (1) activities of daily living, (2) readmission to the hospital, and (3) institutionalization. Secondary outcomes include (a) frailty, (b) delirium, (c) quality of life, (d) cognitive status, (e) behavioral and psychological symptoms of dementia, (f) utilization of services, and (g) informal caregiver burden.

We describe first results since recruitment and baseline assessment is planned to end 31st of January 2020.

Discussion In the event of proving efficacy, this trial delivers proof of concept for implementation into routine care. Cost-effectiveness analyses as well as an independent process evaluation increase the likelihood of meeting this goal. The trial allows in-depth analysis of mediating and moderating effects for different health outcomes at the interface between hospital care and primary care. Highlighting treatment and care, the study will provide insights into unmet needs at the time of hospital admission, the opportunities and barriers to meeting those needs during the hospital stay and after discharge.

Ref: Nikelski et al. (in press). *Supporting elderly people with cognitive impairment during and after hospital stays with Intersectoral Care Management [intersec-CM]*. TRIALS

Poster Presentation Abstracts

ID: 191

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: Integrative physical and cognitive activity, Mild cognitive impairment, Chinese version of Mini-Mental State Examination (CMMSE), Kihon Checklist (KCL)

The effect of integrative physical and cognitive activity on older adults with mild cognitive impairment.

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Objectives

Mild cognitive impairment (MCI) is a high-risk group that develops into elderly dementia. Several studies have demonstrated that cognitive and behavioral symptoms can be improved through cognitive and/or physical training. Therefore, the objective of this study is to test the effect of physical and cognitive integration activity intervention on cognitive functions, performance of frailty and performance of Daily Living of older adults with mild cognitive impairment.

Methods

The study used a quasi-experimental design. The research participants were collected from 65 years old and above with MCI from geriatrics clinics or dementia integrated memory clinics in a regional hospital in Taichung, Taiwan. The experimental group entered a well-designed "integrative physical and cognitive activity" that is two hours, twice a week, 12 weeks long program. The control group maintained original daily activities. Chinese version of Mini-Mental State Examination (CMMSE), Kihon Checklist (KCL), Katz ADL and IADL were used to measure the effect of the intervention. Pre and post-testing was performed at the beginning of the study and after 12 weeks. The software SPSS 24.0 is used, descriptive statistics, Chi-square test, independent t-test, paired t-test and generalized estimating equation (GEE) is used to estimate the parameters of a generalized linear model with a possible unknown correlation between outcomes.

Result

A total of 32 older adults with MCI participated in this study, 17 in the experimental group and 15 in the control group. The results of the study demonstrate that the experimental group improved cognitive function (CMMSE) than the control group ($P = 0.001$) (Table 1), especially in memory scores ($P = 0.04$). In the performance of frailty (KCL) section, the experimental group were significantly improved compared with the control group ($P < 0.001$) (Table 2), especially in social ($P = 0.008$) and emotional ($P = 0.001$) scores. In terms of performance of Daily Living, the experimental group were significantly better than the control group in Katz ADL scores ($P = 0.001$), but there is no significant difference between the two groups in the IADL scores.

Conclusion

The results of this study verify that older adults with MCI have significantly improved overall cognitive function, performance of frailty and performance of Daily Living after participating in "integrative physical and cognitive activity". Inferring that this "integrative physical and cognitive activity" can be a supplementary nursing measure outside the treatment of medical drugs. To strengthen the medical care of the whole person, delay the deterioration of cognitive function and reduce the effectiveness of physical weakness. It is suggested that in the future "integrative physical and cognitive activity" can be added to the reference of non-pharmacological interventions for MCI.

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Poster Presentation Abstracts

Keywords: Integrative physical and cognitive activity, Mild cognitive impairment, Chinese version of Mini-Mental State Examination (CMMSE), Kihon Checklist (KCL)

Poster Presentation Abstracts

ID: 192

Abstract Topic: Psychosocial interventions

Keywords: well-being, inter-generational programs, dementia

The impact of an inter-generational program on the well-being of persons with dementia

May Wong, Hsiu Li Tan

St Joseph's Home, Singapore

Abstract:

Background and objectives

This paper features an inter-generational expressive arts program (IGEAP) between residents of a nursing home and children from the childcare centre co-located on the same site. It integrates knowledge and practices from art therapy, early childhood development and dementia care. In 2017, art therapy was introduced for residents with dementia (RWD) to promote motor and cognitive skills as well as engagement in creative expression in a planned and intentional way. This IGEAP however, aims primarily to address the psychosocial and emotional needs of the RWD.

The goal of the IGEAP is to improve the well-being of RWD by promoting inter-generational bonding between them and young children through arts. The intent is to reduce social isolation of RWD and address stigmas and fear of RWD in children. The creative environment provides a common space for the two groups to learn how to nurture each other's capacity to care.

Methods

The IGEAP has three phases over a period of 12 months, with each comprising of eight weekly sessions. The RWD are paired with selected children and they become and stay as 'art pals' for the entire program. In phase one, both child and elderly begin forming a relationship and learn to work as a dyad. In phases two and three, the various dyads come together to learn to work as a group. At each session, a happiness scale is conducted on the RWD pre and post attendance to assess the immediate impact of participating in the IGEAP.

Results

Overall, the ratings of happiness of the RWD after attending the IGEAP sessions were positive. When surveyed, RWD were generally in high spirits after each session. They articulated that they look forward to the next session with their art pal.

Conclusion / Perspectives

Although happiness ratings were positive in this initial IGEAP, it is not a validated assessment to quantify well-being or the psychosocial and emotional state of RWD. While bonding between the dyads was observed to have improved and strengthened as the program moved from phase one to three, more data is needed to ascertain the positive impact of IGEAP on the well-being of the RWD because of relationship building and bonding with the children. Hence, for the next IGEAP, the plan is to use the Well-being Profiling Tool to assess the impact of the program on the psychosocial and emotional state of RWD. Qualitative data will also be collected to support the findings.

Poster Presentation Abstracts

ID: 193

Abstract Topic: Epidemiology

Keywords: Disease progression; Primary Care; Electronic health records; Medical Records;

Can markers of dementia progression be derived from primary care electronic health records?

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Background

Understanding the progression of dementia is central to its management. Whilst there are recognised long-term outcomes, such as care home admission and early mortality, earlier markers of dementia progression are less well understood. Electronic health records (EHR) from primary care provide a potentially rich resource to measure progression. Dementia research using EHR has already produced information on factors that can identify those at risk of dementia onset, but no study has yet examined the feasibility of determining the progression of dementia post-diagnosis in EHR. The aim of this study was to investigate whether a set of credible markers of dementia progression can be identified from routine EHR primary care data.

Methods

An initial rapid literature review of previous studies of dementia in EHR was followed by consensus exercises (including GPs, dementia experts, and primary care EHR researchers) to determine a pool of potential markers of progression of dementia that were considered feasible to be identified in UK primary care EHR.

An EHR database (CiPCA) of consultation records from 9 general practices in North Staffordshire in the UK (annual population >90,000) was used to test the frequency of recording of these markers. Patients with a recorded diagnosis of dementia were compared to age, gender and practice matched (1:1) controls on presence of coded records related to these markers over a twelve-month period.

Results

Sixty-three markers of dementia progression that could feasibly be derived from primary care EHR were identified. These were mapped to eleven domains (including domains related to care, neuropsychiatric symptoms, cognitive function, daily functioning, comorbidity, other symptoms). Two further domains related to changes in medication. There were 2328 individuals identified with dementia in CiPCA. Twelve-month period prevalence of domains ranged from 1% (domain containing markers related to pressures at home) to 69% (comorbidity) in patients with dementia. Eight of the eleven domains had a statistically significant higher prevalence in dementia patients compared with non-dementia patients. One (comorbidity) was higher in non-dementia patients, and two domains (home pressures, diet/nutrition issues) showed no association with dementia.

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Conclusions

This study suggests that primary care EHR are able to capture many of the domains and specific markers that have been identified elsewhere as potentially important measures of progression and outcomes for persons with dementia. The next stage of this research will carry out analysis within a larger UK national primary care EHR dataset to establish longitudinal patterns of progression following a dementia diagnosis. This research has the potential to provide clinically useful information to identify individuals with dementia at risk of more rapid progression and can provide a readily available method that may be useful as an outcome measure in future research.

Poster Presentation Abstracts

ID: 200

Abstract Topic: Environment and architecture for dementia

Keywords: enable, southeast asia, east asia, built environment, design

Characteristics of the built environment for people with dementia in east and southeast Asian nursing homes: a scoping review

Joanna Shuzhen Sun, Richard Fleming

University of Wollongong, Australia

Abstract:

Background:

This scoping review explores the characteristics of the current built environment used to accommodate people with dementia in East and Southeast Asia. It is structured around the eight principles of design found in the Environmental Audit Tool High-Care. In addition, the review examines the level of knowledge and other influences contributing to the development of nursing homes in the region.

Methods:

The review was carried out utilizing the methodological framework recommended by Arksey and O'Malley. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses provided an overarching structural framework for the reporting process and the Population, Intervention, Comparison, Outcomes, and Context framework defined the scope of the review and focused on the research question. Six databases were accessed for the search, and 1,846 publications between 2001 and 2015 were retrieved.

Results:

A total of 48 articles from 9 countries met the inclusion criteria. All articles presented discussions that fundamentally included at least one principle of design and with some including all principles. The most prevailing principle discussed, found in 59% of all the articles was the need for familiarity for residents in the environmental design of facilities.

Conclusions:

The review found that the eight principles of design, when applied with cultural sensitivity in countries in East and Southeast Asia can identify gaps in knowledge of the design for dementia enabling environments and suggest areas for improvement. An assessment tool based on the principles of design will be able to provide a guide for stakeholders in the design, development, or modification of nursing home environments.

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Poster Presentation Abstracts

ID: 201

Abstract Topic: Environment and architecture for dementia

Keywords: enable, knowledge translation, framework, built environment, design

Knowledge translation: a progress report on the culturally sensitive application of a dementia environment audit tool in Asia.

Joanna Shuzhen Sun, Richard Fleming

University of Wollongong, Australia

Abstract:

The provision of dementia-enabling environments for residents with high care needs in nursing homes in Asia has been stifled by the lack of a sustainable knowledge translation framework. Failure to translate knowledge into action is prevalent across the regions resulting in the design of homes that do not support the quality of life and care for residents. Utilising the introduction of an environmental audit tool into Singapore, this report examines the current issues in the design, construction and management of dementia-enabling environments and how the knowledge-to-action framework can provide a solution to them. This report suggests the adoption of a knowledge-to-action framework, consisting of knowledge creation and action cycles. The strengths and limitations of the framework as it applies to the provision of dementia-enabling environments in Asia, including the need to interpret and apply the existing evidence in a culturally sensitive manner is a vital element in the process.

Poster Presentation Abstracts

ID: 204

Abstract Topic: Informal carers training

Keywords: dementia, communication, carers, training, strategies

AID-COM: an innovative communication-focused program for family carers of people with early-stage Alzheimer's disease

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Abstract:

Background and objectives

People with Alzheimer's disease (AD) have a variety of difficulties that affect communication even at the early stage. Such communication difficulties can lead to frustration and/or aggressive behaviours and have devastating impacts on the patient-carer relationship, as well as on their well-being. It is therefore essential to reduce communication problems considering that communication is crucial to maintain relationships and mutual understanding. One way to accomplish such a goal is to teach communication strategies to the carer. However, no current program combines all of the known variables that should be included when designing training for carers (described below). The present work aimed to explore the qualitative and quantitative effects of a communication-based training program "AID-COM", designed for carers of people with early-stage AD.

Methods

5 women carers, aged between 56 and 70 years, of people with early-stage AD participated. Before and after AID-COM, participants completed measures of communication strategy use and perceived efficacy in daily life. They also took part in a focus-group interview following the last session, designed to probe the effects of the program on their perceptions of communication with the person with AD and their evaluation of the program. Thematic analysis was conducted on the transcribed interview.

AID-COM, a small-group 6-week 3-session program, was designed based on available evidence about variables to be included. Communication training included both information and practice components. The information component addressed the language and memory problems typical of early-stage AD, their impact on communication and useful communication strategies to avoid or repair communication failure. The practical component included video clips illustrating communication failure within a daily life scenario and the same daily life scenario illustrating a carer applying communication strategies to prevent, compensate or repair communication failure. Discussion periods followed the presentation of each video clip.

Results

Quantitative descriptive measures showed that every carer reported an increase in the use and perceived effectiveness of communication strategies. The qualitative analysis showed similar findings: participants felt better able to use strategies for composing with a number of difficulties experienced in communication. They were more confident in facilitating communication and overall, they expressed satisfaction with the program, their newly acquired skills, and the relationship with the person who has AD.

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Conclusions and perspectives

Considering the positive results obtained, further work leading to a randomized control trial should be undertaken to measure the efficacy of AID-COM in optimizing carer communication skills and quality of life. Such skills may aid carers in accomplishing positively the complex caring role.

Poster Presentation Abstracts

ID: 206

Abstract Topic: Psychosocial interventions

Keywords: Dementia, Dementia Care Mapping, Community Activities.

My morning venture: benefits of innovative integrated physical, social and cognitive stimulation in-community programme for elderly with dementia

Sathiyaseelan Ganesan, Athmanathan Ramamoorthy, Jing Yi Lim, Melsion See

Apex Harmony Lodge, Singapore

Abstract:

Background

The progressive and irreversible degeneration of brain tissue in older adults with dementia eventually leads to a loss of cognitive and physical functions (Telenius, 2015). People living with dementia manifest cognitive/ behavioural changes and decline of physical functions. (Patterson, 2005). Research has shown that interaction and socialisation encourage a greater sense of inclusiveness and belonging, improve brain health and enhance focus. Regular ambulation in the public space maintains physical and functional mobility of older adults. In short, physical activity with cognitive functions can be beneficial and can enhance the well-being and life of older adults.

Since 2014, Apex Harmony Lodge, a Dementia Residential Care Home, has developed and implemented an initiative, Morning Venture (MV), integrating therapeutic benefits of physical exercise, cognitive stimulation through reminiscence and social benefits of being in the community for its residents. The initiative is part of our Fun and Fit Strand which aims to promote independence and dignity through socialization and normalization outside of the Lodge, in a natural environment, and improvement of health and well-being through outings which entail and enhance physical, cognitive aspects and psychosocial well-being of residents.

Methods

A total of 53 residents participated in 310 MV sessions from 2014-2019. The integrated physical, cognitive stimulation and social engagement programme took place thrice weekly for two hours per session. Each session comprises 0.5 hour of physical activity i.e. walking about 1.3km, 0.5 hour of cognitive activity and one hour of social activity. Each outing involved 10 residents who take public buses using stored valued transit card to travel to a nearby neighbourhood mall. Residents will then take a leisurely walk to the mall and enjoy their morning tea as they engage in light conversation, read newspapers or watch the world go by.

Upon review in 2017, enhanced person-centred care was implemented and Dementia Care Mapping (DCM) used to assess residents' mood, engagement and behavioural category coding. Pre-test DCM was done to gather baseline and post-test DCM after implementation of the improved Person-centred programme over 24 weeks. This presentation will share DCM findings and enhanced person-centred care such as personalisation of food and drinks to residents and provision of newspapers leading to improved well-being of residents. Challenges and recommendations to improve My Morning Venture will be discussed.

Conclusion

Overall, the results showed improved well-being to residents through physical activity which stimulate and maintain functional abilities coupled with leisure and meaningful social engagement which provides a context with personal meaning, a sense of choice and fun. Moreover, it also enables integration, and inclusion of people with dementia in the community.

Poster Presentation Abstracts

ID: 208

Abstract Topic: Cognitive reserve, brain resilience and dementia prevention – NEW

Keywords: cognitive stimulation therapy, dementia, executive function, elderly women, Indonesia

Cognitive stimulation therapy on older women with dementia in Indonesia; the impact on executive function

Virginia Geraldine Hanny Prasetya¹, Magdalena Surjaningsih Halim¹, Widhi Adhiatma¹, Yuda Turana², Tara Puspitarini Sani²

¹Faculty of Psychology, Atma Jaya Catholic University of Indonesia; ²Neurology Department, School of Medicine & Health Sciences, Atma Jaya Catholic University of Indonesia

Abstract:

Background: Cognitive Stimulation Therapy (CST) has been proven to improve some areas in cognitive function on Person with Dementia (PwD) with mild and moderate dementia. The objective of this study is to see if cognitive stimulation therapy has an impact on elderly women with dementia.

Methods: Quasi-experimental method and between-subject design was used in this research. The participants were divided into two groups. Treatment group contain 5 people meanwhile control group contain 4 people. The inclusion criteria of each group were individuals above 60 years in age and diagnosed with mild to moderate dementia. They originated from one of the nursing home in Jakarta, Indonesia. The participants were chosen based on their 3MS, HVLIT, ADL, and IADL screening results, which indicated whether they had dementia. We analyze 3MS and HVLIT scores as the pretest, posttest and follow up data, and at the end of the therapy, we also used FPT score and researcher's observation on participants executive function based on their everyday action as an additional analysis. The observation was made into a checklist form and was derived from Lezak's theoretical model.

Result: There was a significant difference in terms of executive function between treatment group and control group ($p = .002$), nevertheless, the score differs when taken once again at one month after the therapy ($p = .503$). At the same time, there was no significant difference on memory among each group ($p = .286$) until one month after the therapy ends ($p = .710$)

Conclusion: CST appears to have a particular effect on the executive functions of the PwD who attended all the session of CST. It is also clear that the score of the treatment group remain stable even for one month after the therapy ends.

Poster Presentation Abstracts

ID: 209

Abstract Topic: Psychosocial interventions

Keywords: Collaboration, Creative, Inclusion, Storytelling, Drama

Story 2 Remember: a collaborative, cross-European storytelling and creative drama programme for people with dementia

Ben Hicks¹, Danielle Laura Wyman²

¹Bournemouth University, United Kingdom; ²Brighton and Sussex Medical School, United Kingdom

Abstract:

Background and objective: Emerging research has demonstrated the potential for creative psychosocial initiatives to support well-being in people with dementia and their care partners. With funding from ERASMUS+ 2018, a European project team consisting of partners from the UK, Ireland, Romania, Greece and Bulgaria worked in collaboration with people with dementia to develop a storytelling and creative drama programme that aimed to enhance communication within this population, and promote inclusion and a positive sense of identity.

Method: The initiative was informed by a systematic scoping review of the literature, which identified key components that were essential to incorporate into the programme. This was then developed in collaboration with people with dementia, by the Gaiety School of Acting, Dublin. This resulted in *Story 2 Remember*, a programme consisting of six, one-hour workshops designed to support people with dementia to engage in a range of creative activities including story writing, poetry and creative drama.

Results: The programme was trialled across the European countries and was evaluated positively; providing people with a safe space to participate in fun, collaborative activities where they could express themselves both verbally and non-verbally, as well as the opportunity to lead conversations and contribute their opinions as 'experts by experience.' This data has been used to refine the initiative, and this will form part of a free online practitioners' toolkit that will be developed in early 2020.

Conclusions: The research demonstrates the importance of storytelling and creative drama for enhancing wellbeing and identity in people with dementia, and calls for their wider use within the dementia care field. It also emphasises the need to work in collaboration with people with dementia throughout the design, delivery and evaluation of creative initiatives to ensure they remain fit for purpose.

Poster Presentation Abstracts

ID: 211

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: dementia, relationship, couplehood, sexuality, intimacy, inappropriate sexual behaviour

Couplehood in dementia - a review on relationship issues faced by people with dementia and their intimate partners

Intan Sabrina Mohamad^{1,2}

¹Tung Shin Hospital, Malaysia; ²Hospital Rehabilitasi Cheras

Abstract:

Background

People with dementia are often thought as asexual beings with no sexual desires and ability to give consent. Caregivers face challenges in dealing with the burden of role reversal, self-esteem and maintaining relationship satisfaction in a future of uncertainty.

Objective

To review the current literature on relationship issues faced by people with dementia and their intimate partners.

Methods

An online search was conducted using PubMed from 1992 to 2019 using keywords like 'dementia', 'intimacy', 'sexuality', 'behaviour' and 'relationship'. Studies not related to dementia were excluded. General themes were collated and categorized into five sub-themes: i) marital cohesion ii) roles and responsibilities iii) empathy and self-esteem iv) resilience in the face of uncertainty and v) communication and affectional expression

Results

Of the 23 studies identified, 13 studies investigated the relationship, intimacy and sexuality from the perspective of the partner. Only four studies reported the patient's perspective. Changes in roles and responsibilities in caring for a partner with dementia shift the balance of power within the relationship and can impact upon both partners' sense of identity, the couples' efforts to maintain their sense of togetherness. Empathy and sensitive attunement between couples with regards to perceived selfish demands on sexual responses may affect relationship satisfaction and the couples' resilience to deal with uncertainty. Deficits in communication and expression of affection may be perceived as 'inappropriate sexual behaviour' (ISB); prompting unnecessary pharmacotherapy and social isolation. Female caregivers who were less sexually satisfied reported significant higher levels of stress and depressive symptoms than male caregivers. Change in sleeping arrangement and lack of communication around sexual issues contributes to isolation and loneliness in dementia sufferers and their intimate partners.

Conclusions

Dementia affects couples' marital cohesion and relationship satisfaction. Dementia care should include services to support couples in modifying activities, behaviours and expectations in order to reduce burden and enhance couplehood in spite of dementia.

Poster Presentation Abstracts

ID: 212

Abstract Topic: Psychosocial interventions

Keywords: dementia, delusional jealousy, Othello's syndrome, morbid jealousy, psychosis

Delusional jealousy in dementia - a review paper

Intan Sabrina Mohamad^{1,2}, Anandjit Singh³

¹Tung Shin Hospital, Malaysia; ²Hospital Rehabilitasi Cheras; ³Hospital Tuanku Ja'afar

Abstract:

Background

Delusional jealousy (DJ or Othello syndrome) is a psychotic syndrome characterized by a belief in the infidelity of one's spouse that reaches delusional intensity. DJ can occur in dementia and may be a major motive for violence and forensic psychiatry entanglement between intimate partners.

Objective

To review the current literature on the prevalence and characteristics of DJ in people with dementia.

Methods

An online search was conducted using PubMed from 1995 to 2018 using keywords like 'dementia', 'delusional jealousy', 'Othello syndrome', 'morbid jealousy' and 'sexual behaviour'. Studies not related to dementia and DJ were excluded. General themes were collated and categorized into clinical characteristics, anatomy and treatment.

Results

Of the 38 studies identified, seven reported DJ in various types of dementia. DJ was present in 15.8% of dementia patients in a geropsychiatric ward and were more common in Lewy bodies dementia (26.3%) than Alzheimer's Disease (AD) (5.5%). DJ was equally prevailing among both gender, age, age of onset, educational level, Mini-Mental State Examination (MMSE) score or presence of other persons living with the couple. DJ was preceded by the onset of serious physical diseases in nearly half of demented patients. Four studies reported a higher occurrence of DJ in right frontal lobe and amygdala dysfunctions, while three studies suggested the role of amygdala and hippocampus dysfunction for the loss of rational thinking in DJ. There is evidence of dopaminergic and serotonergic hyperactivity in the neuropathological basis of DJ, particularly in the ventromedial prefrontal cortex (vmPFC), amygdala and cingulate gyrus (CG). Treatment options include early recognition, managing underlying neuropsychiatric disorders, psychoeducation, cognitive psychotherapy and choosing an effective psychopharmacological agent, which includes reducing dopamine-agonist dosage. DJ inherits high-risk forensic psychiatry entanglement, which may warrant geographical interventions such as separation between both persons and hospital admission.

Conclusions

DJ in dementia is not uncommon and occur more in right frontal and amygdala dysfunctions. Early detection and treatment may prevent forensic psychiatry implications.

Poster Presentation Abstracts

ID: 213

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, sexuality, intimacy, inappropriate sexual behaviour, nursing home

Sexual behaviours in dementia - a review paper

Intan Sabrina Mohamad^{1,2}

¹Tung Shin Hospital, Malaysia; ²Hospital Rehabilitasi Cheras

Abstract:

Background

Dementia can change expressions of affection in both the persons with dementia and their intimate partner. People with dementia are often thought as asexual beings with no mental capacity to engage in sexual activities. Caregivers face challenges in dealing with the burden of role reversal and sexual behaviours in people with dementia.

Objective

To review the current literature on sexual behaviours in people with dementia.

Methods

An online search was conducted using PubMed from 1992 to 2019 using keywords like 'dementia', 'intimacy', 'sexuality' and 'behaviour'. Studies not related to dementia were excluded. General themes were collated and categorized into four sub-themes: i) hypersexuality ii) hyposexuality/apathy iii) delusional jealousy iv) non-sexual.

Results

Of the 38 studies identified, 23 fulfilled the criteria. Behavior type was associated with dementia severity, sexuality, love and companionship. Sexual behaviours in dementia may present as intimacy-seeking, disinhibition and nonsexual. Increase in sexual demands (hypersexuality) is rare and are seen in cerebellar atrophy or as a consequence of dopaminergic drugs. Apathy or blunted affect is more common in Alzheimer's Disease (AD) and behavioural-variant frontotemporal dementia (bvFTD). Hyposexuality are seen in all types of dementia and correlates with atrophy of the fronto-insular, limbic regions, hypothalamus, middle frontal gyrus and supramarginal gyrus. Delusional jealousy (DJ) or Othello syndrome, have been reported in various types of dementia, especially those with right frontal lobe dysfunction. Non-sexual behaviours may present as day-dreaming and dressing-up. Disinhibited behaviours which are perceived as inappropriate sexual behaviours (ISB) may actually be expressions of affective needs related to changes in cognitive and communication abilities. Female caregivers who were less sexually satisfied reported significant higher levels of stress and depressive symptoms than male caregivers. Staff perceptions and responses to resident's sexual behavior were influenced by their own level of comfort and organizational policies on sexual issues.

Conclusions

Sexual behaviors are associated with dementia severity, communication deficits and unmet sexual needs. Healthcare professionals need to adopt a neutral and non-censorious position when dealing with sexual issues in people with dementia and their intimate partners. Dementia care should include services to support couples in modifying activities, behaviours and expectations in order to reduce burden and enhance couplehood in spite of dementia.

Poster Presentation Abstracts

ID: 217

Abstract Topic: Education and training in hospitals – NEW

Keywords: Dementia, Knowledge, Intermediate Care Facilities, Health Personnel, Singapore

Dementia knowledge in healthcare staff working in community hospitals

Hsu-Chen Andrea Tan

St Luke's Hospital, Singapore

Abstract:

Background and Objectives: As Singapore's population continues to age, community hospitals will play an increasingly important role in providing intermediate step-down care for persons living with dementia. Adequate knowledge of dementia is essential to enable healthcare staff to provide effective and person-centred care. This study aims to assess dementia knowledge and associated factors in healthcare staff working in community hospitals in Singapore.

Methods: Healthcare staff from medical, nursing and allied health departments in 4 community hospitals were invited to participate in an online survey. Level of dementia knowledge was assessed via the validated 25-item Dementia Knowledge Assessment Scale (DKAS) comprising 4 sub-scale content domains. Knowledge levels were compared across demographic categories, professional groups and educational backgrounds. Prior professional or personal experience caring for patients with dementia and exposure to dementia-specific education via traditional or self-directed learning were also evaluated. Staff were asked to self-rate their own level of dementia knowledge and confidence in caring for persons with dementia.

Results: A total of 197 eligible staff participated in the survey. The mean total DKAS score was 35.1 (SD= 8.33) out of a maximum total of 50 points (70.2% correct). Mean sub-scale scores were highest for the domain of "Care Considerations" (10.1 (SD= 2.17) out of a total of 12 points, 84.2% correct) and lowest for the domain of "Communication and Behaviour" (7.6 (SD= 2.92) out of a total of 12 points, 63.5% correct). 24.4% of participants rated their level of dementia knowledge and 28.9% rated their confidence level in caring for patients with dementia as "fairly high" to "very high".

Factors associated with a higher DKAS score included professional group, educational level and prior dementia-specific education.

Conclusions: Dementia-specific education, targeting deficits in specific knowledge domains, may help to improve dementia knowledge in healthcare staff in community hospitals and enhance patient care.

Poster Presentation Abstracts

ID: 223

Abstract Topic: Attitudes, awareness and stigma

Keywords: dementia, dementia friendliness, dementia care, medical education, stigma

Knowledge, friendliness, and willingness of engagement in caring for people living with dementia among the students in a medical university

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Abstract:

Background and purpose: University students in health care fields learn about dementia. However, their friendliness and the engagement in caring people living with dementia may affect their engagement and quality of life in caring for people living with dementia. The purpose of this study was to explore the knowledge, friendliness, and willingness to engage in caring for people living with dementia in among the senior students in a medical university in Taiwan.

Methods: The survey was conducted by self-filled questionnaire in 2019. The sample was from the senior university students in a medical university, consisted of the schools of medicine, nursing, gerontology health management, public health, and healthcare administration. The completed sample was 540 persons, with a completion rate of 73.0%. Demographics, knowledge of dementia, friendliness to people living with dementia, motivation to learn dementia friendliness, and willingness to engage in the job related to people living with dementia in the future were explored.

Results: The average score of dementia knowledge was 13.47 (score 5-16); the willingness score to learn dementia friendliness was 9.24 (score 4-12); and the engagement to dementia care was 20.14 (score 10-25). The students who were in school of medicine, lower grade, and more supportive for social participation for people living with dementia had higher knowledge about dementia. Those students who were females, study in school of gerontology health management, more often searching dementia information, and more supportive in social participation had higher willingness to learn dementia friendliness. Those who were females, study in school of medicine, nursing, or gerontology health management, more supportive social participation for dementia, having more dementia knowledge, and higher willingness in dementia friendliness, were more likely to engage in dementia care in the future.

Conclusion: Better knowledge is not necessarily related to higher friendliness, but both knowledge and friendliness are positively related to the future engagement of university students in dementia care. We suggest dementia friendliness should be included in the education for all health-related departments of universities.

Poster Presentation Abstracts

ID: 224

Abstract Topic: New and future treatments

Keywords: 5XFAD, CRaR, Phagocytosis, Amyloid

C5aR agonist enhances phagocytosis of fibrillar and non-fibrillar $A\beta$ amyloid and preserves memory in a mouse model of Alzheimer's disease

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Abstract:

Background: According to the amyloid hypothesis of Alzheimer's disease (AD) the deposition of prefibrillar and fibrillar $A\beta$ peptide sets off the pathogenic cascades of neuroinflammation and neurodegeneration that lead to synaptic and neuronal loss resulting in cognitive decline. Various approaches to reduce amyloid load by reducing prefibrillar production of the $A\beta$ peptide or enhance amyloid clearance have not proven successful in clinical trials. Complement C1q has been found to modulate disease pathology and in particular neuronal loss in the AD mouse model but its mechanism of action is controversial. C1q has been shown to facilitate phagocytosis but also lead to neuroinflammation and more amyloid deposition. Experiments in AD mouse models show that inhibition of complement component C5a (a terminal product of complement activation) reduces amyloid and alleviates the pathology. Phagocytes including microglia, monocytes and neutrophils carry C5a receptors.

Methods: A widely used mouse model of AD, 5XFAD, was intermittently treated with the oral C5a receptor agonist EP67 and several neuronal and neuroinflammatory markers as well as memory function were assessed.

Results: EP67 treatment enhanced phagocytosis, resulting in a significant reduction of both fibrillar and non-fibrillar $A\beta$, reduced astrocytosis and preserved synaptic and neuronal markers as well as memory function.

Conclusions: Once $A\beta$ plaques form, C1q may facilitate their opsonisation and by activating C3 and C5 enhance their phagocytosis. Thus C1q activation may be a double edge sword. C5a agonists by activating microglia and other phagocytes may be detrimental on a continuous basis due to exacerbating neuroinflammation but in short bursts may be beneficial by reducing both pre-fibrillar and fibrillar $A\beta$.

Poster Presentation Abstracts

ID: 232

Abstract Topic: Young onset dementia

Keywords: young onset, social engagement, clubs

They remind me that I am still me: clubs for people with young onset dementia

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Abstract:

Background: Young onset dementia (YOD) is defined as dementia that is diagnosed before the age of 65. It is estimated that YOD comprises 2-8% of all dementias (World Alzheimer Report, 2015). The personal and social consequences of YOD differ from those experienced by persons with dementia who have been diagnosed later in life. Challenges of YOD can include trouble getting a diagnosis, employment or financial struggles, changing family roles and social isolation, among others. A lack of knowledge about YOD among health and social care providers further contributes to these challenges. Age-appropriate activities can help support people with YOD through these challenges to continue engaging in their communities. Tools and resources are needed to help create and facilitate these kinds of activities.

Method: In 2016, using a literature review, focus groups and an online survey the Alzheimer Society of Canada (ASC) conducted a YOD Gap Analysis where persons with YOD, their caregivers and the healthcare providers who support them identified the gaps in their service needs. One key recommendation was the development of separate support groups and clubs for people with YOD. A Working Group was formed to act on this recommendation comprised of professionals currently facilitating clubs for people with YOD as well as people with lived experience. The group guided the development of a Young Onset Dementia Facilitator's Resource Manual to be used as an informational tool to support organizations in creating clubs for people with YOD in their own communities.

Results: A Young Onset Dementia Facilitator's Resource Manual was developed based on best practices and available research. The manual (available in English and French) provides practical, user-friendly strategies that will assist community organizations in creating, implementing and evaluating clubs for people with YOD and their families. The manual's practical strategies include: tips for assessing needs and what to offer, special considerations for planning and implementing online groups, tips for program planning, tips for program implementation, strategies for success, and self-care tips for facilitators. The manual will be reviewed regularly as new input is received to reflect emerging best practices.

Conclusion: Connecting people with YOD and their families with their peers and providing meaningful activities can help the individual regain a sense of control and lessen social isolation. Identifying the gaps that exist in the services that are available to people with YOD, and creating the tools to address them, are important steps towards supporting people with YOD throughout their dementia journey.

Poster Presentation Abstracts

ID: 234

Abstract Topic: Non-pharmacological interventions

Keywords: 'Safer walking technology', 'dementia'

GPS safer walking technology for people with early-stage dementia, how is it used?

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Abstract:

Introduction

People living with early stage dementia are using different forms of GPS safer walking technology to support or maintain access to outdoor environments. Provision of safer walking technology through state services in the UK is variable and there is a growing commercial market in this field. Although initially developed to track individuals who may become lost, the use of safer walking technology has developed to include enabling a person to independently navigate and locate themselves. This study sought to understand the experience of using safer walking technology, through the lived experience of both people living with dementia and family carers.

Methods

This qualitative study was designed with the support of a stakeholder advisory group that included occupational therapists, people with dementia, family carers and older people with an interest in technology. The group had a central role in the design of the overall research, participant recruitment materials and semi structured interview schedule. Data was collected from 18 in-depth interviews with two groups of people; people living with early stage dementia and family carers of people with dementia. The interviews were analysed using Interpretative Phenomenological Analysis (IPA).

Results

Within this study, family carers were more likely to adopt a purpose built device to track their relative; where as people living with dementia are more likely to use technology to way-find and seek to use existing technology they were familiar with, such as their smartphone. The findings also identified several barriers and enablers to the use of this technology. The reasons behind the difference in technology adopted across the two participants groups were complex, but the original motivations for use, challenges of adopting new technology and ability to combine technologies in a form of 'bricolage' were all contributing factors.

Conclusion

The use of safer walking technology to support access to outdoor environments is growing within the UK. Within this field there has been a shift away from the need to manage risks associated with outdoor spaces and an increased focus on the need to support independence and autonomy. This shift has been driven by both social policy and the needs and wishes of people living with dementia. The current range of safer walking technologies and smartphone apps rarely meet all the needs of people living with dementia, and so people living with dementia and family carers are using this technology in innovative ways to compensate for the lack of suitable technologies to meet their needs.

Poster Presentation Abstracts

ID: 240

Abstract Topic: Models of care

Keywords: integrated dementia team, interdisciplinary, community, value care

Enhancing value for people with dementia through an integrated inter-disciplinary dementia team in partnership with the community

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Abstract:

Background: Under the Yishun Health (YH) Unified Care Model (UCM), residents living with complex and permanent medical conditions will be enrolled into the Relationship-Based Healthcare team (RBHCT) ownership segment to optimize lifelong care outcomes using a “One-Care-Plan” (OCP). Each RBHCT is an interdisciplinary team helmed by a specialist in partnership with community partners to improve value. Integrated Dementia Team (IDT) was designed to center care around people with dementia (PWD) using the RBHCT model. We aim to assess value created by IDT using the RBHCT service model.

Method: Outcomes were measured using the YH Patient Value Compass (PVC), and total costs before government grants was used as the surrogate costs-of-delivering-outcomes. YH Optimal Care Index (OCI), or value, was derived by dividing the PVC score by costs.

Results: 362 PWD out of approximately 800 enrolled were evaluated. PVC outcomes were: 1) Clinical and Functional: a) 65.1% improved in behavioral symptoms (Revised Memory & Behavior Problems Checklist); b) 66.0% improved in quality of life (EQ5D); c) 81.0% had decreased caregiver burden (Zarit Burden Interview); 2) Experience: a) 95.7% rated ‘good’ and ‘excellent’ in the Client Satisfaction Questionnaire (CSQ); b) Patient Satisfaction Survey score was 95.2%. 3) Cost-to-Patient: Out-of-pocket costs for 2018 averaged \$488; 4) Cost-of-Delivering-Outcome: Cost of IDT averaged \$820.

Key cost drivers were a) clinic-based consults, b) laboratory investigations, c) dementia programmes and interventions; 5) OCI was +113.1/\$1,000.

Conclusion: PWD with multiple medical and social care needs benefit from an integrated interdisciplinary care approach involving the hospital team in partnership with community providers. Use of YH Value Driven Care methodologies has evidenced value in care of PWD with IDT’s RBHCT approach. Continuous trending of value can help the IDT systematically track progress and identify gaps to consistently secure value for patients.

Poster Presentation Abstracts

ID: 242

Abstract Topic: Dementia policies and public policy

Keywords: national dementia service delivery system, national health insurance service, public health and social care, long-term care insurance, South Korea

Overview of the Korean national dementia management delivery system

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Abstract:

In South Korea (hereafter, Korea), the number of people with dementia (PWD) is 0.75 million in 2018, will double every 17 years, and will reach 3 million in 2050.

Korean government has established the National Dementia Service Delivery System (DSDS) to cope with this dementia epidemic effectively and efficiently without regional disparity across the country. The National Health Insurance Service (NHIS), National Long-Term Care Insurance (LTCI) Service, Public Health and Social Care (PHSC) are the three major service providers in the DSDS. NHIS ensures access to high quality health care services with universal coverage through the mandatory participation of healthcare institutions and cost sharing since 1989. Especially, cost-sharing rate for 'the advanced dementia' which is one of the diseases eligible for 'relieved Co-payment Policy on for the serious and the rare diseases' is reduced from 20%~60% to 10% of the total costs. LTCI was introduced in 2008 cope with the rapid population aging and the health security of low-income old people. Since 2017, PWD, regardless of the type and severity of dementia, became eligible for the LTCI. Its cost-sharing rate by service users is 20% for institutional services and 15% for home-based services and there is a 50% subsidy of copayment to the low-income group and zero copayment for beneficiaries of the medical aid program. In PHSC, a community-based dementia management services (CDMS) for PWD is provided through the central, metropolitan/provincial, and local governments based on the Dementia Management Act and the National Dementia Plan. To provide CDMS to Korean people without regional disparity, the National Institute of Dementia (NID) was established as the headquarter of CDMS in May 2012, 17 Metropolitan or Provincial Dementia Centers (MDC/PDC) were established in all provinces and metropolitan cities between 2013 and 2015 as the regional education and support centers for Local Dementia Centers (LDC) , and 256 LDC were established in all local public health centers around country between 2017 and 2019 as the end-service organizations. LDC provide Korean people with counseling/registration/case management, early diagnosis, daycare, family support, and awareness campaigns in their respective districts.

The Korean DSDS may help Korean people live without discomfort even if they have dementia and be free from the risk of dementia, and Korean society become dementia-friendly.

Poster Presentation Abstracts

ID: 245

Abstract Topic: Risk factors

Keywords: Motoric Cognitive Risk Syndrome, Personality, Pre-dementia, Big Five Inventory

The effect of personality traits on risk of motoric cognitive risk syndrome.

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Abstract:

Background and objectives of the study: Personality traits have been shown to be associated with risk of cognitive decline and dementia with effects similar to those of certain behavioral risk factors such as physical inactivity. The present study aimed to examine the association between personality traits and risk of a pre-dementia syndrome called Motoric Cognitive Risk syndrome (MCR). MCR is characterized by the presence of cognitive complaints and slow gait and is common in older adults with a global prevalence of 9.1%. MCR was associated with a 2-fold increased risk of developing incident cognitive impairment, and was shown to be predictive of both Alzheimer's Disease and vascular dementia.

Methods: We examined the association between personality traits and risk of developing MCR in 539 older adults without dementia enrolled in the Central Control of Mobility in Aging Study. Personality traits were defined using the Big Five Inventory (BFI), a self-report measure designed to assess five aspects of personality: neuroticism, extraversion, conscientiousness, agreeableness, and openness. Cox proportional-hazard analysis was used to evaluate the risk of MCR based on baseline personality traits adjusted for age, sex, education and comorbidities.

Results: Of the 539 non-demented participants in the baseline sample, 39 (7.2%) had prevalent MCR. Those with MCR had fewer years of education (13.3 vs 14.7, $p=0.005$), and had lower scores for personality traits of extraversion (25.0 vs. 27.8, $p=0.006$), conscientiousness (35.9 vs. 37.8, $p=0.035$) and openness (35.3 vs. 38.0, $p=0.015$). After excluding participants with prevalent MCR ($n=39$), 38 participants developed MCR over a median follow-up of 2.5 years. Of the five personality traits examined only openness was associated with reduced risk of MCR (adjusted Hazard Ratio: 0.94, 95% Confidence Interval: 0.89-0.99).

Conclusions: Openness is associated reduced risk of MCR, and may provide evidence for a protective strategy in reducing risk of dementia. Results from this study are consistent with previous studies that have shown that individuals who score higher in personality traits of openness perform better cognitively and are at a reduced risk for dementia. This may be attributed to a higher level of education that more open individuals tend to have as well as to an increased engagement in cognitive, social, and physically stimulating activities in older age and throughout their lifetime.

Poster Presentation Abstracts

ID: 246

Abstract Topic: Informal carers support – pre, during and post

Keywords: dementia, caregiver, grief, determinants

Contrasting the various dimensions of loss and grief in dementia caregivers: multivariate analysis

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Abstract:

Background:

The experience of grief and loss in family caregivers, as they provide care for persons with dementia (PWDs), is not well understood. The Marwit-Meuser Caregiver Grief Inventory (MM-CGI) is one of few scales that capture caregivers' grief experiences. Liew et al identified three dimensions of grief in MM-CGI- Personal Sacrifice Burden (PSB), Heartfelt Sadness, Longing and Worry (HSLW), and Felt Isolation (FI). We evaluated the determinants of each dimension and summarized them in a framework to better guide caregiver grief support.

Methods:

Family caregivers (n=394) completed self-administered questionnaires comprising caregiver and PWD demographics, MM-CGI, caregiver burden, depression and gain scales. Determinants of each MM-CGI dimension were identified using multivariate linear regression analyses.

Results:

Each dimension of MM-CGI exhibited distinct determinants—PSB was significantly associated with primary caregiving role ($p<0.001$), HSLW with lower education ($p<0.001$), and FI with caregivers who were not married ($p<0.05$). Other determinants shared between ≥ 2 subscales included: age of PWD, spousal relationship, severe stage of dementia and presence of behavioural problems.

Conclusions:

The different determinants support the three distinct dimensions of grief identified in the MM-CGI subscales. Based on our prior work, extant literature and clinical experience, these determinants are postulated to contribute to four relevant concepts: caregiver burden (associated with high PSB), loss of emotional closeness (high HSLW), coping strategies (high HSLW) and lack of social support (high FI). Using this framework, possible directions for caregiver grief support include reducing caregiver burden, initiating discussions on loss of closeness, providing training on better coping strategies and building social support.

Poster Presentation Abstracts

ID: 250

Abstract Topic: Consumer empowerment

Keywords: research, recruitment, evaluation, dementia, participation

An evaluation of the Alzheimer society of Canada resource guide to support research recruitment

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Abstract:

Background: In 2016, the Alzheimer Society of Canada along with Federation Partners led the development of a Resource Guide for ethical recruitment of research volunteers within the client population. In late 2017, a qualitative, retrospective outcome evaluation was undertaken of the Resource Guide. The Resource Guide was produced to serve a catalyst for discussion and self-directed action toward organizational change and cultivation of a positive research culture through the provision of evidence-informed and practical solutions to help organizations achieve this goal.

Method: A qualitative, retrospective outcome evaluation was undertaken to answer the following questions:

1. *What practice changes were put in place to support research recruitment, following review of the Guide?*
2. *What features of the Guide, and / or supports provided during the review and feedback process contributed to practice changes to support research recruitment?*
3. *If other factors influenced practice changes to support research recruitment?*

An evaluation framework that aligned with these questions, with anticipated outcomes across the level of clients, the staff, and researcher involved in the development of the Resource Guide was used to organize data collection and analysis. Semi-structured telephone interviews were conducted. Content analysis was carried out on the open-ended data and using a directed approach, analysis began with the anticipated outcomes outlined in the evaluation framework. Frequencies and per cents were calculated for quantitative data.

Result: Overall, the findings demonstrate a strong positive trend with several Federation Partners implementing practice changes to support research recruitment as a result of participating in the Guide developmental process. Many Federation Partners put in place new or updated practices that aligned with the anticipated outcomes of the Guide.

Conclusion: Federation Partners shared ways that ASC could continue to build their capacity to support research engagement. Notably, these findings align with key findings from consultation activities including feedback from people living with dementia and their care partners, dementia researchers and physicians and include placing a greater emphasis on sharing research funding and recruitment opportunities with the public.

Poster Presentation Abstracts

ID: 254

Abstract Topic: Dementia friendliness

Keywords: dementia-friendly community, healthy city, dementia friendliness, age-friendly community

Awareness of dementia friendly community is associated with quality of life among the older adults: a case from Xinyi district of Taipei, Taiwan

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Abstract:

Background and purpose: Dementia-friendly community has been raised as an important issue in building an age-friendly and healthy city. The purpose of this study was to assess the older citizens' attitudes of the Safe, Healthy, and Age-Friendly Community program (SHAFC), including dementia-friendly community component, in Xinyi District of Taipei and the association with quality of life and health outcomes.

Methods: The participants were the older citizens (aged 65 or above) recruited from the 41 neighborhoods of the Xinyi District, Taipei. A face-to-face survey was conducted in July 2019. In total 328 older citizens participated in the survey. The participants were asked to rate the ten dimensions of the SHAFC, i.e., dementia-friendly community, no barrier space, transportation safety, home safety, age-friendly community, social inclusion, social participation, administration support, health services, and smart city. The internal consistency within 10 dimensions ranged from 0.738 to 0.935. Demographics, health status and quality of life were also examined. Descriptive analysis and linear regression models were conducted.

Results: Among the 9 items of dementia-friendly community, the average score for each item was 3.83 (score 1-5), indicating a median high score in rating dementia-friendly community in the Xinyi District. The participants who had better self-rated health, less depressive symptoms and less lonely were more likely to rate a higher dementia friendliness in the community. Reporting a higher quality of life was related to better self-rated health, less loneliness, and better rating in dementia friendly communities by the linear regression model.

Discussion: Dementia friendly community is related to quality of life. Building up a dementia-friendly community is especially important for the frail older adults and people living with dementia. Health education for the public and intervention for building a dementia-friendly community are suggested for the policymakers.

Poster Presentation Abstracts

ID: 265

Abstract Topic: Implementation of risk reduction interventions (Local, regional and national levels)

Keywords: cognitive enhancers, all-cause mortality, cardiovascular mortality, ischemic stroke

The impact of cognitive enhancers (CE) on survival in persons with dementia (PWDs)

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Abstract:

Background

CE, comprising AChEIs and Memantine, are evidenced to attenuate cognitive and functional decline in PWDs. However, its effects on survival are uncertain. We sought to determine if a survival benefit could be seen in PWD on CE over time.

Methods

PWDs (n=2, 686) presenting to a tertiary hospital's geriatric clinic over 7 years (January 2010 - August 2017) were analyzed. PWDs on ≥ 2 years of AChEIs or Memantine or a combination of both were compared against those with 0 to < 2 years of CE. Univariate analyses examined the impact of CE on all-cause mortality. Thereafter, Cox proportional hazards model accounted for potential interaction(s) with other clinically relevant covariates (ie. dementia type and severity, co-prescriptions, etc). Competing risk regression models further examined the effects of CE on cardiovascular mortality and ischemic stroke.

Results

On univariate analyses, AChEIs users (HR:0.38, 95% CI 0.29-0.50) and combination users (HR:0.31, 95% CI 0.18-0.52) saw a protective effect on all-cause mortality. In the Cox proportional hazards model, AChEIs remained a significant predictor of all-cause mortality but not Memantine or combination users. Competing risk analyses revealed AChEIs users to have a protective effect specifically on cardiovascular mortality (HR:0.60, 95% CI 0.37-0.98) and ischemic stroke (HR:0.39, 95% CI 0.19-0.80).

Conclusion

PWDs on CE appear to have a lower risk of all-cause mortality than non-users. Sub-group analyses suggest that this is contributed by reductions in cardiovascular mortality and ischemic stroke. This study adds to a mere handful of recent publications demonstrating survival benefits of CE and is a first in an Asian population.

Poster Presentation Abstracts

ID: 266

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: rehabilitation, care strategies, younger-onset dementia

Rehabilitation and care strategies for people with younger onset dementia in rural area of Taiwan

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Abstract:

The Yunlin Long-term Elderly Care Association (Known as the Little Sun), a community based association, started in 2000 in the central part of Taiwan. Yunlin is the 2nd highest ageing county with 18% index. The Little Sun had developed services including home service, meal delivery, 3 day care centers and a group home to meet the needs of people with dementia in this agricultural area. There has been a long-term care demand for people with younger onset dementia in the past years. However, this target group is not included within the social welfare policy until 2017.

This article will discuss care approaches that team members had managed to three young persons with Vascular and Frontotemporal dementia, Alzheimer's disease, and Vascular dementia respectively. Individual care plan is conducted by the collection of cultural background, life story interview, remaining and potential capability, causes of confusion and fear, reasons for BPSD. Focuses on physical as well as cognitive rehabilitation, interaction and support have been applied.

Due to care needs and challenges of people with younger onset and elderly onset are quite different, we will also share caregiver's awareness, education and empowerment in this rural area. The care strategies increase self-confidence of people with younger onset dementia, improve their family relationship and live more closely in the community they are familiar with.

Poster Presentation Abstracts

ID: 267

Abstract Topic: Diagnostic tools

Keywords: Inhibition, distractor, Alzheimer's, cross-cultural, ageing

A target-distractor inhibition effect is preserved in healthy ageing, Alzheimer's disease and across ethnicity.

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Abstract:

Eye-tracking has the potential for use as a diagnostic tool for cognitive impairment in Alzheimer's disease. It is important that potential diagnostic tools are applicable across various age, ethnicity/cultural and clinical groups. The WEIRD (western, educated, industrialised, rich and democratic) problem describes a participant sample often used, creating issues for replicability, generalisability and interpretive power. It is vital that we take seriously the challenge of incorporating diverse ethnic, clinical and non-clinical age groups in all areas of research. The current study investigated the use of the Recent distractor task as a diagnostic marker for cognitive impairment and its generalisability. The Recent Distractor Effect (RDE) refers to an inhibitory spatial effect that is characterised by the slowing in the reaction times to a target, that is presented at the location of a previous distractor (Crawford et al, 2005). The task involves two display screens; the first screen presents a red target and a distractor in a different colour. In the second screen, a single red target is presented at one of three possible locations: the location of the previous target, the previous distractor or at a new location. The study investigated the RDE with wider population samples such as healthy young (N=75) and healthy older western adults (N=119), healthy south Asian participants (N=83), Alzheimer's disease participants (N=65) and participants with Mild cognitive impairment (N=91). The results showed that AD participants made more error saccades towards the distractor, however, all participants displayed the RDE and were significantly slower on target to distractor trials compared to target to target trials. Thus, the inhibition of a visual distractor was preserved in participants with AD and was also preserved across these cultural groups and age cohorts. This RDE effect is apparently stable across cultures and age groups.

Poster Presentation Abstracts

ID: 269

Abstract Topic: Fundraising for dementia – NEW

Keywords: fundraising, self-advocacy, inclusion, Article 19, CRPD

Fundraising from the perspective of a person with dementia

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Dementia Alliance International, Canada

Abstract:

This presentation will highlight the frustrations felt by people with dementia, who struggle to find funding to attend events and conferences such as ADI2020. As a person living with younger onset dementia, watching the many advocacy organizations use people with dementia to support their own fund raising under the guise it is to support us, and provide more services for us, but who are rarely willing to share it to ensure we have the opportunity of full and equal inclusion at events leaves us with deep frustration, as well as without the equal opportunity of full inclusion, which is provided to the staffs of advocacy organisations. Fund raising is hard work, and money is now a scarce commodity. It seems philanthropy is also limited, and too few professionals actively donate to DAI, even to attend a Webinar. To help those living with dementia and their families, they fund raise to the point that when I want to fundraise to gather enough funds to attend an event like this or the one in 2018 in Chicago, I can't raise the funds because everyone has given to all the big Alzheimer's organizations. They suggest I get them to fund me, to which I must reply they can't or won't because the money they raise is for them. But wait ... isn't it about helping improve the lives of those living with Dementia... this is all in contradiction of itself. Every Organization and every researcher, and scientist, only have their jobs because of us. They all need us, yet they rarely support us with our own fundraising, or inclusion. It so difficult to get organizations to collectively look at how they can help organizations like Dementia Alliance International, by providing funds that allow us to do more, to help you all do what you do best. Sometimes we over analyze things and in the case of fundraising those that do it well should be the ones doing it, but those funds should and must be used in a way that is more in line with what they fundraise under, that being it's to people with living with dementia. So let's begin by stripping away the policies and procedures let's look at who is providing what services, let's help ensure the funds raised are distributed in a way that there is a direct impact on those living with dementia.

Poster Presentation Abstracts

ID: 273

Abstract Topic: Diagnostic tools

Keywords: Dementia, mild cognitive impairment, modified Chinese Mini-Mental Status Examination, Clinical Dementia Rating Scale

Modified Chinese mini-mental status examination (mCMMSE): cohort effect in cut-off scores and diagnostic performance as a cognitive screening tool

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Abstract:

Background:

The 28-item modified Chinese Mini-Mental Status Examination (mCMMSE) was validated in Singapore as a cognitive screening tool for dementia in 2000. It is unclear if the age-education adjusted optimal cut-off scores then are still applicable. This study aims to determine updated mCMMSE cut-off scores and its discriminatory ability across mild cognitive impairment (MCI) and different dementia severity.

Methods:

We studied 174 controls (community-dwelling older adults with intact cognition) and 590 outpatients who attended a memory clinic between 2011 to 2013. Clinical Dementia Rating (CDR) scale was used to rate the severity of cognitive impairment. We performed Receiver-Operating Characteristic (ROC) analysis to determine optimal mCMMSE cut-off scores adjusted for age (≤ 74 vs ≥ 75 years) and education (≤ 6 vs > 6 years), and compared area under the curve (AUC) for MCI, mild (CDR 0.5-1) dementia and moderate (CDR 2) dementia.

Results:

Our outpatient sample comprised 26 (4.41%) MCI, 380 (64.40%) mild dementia, and 184 (31.19%) moderate dementia. Higher cut-off scores were noted in each age-by-education subgroups for dementia diagnosis compared to the earlier validation study. The optimal cut-off scores are ≤ 26 (AUC:0.839), ≤ 23 (AUC:0.964), and ≤ 20 (AUC:0.998) for MCI, mild and moderate dementia respectively. Diagnostic performance was better for mild and moderate dementia compared with MCI ($p=0.002$ and <0.001 respectively).

Conclusion:

The higher mCMMSE cut-off scores in this study supports a cohort effect due to higher educational attainment and other population-specific characteristics over time. The good discriminatory ability of mCMMSE (albeit better for dementia compared with MCI) supports its continued use as a cognitive screening tool.

Poster Presentation Abstracts

ID: 275

Abstract Topic: Well being and quality of life

Keywords: Montessori, dementia management

The Montessori method in dementia management

Luca Croci

iSenior, Italy

Abstract:

The Montessori method, an educational system traditionally aimed at children, seems to be a valid non-pharmacological therapy for dementia in the elderly, where dementia means the degradation of cognitive, memory, behavioural and communicative functions and the consequent loss of autonomy.

Montessori pedagogy is based on respect for individual peculiarities and learning rhythms, on self-construction, encouragement of independence and the elimination of negative evaluations. The child evolves in an adequate, structured, orderly and welcoming environment in which simple pedagogical material is used, suitable for providing clear feedback on errors and the possibility of self-correction. Manipulation, concentration and freedom to choose which activity to perform, whether to perform it and how many times to repeats it is encouraged.

The adaptation of the Montessori method to dementia excludes the notion of infantilisation of the elderly, but highlights the peculiarity of being able to draw on the skills acquired over the course of a lifetime to carry out the activities proposed.

To support autonomy and improve the quality of life of the patient with dementia, the Montessori method tends to reinforce residual abilities such as the emotional brain and procedural memory, rather than recovering the cognitive skills lost such as explicit memory.

Structured environments are defined with material suitable for carrying out activities which take into account the specific interests of the patient and show a strong connection with the everyday. Complex activities are broken down into simple activities, distinct in sensory, motor (important when the verbal function is compromised), cognitive and social (suitable for early stages of dementia).

We follow a horizontal progression through the repetition of the activity or the possibility to choose different activities centred on the same competence, or a vertical progression through activities which go from the simple to the complex and from the concrete to the abstract, minimising failure, favouring self-correction and enhancing the positive result.

The role of the educator, here the caregiver or the family member, is to act as a facilitator and opportunity builder, able to redesign and optimise the activity on the basis of a careful observation of the elderly person's skills.

Clinical assessments unanimously indicate that this approach, introduced in Italy around 2013/2014, strengthens self-esteem, motivation and concentration, while reducing wandering, frustration and aggression.

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The positive impact of the Montessori method involves not only the autonomy of the elderly, but also the emotional sphere, ultimately improving the quality of their social and family relationships and successfully supporting the pharmacological approach of dementia and related diseases.

Poster Presentation Abstracts

ID: 277

Abstract Topic: Attitudes, awareness and stigma

Keywords: People with dementia, information, awareness, inclusion, webradio

"Radio Alzheimer!" a new information channel for people with dementia, their caregivers and the general public

Joël Jaouen

France Alzheimer and related diseases, France

From the very start 34 years ago, France Alzheimer has made the dissemination of information one of its 4 core missions. To honor it, the Association has engaged in multiple endeavors.

It is indeed crucial to inform and educate patients and their caregivers on all the issues they face. Many families are looking for knowledge about the illness and its consequences, available financial aid, daily help, in particular for working family members...

In order to bring direct and interactive support, France Alzheimer has recently chosen to launch **Radio Alzheimer!** To this day, it is the only Internet radio in France fully dedicated to the topic of Alzheimer's and related diseases.

There are multiple issues at stake:

- to inform the listeners about the illness, its evolution and care methods,
- to give practical advice and to share knowledge from experts (neurologists, psychologists, nutritionists, occupational therapists, researchers) by means of a broad variety of programs addressing various topics,
- to win over the public opinion battle by lifting stigma and discriminations endured by patients and their caregivers.

The radio also helps raise awareness by giving a voice to those who are primarily concerned: people with dementia and their caregivers.

Radio Alzheimer is not only a great way to spread information, it is also a place for debate and dialogue. It is an interactive tool thanks to the "Comments" section of the radio which enables listeners to share their point of view, questions, rants and experiences.

Since March 2018, two shows have been set up and air on a regular basis:

1. A weekly segment titled "**5 minutes to understand**" during which an expert is interviewed to help decipher and explain a precise topic, with the intention of educating the audience in a simple and practical manner.
2. A live bimonthly show "Your questions, our answers": several experts speak and answer audience questions on a specific and current topic.

Poster Presentation Abstracts

ID: 279

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: People with dementia, information, support, living with the disease, resources, post diagnostic

Living with Alzheimer's or a related disease

Joël Jaouen

France Alzheimer and related diseases, France

Abstract:

On the early spring of 2018, France Alzheimer and related diseases launched a program dedicated only to people with dementia. With this program, the French organization wishes to provide new answers to those recently diagnosed.

One of the main objectives of this program is to improve the quality of life for people with dementia and their caregivers and especially to enable the newly diagnosed person to be proactive in dealing with what they are going through by helping them to process the situation. During these sessions, the people with dementia are invited to mobilize their own resources to enable them to adapt their daily lives to the new situation.

Furthermore, the pilot of the program suggests them to share their experience and needs within the group in order to find appropriate answers, strategies and compromises to maintain family, friend and social relationships.

France Alzheimer's and related diseases identified 3 main admission criteria to the program for the future beneficiaries. First of all, the diagnosis must have been made and announced. Then, essentially, the person concerned is interested in the program, wishes to participate and expresses a will to share her experience within a group.

This program, in which the caregiver may not participate, is threefold:

- **a personalized group information session** to identify the needs and define priorities for people with dementia.

- **several group workshops** lasting 2 hours each :

- Workshop 1 : Share my experience and knowledge of the disease
- Workshop 2 : Emphasize my skills and share my solutions
- Workshop 3 : Identify my available tools to help in my daily life
- Workshop 4 : My family and social environment, and me
- Workshop 5 : Managing my stress
- Workshop 6 : What are my wishes?

- **a final individual overview** led by the workshop moderator who will be able to assess the impact of the program on the quality of life of the person concerned and her surroundings.

The evaluations carried out after the first experienced programs have shown a high level of satisfaction among the beneficiaries. They mention in particular a less frequent feeling of isolation and a higher self-esteem, benefits from supporting each other and sharing strategies and a resumption of activities along with a feeling of success.

Poster Presentation Abstracts

ID: 281

Abstract Topic: New and future treatments

Keywords: Pannexin 1, Alzheimer's disease, amyloid- β peptide, synaptic plasticity, probenecid

Chronic pannexin 1 blockade improves cognitive performance of app/ps1 mice model.

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⁴Centro Interdisciplinario de Neurociencias de Valparaíso, Universidad de Valparaíso; ⁵Centro Interdisciplinario de Estudios en Salud, Universidad de Valparaíso

Abstract:

Alzheimer's disease (AD) is a chronic, progressive and irreversible neurodegenerative disease with clinical features of memory loss, dementia and cognitive impairment. It has been shown that one of the earliest events in AD is synaptic loss induced by soluble oligomeric forms of the amyloid β peptide (sA β os) that is thought to be the major cause of the cognitive deficits. Pannexin 1 (Panx1), a membrane protein implicated in cell communication and intracellular signalling, modulate the induction of excitatory synaptic plasticity under physiological contexts and contribute to neuronal death under inflammatory conditions. Probenecid is an FDA approved drug used for gout treatment, a chronic inflammatory condition of the joints by accumulation of uric acid and also is a Panx1 blocker. Previously in our lab, we have seen improvements in synaptic plasticity, some biochemical markers, and histopathological markers of the AD with acute (1 hour) blockade of 100mM of Probenecid (PBN) in 6 months old APP/PS1 mice. In order to find a time window in which probenecid treatment is most effective, we evaluate chronic treatment in 12 and 18 mo. APP/PS1 mice. We assessed a battery of behavior paradigms, before and after treatment, synaptic plasticity, histopathological markers of the disease and morphological changes of dendritic arborization. Interestingly, we found that PBN improves spatial memory of 12 and 18 mo. APP/PS1 mice using the Morris Water Maze paradigm, also lead to basal levels two different mechanisms of synaptic plasticity, long term potentiation (LTP) and long term depression (LTD) at both ages, does not affect the number of amyloid β -plaques at 18 mo., but we see a change in the number of reactive astrocytes at this age, and we saw Panx1 expression in reactive astrocytes surrounding amyloid plaques. Surprisingly, we also observed that PBN treatment increased dendritic morphology in both WT and APP/PS1 mice, suggesting that acting cytoskeleton dependent changes in neuronal morphology can be involved in dendritic remodeling induced by PBN treatment. Our results suggest that Panx1 blockade with PBN could interfere with toxic signaling induced by soluble oligomers of the amyloid- β -peptide and support Panx1 as a potential AD therapeutic target and suggest PBN as a promising treatment to ameliorate synaptic defects of the disease.

Poster Presentation Abstracts

ID: 282

Abstract Topic: Non-pharmacological interventions

Keywords: Non-pharmacological interventions, active aging approach, cognition and emotions, Nuns

“Aging actively care of cognition and emotions in a group of religious people of the sacred Corazon de Jesus community (RSCJ) cali Colombia” (RSCJ)

Jacqueline Arabia, Angela Maria Caicedo

FUNDACION ALZHEIMER, Colombia

Abstract:

Abstract topics: Dementia research and innovation, Non-pharmacological intervention

Introduccion: The Alzheimer's Foundation of Cali Colombia is a non-profit institution whose mission is to improve the health and quality of life of people, through humanized and specialized care that prevention, diagnosis, treatment and care activities the affected person and their family and / or caregiver.

A non-pharmacological intervention program was designed with an active aging approach for the religious community of the sisters of the Sacred Heart of Jesus (RSCJ) oriented to the care of cognition and emotions.

Objective: The purpose of this study was to evaluate the effectiveness of a non-pharmacological intervention program with emphasis on cognition and emotions to improve the mental health of a group from RSCJ.

Method: The sample consists of a group of religious from the RSCJ with a long-lived population whose average age 85 years, with a work of life trajectory framed in educational work in vulnerable territories. It was administered pre y pots test Instruments such as the Montreal Cognitive Assessment(MOCA), Geriatric Depression Scale (Yesavage), Blessed s Dementia Scale(BDS), general health and quality of life questionnaire among others were applied.

It was found that 40% presented moderate and severe cognitive impairment, 33% of nuns reported having depressive symptoms.. Functions of language and biographical memory were the domains with the best positive results since most retain these functions of comprehension, denomination, writing, reading and verbal fluency. The perspective of the life cycle allowed recall childhood and family life events stimulating cognitive processes, learning from the constructive expression of emotions, strengthening community ties, in the musical activity it was easy to remember and concentrate with experiences and emotions that have the possibility of remembering significant and negative situations in your personal history through musical memory, in body and dance expression their responded is natural despite the fact that they are activities that have never been experienced, it stands out that despite its limitations.

Conclusions

The program improve the quality of life of the of participants, there was an improvement in cognitive performance, in the participants with a diagnosis of dementia, the reactivation of mental functions were observed. In the emotional component there was an increase in self-esteem, reinforcement of the links between the participants, and expression of emotions that impacted the community's social dynamics.

Prospects

The provincial management team of the RSCJ community, it is planned to replicate the intervention in others regions. The program will be adapted to other religious communities, including the masculine ones, applying the gender perspective.

Jacqueline Arabia BurayeJaquibu@hotmail.com (*)[1]

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Poster Presentation Abstracts

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Poster Presentation Abstracts

ID: 283

Abstract Topic: Informal carers support – pre, during and post

Keywords: GPS tracker, Families of people with dementia

The experience and effect of GPS tracker for the people with dementia

JeongLan Kim, Jaehwa Chung, KyuJoon Kwon

Sejong Special Self-Governing city Dementia center, Korea, Korea, Republic of (South Korea)

Abstract:

Background and objectives of the study

The purpose of this study is to collect the data on the prevention of missing of the people with dementia in Sejong City, and to analyze the experiences of GPS tracker users and effects of GPS tracker.

Methods

The study was conducted from April to November 2018 using the telephone survey, focus group interview and individual interview method based on the experiences of people using the GPS tracker.

The GPS tracker was manufactured by Samsung Electronics using KT's IoT(NB-IoT) technology. The location tracking module is installed in the GPS tracker so that the location of people with dementia can be confirmed in real time through the guardian's mobile. When people with dementia are missing, they can be easily found the exact location and route of travel. Other features include a line that can be worn on the clothing of people with dementia, making it easy to carry, small in volume, and incurring a small fee.

GPS tracker were distributed to 94 families of people with dementia over 60 years old living in Sejong City. Data from 48 telephone surveys, 5 focus group interviews, and 5 individual interviews were analyzed.

Result

In a telephone survey, 79.2% of all respondents were children(son/ daughter) of the people of dementia, and the average age of the respondents was 49.9 years \pm 9.9 old. The service satisfaction level of the GPS Tracker project was very satisfied with an average score of 9.15 \pm 1.53 out of 10 points, and the product satisfaction of the GPS Tracker was 7.46 \pm 1.74 points on average, which was lower than the service satisfaction.

Participants in focus group interviews and individual interviews have experienced a loitering or missing of the people with dementia they care. Among them, three of them had no suffering due to loitering, and 6 had a slight seriousness about loitering. The results were shown that families of the people with dementia feel burdened about loitering.

The Families of people with dementia had positive and negative experiences using GPS Tracker. The positive factors that families experienced were prevention of missing, early detection and emotional stability. On the other hand, the negative factors they experienced includes were difficulty in product management, difficulty in battery management, instability in app connection, lack of app accuracy and difficulty in using apps.

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Conclusion

This study was conducted to investigate the experiences and effects of using GPS Tracker in families of the people of dementia in Sejong City who may be loitering.

Based on the GPS Tracker experience analyzed in this study, specific dementia prevention education programs are proposed to understand the positive and negative experiences of the family of people with dementia and to effectively cope with future loitering or missing.

Poster Presentation Abstracts

ID: 293

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia Knowledge Assessment Scale, Chinese

Psychometric properties of Chinese version of dementia knowledge assessment scale

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Abstract:

Background: Education programs have been developed to equip health care providers with knowledge in dementia care. Twenty-five-item Dementia Knowledge Assessment Scale (DKAS) is a validated instrument widely used for assessing knowledge in dementia. The objectives of this study were to translate DKAS into Chinese version (DKAS-C) and test its psychometric properties.

Methods: DKAS was translated into Simplified Chinese following the modified Brislin's Translation Model with forward- and back- translation procedures. The translated Chinese version and back translated English version were checked by the original author of DKAS to ensure the consistency of meaning. The content validity was established by an expert panel. Between June and August 2019, a cross-sectional survey using DKAS-C was conducted in 12 care homes from Nanjing and 2 hospitals from Guangzhou and Suzhou. Health care providers, including nurses, doctors, social workers, physical therapists and care assistants were recruited to self-administer the DKAS-C. Item-total correlation was calculated to preliminary assess the scale and refine the items. Exploratory factor analysis with principal components analysis with varimax rotation was used to explore the factor structure of DKAS-C. Test-retest reliability measured by intra-class correlation and internal consistency measured by Cronbach's alpha coefficient were used to evaluate the reliability. Concurrent validity was established by comparing the DKAS-C score with Alzheimer's Disease Knowledge Scale (ADKS). Known-groups test was used to measure the discriminant validity of DKAS-C.

Results: Six experts included in the expert panel and the content validity index was 0.98. A total of 390 completed questionnaires were included for analysis. Four items (item 2, 17, 18, 23) in DKAS with item-total correlation less than 0.25 were removed. Principal components analysis yielded a four-factor structure. The internal consistency of the overall scale was acceptable, with Cronbach's alpha coefficient of 0.79 of overall scale and the subscales ranged from 0.58 to 0.65. Intra-class correlation coefficient among 56 respondents of two-week interval test-retest reliability was 0.93. The total score of DKAS-C was significantly correlated to the score of ADKS ($r=0.53$, $P<0.001$). Known-group comparison showed that the mean DKAS-C score of health professionals was significantly higher than the care assistants.

Conclusion: The 21-item DKAS-C is a valid and reliable tool to assess the level of knowledge related to dementia of Chinese health care providers. Removal of item 2 and item 17 were regarded as appropriate from a conceptual perspective given that item 6 and item 14 were about the same concepts. Removal of item 18 and item 23 may be explained by limited awareness towards people with dementia in China, for example, care staff may never think of the unmet needs of people with dementia (item 18) and link learning new skills with persons with dementia (item 23).

Poster Presentation Abstracts

ID: 294

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Dementia, diagnosis, post-diagnostic support, co-design

Codesigning dementia diagnosis and post-diagnostic care (cognisance)

Henry Brodaty¹, Lee-Fay Low², Frans Verhey³, Louise Robinson⁴, Greta Rait⁵, Joanna Rymaszewska⁶, Isabelle Vedel⁷, Kate Swaffer⁸, Lyn Phillipson⁹, Yun-Hee Jeon², Meredith Gresham¹, Carrie McAiney¹⁰, Dorota Szczesniak⁶, Wendy Weidner¹¹, Vienna Kooijman³, Marie Poole⁴, Claire Wolfs³

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Abstract:

Despite many national guidelines for diagnosis and management of dementia, persons diagnosed with dementia and their family carer partners are often dissatisfied with the diagnostic process and receive limited post-diagnostic support.

Our aims are to co-design and deliver in partnership with people with dementia, family care partners and health care professionals, toolkits and campaigns to improve the dementia diagnostic process and post-diagnostic support in Australia, Canada, the Netherlands, the UK and Poland; and to evaluate the campaigns.

Work packages will: (1) explore through surveys and focus groups current experiences, barriers and facilitators to dementia diagnosis and post-diagnosis support from the perspectives of persons with dementia, care partners and health care professionals; (2) develop internationally-applicable toolkits supporting guideline implementation for diagnosis and post diagnostic support for the at-risk public and health care professionals; (3) devise and deliver public campaigns to produce behavioural change using the aforementioned toolkits in selected regions; (4) evaluate the campaigns using the RE-AIM framework including measuring impact on the diagnosis, post-diagnosis experiences, and practitioner attitudes and behavior; (5) develop an implementation playbook outlining how to deliver similar campaigns in other countries

CO-desiGning demeNtia dIagnoSis ANd post-diagnostic CarE (COGNISANCE) will provide a new internationally adaptable set of recommendations, toolkits for persons with dementia, care partners and health care practitioners on how to make the diagnostic process and post-diagnostic care as positive an experience as possible, and a playbook to assist other countries with implementing their own change campaigns.

Awarded by JPND; funded by national funding bodies.

Poster Presentation Abstracts

ID: 295

Abstract Topic: Informal carers training

Keywords: caregiver, dementia, Vietnam, modules, Care

Establishing a training programme for family caregivers of people with dementia in a memory clinic in Ho Chi Minh city - a Vietnamese German collaboration project

Thi Thanh Tam Pham¹, Sarah Weschke², Cong Thang Tran¹, Thu Nga Le¹, Thi Luu Phan¹, Thi Thu Huong Tran¹, Thanh Liem Do¹, Ingo Kilimann³

¹Memory and Dementia Unit of 30/4 Hospital, Ho Chi Minh City, Vietnam; ²QUEST Center for Transforming Biomedical Research, Berlin Institute of Health (BIH), Berlin, Germany; ³German Center for Neurodegenerative Diseases (DZNE), Rostock, Germany

Abstract:

Background and objectives of the study / Introduction: In Vietnam, the vast majority of persons with dementia receive informal care solely from their family members. In addition, the knowledge that dementia might be caused by a disease of brain is uncommon in Vietnam, so many people do not seek for support for their relatives or for themselves. However, caring for persons with dementia can be associated with high psychological and physical stress for family caregivers.

Methods: A research institute in Germany specialised in neurodegenerative diseases together with the local Alzheimer's Society developed the training programme "Living with Dementia" to support family caregivers of persons with dementia. Primary goals are psychoeducation about dementia to better understand and to cope with behavioural and emotional changes of their family members, fostering positive interactions and adapting the environment to the needs of the persons with dementia. Caregivers also receive information about legal aspects and the availability of further support services. As part of a cooperation project of the German research institute with a Vietnamese hospital which established the first memory clinic in HCMC, we modified and implemented a training programme for family caregivers in addition to diagnosis and therapy of the persons with dementia in the hospital. In two workshops in Vietnam with physicians, nurses and a psychologist, the partners from Vietnam and Germany discussed which parts of the training programme would be suitable for a Vietnamese audience. In one of the workshops, a family caregiver was present to give valuable input. The selected modules were modified according to the local requirements and translated into Vietnamese.

Results / Positive impact: We start to implement the training programme in October 2019 in the Vietnamese hospital. The programme contains of 4 modules on a weekly basis with 1-2 hours each and 5 to 10 participants per training course. The contents of the modules are:

1. Basic knowledge about dementia
2. Care for persons with dementia
3. Coping with behavioural changes
4. Review and outlook

The programme will be evaluated by measuring the burden of caregivers before and after the programme with the Zarit Burden Interview. Feedback questionnaires will help to further improve the programme for Vietnamese family caregivers. First results of the evaluation will be presented at the conference.

Conclusions / Perspectives: After successful implementation and evaluation, the training programme can also be established in other hospitals and cities in Vietnam. It can also facilitate the organisation of self-help groups for caregivers.

Poster Presentation Abstracts

ID: 296

Abstract Topic: Dementia policies and public policy

Keywords: Family carer, Integrated health and social care, Chinese, Mixed-methods study, Dementia policy

Process and outcomes of an integrated health and social care model supporting older people with dementia and family carers in the community: evidence from a mixed-methods study

Cheng Shi, Gloria HY Wong

University of Hong Kong, Hong Kong S.A.R. (China)

Introduction: Integrated care is widely recommended to address the fragmentation of the health and social care system to ensure patients and their carer to receive a person-centred and continuous service. Its application in dementia care has received increasing attention in recent years, although empirical evidence of care outcomes and understanding about facilitative factors and barriers in the implementation process remain limited.

Methods: A mixed-methods study was conducted to investigate the process and outcomes of integrated community health and social care support service for families with mild and moderate dementia in Hong Kong. This public service is under a two-year dementia policy pilot, delivering multi-component interventions based on the carer burden level by community elderly service centres and outpatient clinics. In the quantitative study, outcome measures were available from family carer and persons with dementia including carer burden (Zarit Burden Inventory, ZBI), functioning (Chinese version of the Disability Assessment for Dementia, CDAD), and quality of life upon service exit (n=824) and 6-month follow-up (n=678). In the qualitative study, focus groups and individual interviews were conducted, including service users (carers) and providers (health and social care staff) at the beginning (n=59) and after 1 year of service commencement (n=61).

Results: Carer burden was reduced at service exit and maintained at follow-up, with carers at-risk of depression (defined as a baseline ZBI score ≥ 40) showing greater reduction in ZBI compared with lower risk carers ($b=-11.4$, $SE=1.4$, 95% CI -14.3 to -8.6, $p<0.01$), after controlling for other participant characteristics, and despite gradual decline in CDAD score. Quality of life of both family carer and the person with dementia was maintained at follow up. Development of a partnership between the community health and social care staff was observed, with the following facilitative factors identified: (1) common service goals across sectors, (2) joint decision making, and (3) timely bi-directional information sharing. Family carers expressed a need for continued service in the same format and site after the service period (5-9 months) while service providers expressed concerns and possible solutions to limited service capacity and sustainability.

Conclusion: An integrated care model in the community with collaboration between health and social care appeared to be effective in reducing carer burden, especially in family carers at risk of developing depression, and in maintaining quality of life of carers and people with dementia. Key factors in the implementation of this integrated care model have been identified. The service has also catalysed the development of diversified and continued service, as part of the integrated care concept, in the larger service system.

Poster Presentation Abstracts

ID: 299

Abstract Topic: Formal carers education and training

Keywords: leaders, transform practice, excellence, culture change, partnerships

Developing leaders in aged care - education alone is not enough to transform practice.

Amanda Kay Warman

Dementia Australia, Australia

Abstract:

The provision of person-centered support and care for people living with dementia relies on an informed and effective workforce; this continues to be of global concern. Excellent dementia care relies on a workforce working as a team for the benefit of their consumers. Excellence is achieved not through traditional training and education alone; excellence requires a deep commitment to transforming practice.

At (Dementia Australia) we have recognized the gaps between training, education and excellence in care. This is the gap between theory and practice; and the gap widens with the complexity of the practice in excellence in dementia care. Dementia is a complex disease to understand, in both the clinical and humanistic sense and while it is important for all staff to have an understanding of dementia and its manifestations in behavior, also of importance is for the organisation providing the service to possess the suitable working environment and culture to support the complexities that arise when providing support to people living with dementia.

To inform and support excellent practice, a flexible and uniquely designed program has been developed, that has proven to assist care organisations in developing their capacity to build and implement a model of care that not only fits their organisations values, but ultimately delivers a care framework that results in excellent care for consumers.

The process reflects the well regarded 70:20:10 training model, holding that only 10% ; a small percentage of developing leaders, or excellence is derived from formal education alone, that in order to achieve the goal of transforming practice, much of that process, the 70 and 20%, involves on-the-job projects and experience, alongside mentoring and opportunities to learn from others.

In line with this framework, The (Centre for Dementia Learning) team work with the organisation to develop an internal leadership team. This team reflects the variety of knowledge and resources required to provide excellent care services. This is also the team who will take the lead on culture change and transforming practice within the organisation. Leaders are empowered to build capacity in partnership with staff, consumers and family members, with the clear focus on improving quality person centered care for people living with dementia achieved through interactive and experiential education and mentorship involving workplace partnerships with consultants who possess expert knowledge and experience in dementia care.

This presentation will highlight that education is not enough to transform practice and poses many barriers if relied upon alone. Through this presentation the value of building capacity and leadership within the organisation in order to transform practice and deliver excellent dementia support and care will be demonstrated.

Poster Presentation Abstracts

ID: 303

Abstract Topic: Psychosocial interventions

Keywords: Dementia, Cognitive Stimulation Therapy, touch-screen application, bench-testing, user experience.

Bench-testing the ICST touch-screen app with people with dementia and carers: a qualitative study

Harleen Rai¹, Rebecca Griffiths¹, Lauren Yates², Justine Schneider¹, Martin Orrell¹

¹University of Nottingham, United Kingdom; ²University College London, United Kingdom

Abstract:

Introduction: A computerised version of individual Cognitive Stimulation Therapy (iCST) is necessary given the need for more innovative approaches to support people with dementia and their carers. Additionally, there is a great potential for combined benefits of technology and iCST on cognition and quality of life by offering more interactive features and improving the accessibility to iCST. Therefore, the aim of this study was to bench-test the iCST application with people with dementia and carers in order to modify and refine the application and improve its usability.

Methods: A total of 13 people with dementia and 13 carers participated in a series of four focus groups and ten semi-structured interviews to bench-test a prototype version of the iCST application. The purpose was to obtain feedback in key areas such as the lay-out and content of the application, using it as a dyad and any other general points. All interview participants additionally completed a short usability and acceptability questionnaire.

Results: Most participants were enthusiastic about the iCST application. Participants felt that a higher level of familiarity with technology and feelings of empowerment could help facilitate the use of the iCST application. The application was easy to use and the design was appropriate with minor improvements suggested to the lay-out. The activities were enjoyable however there was a need for a broader and more diverse selection in order to appeal to individual preferences. Furthermore, various perceived benefits were reported including mental stimulation, quality time spent together, and enjoyment.

Conclusions: This study gave valuable insights in the usability, feasibility, and perceived benefits of the iCST application according to people with dementia and carers. The feedback from the focus groups, interviews, and questionnaires will be incorporated in the next prototype version of the iCST application which will be taken forward in a feasibility trial.

Poster Presentation Abstracts

ID: 304

Abstract Topic: Psychosocial interventions

Keywords: Cognitive Stimulation Therapy, CST, Implementation, LMIC

COGNITIVE STIMULATION THERAPY (CST) FOR DEMENTIA: PROTOCOL FOR INTERNATIONAL IMPLEMENTATION IN BRAZIL, INDIA AND TANZANIA (CST-INTERNATIONAL)

Aimee Spector¹, Charlotte Stoner¹, Adelina Comas-Herrera², Martin Orrell³, Richard Walker⁴, Thara Rangaswamy⁵, Mina Chandra⁶, Sridhar Vaitheswaran⁵, Murali Krishna⁷, Kunnukattil Sivaraman Shaji⁸, Daniel Mograbi⁹, Jerson Laks¹⁰, Cleusa Ferri¹¹, Catherine Dotchin⁴, Stella-Maria Paddick⁴

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Delhi, India; ⁷Foundation for Research and Advocacy in Mental Health, Mysore, India.; ⁸Department of Psychiatry, Government Medical College, Thrissur, Kerala, India.; ⁹Pontifical Catholic University, Rio de Janeiro, Brazil.; ¹⁰Federal University of Rio de Janeiro, Brazil.; ¹¹Universidade Federal de São Paulo, Brazil

Abstract:

Background: This work forms part of the CST-International research programme. Dementia is largely untreated in low- and middle-income countries (LMICs) due to limited awareness, resources or care pathways. Medication is commonly not viable, relying on ongoing support of care specialist medical professionals. CST is a group intervention with a robust, global evidence-base for improved cognition and quality of life. Crucially, it is culturally adaptable and can be delivered by health workers with no specialist equipment at low cost.

Aims: To develop, test, refine and disseminate implementation strategies in three diverse countries; Brazil (upper middle income), India (lower middle income) and Tanzania (low income). Each have translated and adapted the United Kingdom (UK) CST manual and begun or completed feasibility/pilot work, with positive outcomes. Secondary aim: to increase awareness and skills in the detection and management of dementia for health workers and families.

Methods: Phase 1: investigate barriers to and facilitators of implementation using meetings, qualitative interviews and consensus conferences with stakeholders. Phase 2: develop generic and country-specific implementation strategies. Phase 3: test this strategy through establishing cascade training models and eight CST groups / 50 people with dementia in each country; offer families a brief dementia awareness course. We will examine feasibility (adherence, attendance, acceptability and attrition), agreed parameters of success (numbers of trained facilitators, numbers of groups run), outcomes (cognition, quality of life, behaviour, carer burden) and costs/affordability of models. Phase 4: refine and disseminate implementation strategies.

Results/Discussion: Results from phases 1 and 2 will be presented. We will increase understanding of successful implementation of an effective and cost-effective intervention in LMIC settings, aiming to establish a system of ongoing CST groups, cascade training models and changes in policy and care pathways. Ultimately, this work could lead to improved cognition and quality of life for the current generation of people with dementia, reduce costs of care; and create a more skilled workforce and educated communities. This talk will consider how the methodology might be extended to other countries globally.

Poster Presentation Abstracts

ID: 306

Abstract Topic: Dementia friendliness

Keywords: Dementia, technology, involvement, development, best-practice

Improving the involvement of people with dementia in developing technology-based interventions: a narrative synthesis review and best practice guidelines

Harleen Rai¹, Aline Cavalcanti Barroso¹, Lauren Yates², Justine Schneider¹, Martin Orrell¹

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Abstract:

Introduction

The current lack of involvement of people with dementia in developing technology-based interventions can lead to the implementation of faulty and less suitable technology. The aim of this systematic review was, through narrative synthesis, to appraise the current methods used for involving people with dementia, and to create best practice guidelines/recommendations on how to better involve people with dementia in developing technology-based interventions.

Methods

A systematic search was undertaken in January 2019 in the following databases: EMBASE, PsycINFO, MEDLINE, CINAHL and Web of Science. The search strategy consisted of combinations and variations of search terms in the following three categories: "dementia", "technology", and "involvement in development". Narrative synthesis was used to help bring the evidence together in a structured approach.

Results

Twenty-two studies met the inclusion criteria. Findings were grouped according to the methods used for involvement and the developmental phases of the study. Most studies involved people with dementia in a single phase e.g. development (n = 11), feasibility/piloting (n = 7), or evaluation (n = 1). Only three studies described involvement in multiple phases using an array of qualitative and quantitative methods. Frequent methods for involvement included focus groups, interviews, observations, and user-tests.

Conclusions

Most studies concluded that it was both necessary and feasible to involve people with dementia. This could lead both to improvement in the developed technology and to positive effects for the person with dementia. The process can be optimised by having the right prerequisites in place, and by providing a positive research experience for the participants. In addition, care should be taken when presenting technology to participants by ensuring it meets a standard of reliability and stability. The findings have led to the creation of best-practice guidelines for the involvement of people with dementia in developing technology-based interventions as their involvement helps to create more suitable and effective technology.

Poster Presentation Abstracts

ID: 312

Abstract Topic: Diagnostic tools

Keywords: dementia; cross-cultural; health economics; New Zealand

Living with dementia in Aotearoa (the LiDiA study): a feasibility study for the first dementia prevalence study in new Zealand

Sarah Cullum¹, Adrian Martinez Ruiz¹, Susan Yates¹, Margaret Dudley¹, Gary Cheung¹, Rita Krishnamurthi², Claudia Rivera Rodriguez¹, Fuafiva Fa'alau¹, Ngaire Kerse¹

¹University of Auckland, New Zealand; ²Auckland University of Technology

Abstract:

Background:

Dementia is a global health priority and consequently the World Health Organization has recommended all member states produce a national dementia plan or strategy for 2017-2025. However, at the present time, the Ministry of Health has not developed a plan for New Zealand (NZ). In order to do so, the Ministry requires accurate data on the extent and impact of dementia in all the major NZ ethnic groups, but such data are not available as there has never been an NZ dementia prevalence study. This presentation will describe how we addressed the feasibility issues for a proposed NZ dementia prevalence study that will provide population-based data on the extent and impact of dementia for the major ethnic groups living in New Zealand.

Methods:

1. Adaptation of the 10/66 dementia protocol for use in Māori, Samoan, Tongan and Fijian-Indian communities and testing the diagnostic accuracy and acceptability of the adapted versions of the protocol.
2. Testing the sampling methods for the full prevalence study in Māori, Samoan, Tongan, Indian, Chinese and European communities living in South Auckland including establishing an efficient sampling strategy and corresponding statistical analysis plan, conducting the study in several different cultures and languages, interviewer training and fieldwork procedures.

Results: We will present the findings from the feasibility study including (i) cultural appropriateness and diagnostic accuracy of 10/66 in each community, (ii) the construction and implementation of our sampling frame, (iii) the results from our pilot prevalence study in South Auckland including the psychological and economic impact on families from the different communities.

Discussion: The findings from our study will support the design of our proposed fully powered NZ dementia prevalence study, and also provide preliminary data regarding potential inequities in allocation of resources across NZ ethnic groups. These data will strengthen the NZ evidence base for dementia and help inform the Ministry of Health in directing relevant resources towards developing culturally and linguistically appropriate dementia services, as well as improving public awareness and reducing stigma.

Poster Presentation Abstracts

ID: 317

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: person-centered outcomes research, palliative care, stakeholder engagement

Multi-stakeholder engagement is needed to build evidence around better palliative care for families living with dementia

Carole Leone White, Neela Patel, Sara Masoud, Angelica Davila, Sheran Rivette, Debbie James
UT Health San Antonio, United States of America

Introduction: Persons with dementia and their families have palliative care needs that are not addressed, current care is fragmented and a focus on care that enhances quality of life is often lacking. An understanding of the gaps in research and care to improve quality of life will benefit from engaging stakeholders in the research. Yet, the voice of the most important stakeholder, families living with dementia, has been noticeably absent in informing research. Our objective is to describe the process of engaging multiple stakeholders to participate as partners in person-centered outcomes research.

Methods: A Stakeholder Advisory Council has been established, comprised of people living with dementia, family caregivers, clinicians, pastoral services, representatives from community agencies serving families with dementia, and researchers. Approaches to building the team and capacity in this area include monthly meetings, webinars, and an annual symposium with interactive communication about dementia care and research. A web-based portal has been designed to establish an online community for information exchange and to identify priorities for research.

Results: The council has been meeting monthly, with a person living with dementia and a researcher co-chairing the council. At the annual symposium with 135 people in attendance, 51% were people living with dementia or family caregivers. Through round-table discussion, we began to examine the principles for multi-stakeholder engagement in research for better palliative care among families living with dementia. Important principles identified through this process included: i) allowing time to build relationships and trust to work together, ii) respecting the knowledge and unique perspectives that equip us to evaluate and conduct research in this area, iii) a willingness to mentor one another in this process, and iv) learning how to improve our interactions so we can work together to produce better research. Through the monthly council meetings, the online community, and the symposium, we have also begun to identify areas in dementia-focused palliative care where research is needed, which include non-pharmacological management of behavioral symptoms, the role of activity in slowing dementia symptoms, how best to deliver the diagnosis to families, how best to support people with dementia at the time of diagnosis, and the services and support that impact the well-being of people with dementia and their families. Identified areas will be prioritized through a modified Delphi approach.

Conclusions: A multi-stakeholder perspective is critical to identifying priority areas for patient-centered outcomes research around better palliative care for families living with dementia. Through this process, we are recognizing the importance of the authentic engagement of people living with dementia and recognizing the knowledge that multiple stakeholders are bringing to meaningfully inform the research.

Poster Presentation Abstracts

ID: 318

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: lived experiences, Indian community, dementia, caregiver experiences

Lived experience of dementia in Indian families living in New Zealand

Rita Vanmala Krishnamurthi¹, Ekta Singh Dahiya¹, Susan Yates², Gary Cheung², Ngaire Kerse², Sarah Cullum²

¹Auckland University of Technology, New Zealand; ²The University of Auckland, New Zealand

Abstract:

Background/Objectives: Dementia services in New Zealand (NZ) tend to be designed for English speaking people of European origin. Estimates indicate that the greatest increase in dementia prevalence over the next 20 years will be seen in the Asian population, but there is little dementia-related data in this population. The aim of our project was to describe the lived experience of dementia in Indian families living in NZ.

Methods: Semi-structured interviews were conducted in the community in English, and Hindi by bilingual bicultural researchers. The interviews explored; the Indian cultural understanding of dementia; the dementia journey, from first symptoms to diagnosis and post diagnostic support; and culturally appropriate service needs for dementia. Participants were recruited through a local hospital memory service, and a non-government organisation for Indian senior citizens. To gain a broad perspective we interviewed: people with mild dementia who are able to share their experiences; family members of people with mild dementia; and caregivers of people with more severe dementia. The data were transcribed verbatim and independently analysed by two researchers using the thematic qualitative methodology.

Results: Fifteen participants (five people with dementia and their caregivers, and five caregivers of people with severe dementia) were interviewed. All interviews, except one interview were conducted in Hindi. The most common perception of dementia was “memory loss due to aging”; for example “*this is normal....because he is getting older, he forgets*” (female caregiver of person with mild dementia). Participants identified the need for a diagnosis as crucial for understanding the condition and receiving services. Caregiver stress was common; “*What about me, I have health problems too, I am old and tired. I need help on how to deal with this person – he thinks nothing is wrong with him*” (female caregiver of person with moderate dementia). Culture specific considerations such as serving vegetarian food in rest homes and having care providers who spoke their language were brought up as important service needs.

Conclusions/Perspectives: This study is the first exploration of the lived experiences of dementia in the NZ Indian community. Dementia was commonly perceived as a normal part of aging in the Indian community. Challenges experienced by participants and caregivers included lack of knowledge, understanding of the diagnosis, and stigma, leading to low utilisation of services. Unmet needs included getting a clear and timely diagnosis, culture specific services, carer support and training. Future healthcare planning for people with dementia and their families should be revised to address these needs. These should include the development of culturally tailored services and community awareness campaigns to improve the knowledge of and reduce the stigma associated with dementia.

Poster Presentation Abstracts

ID: 319

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Innovation, multi-disciplinary, acute, meaningful engagement

An innovative approach to the acute hospital journey and experience for people living with dementia.

Meagan Cara Hartley, Jenny Nel

Gold Coast Hospital Health Service, Australia

Abstract:

Care for people living with dementia within an acute hospital environment requires specialist skills and supportive environments that enable person centred care approaches that best meet the needs of the individual.

In June 2018, Gold Coast Hospital Health Service opened a specialist eight bed Geriatric Assessment Unit to support the expression of unmet needs for this population. The unit provided more space for walking, reduced noise and people stimulation, and provided access to a sunroom, dining area and lounge space. Patients continued to experience heightened levels of anxiety and distress, observed through changed behavioural expression, resulting in the use of pharmacological measures. The absence of individualised strategies to enable patients' engagement and participation in meaningful activities were identified. Additionally, staff were at risk of workplace injury and the patients of potential hospital acquired complications impacting their recovery. Interventions were based on crisis management strategies, rather than a multidisciplinary framework supporting preventative and non-pharmacological approaches.

The introduction of an innovative evidenced based, non-pharmacological, systematic and developmental approach to assessment and intervention was commenced. Foundations of this developmental participation framework are based on the theoretical underpinnings of an occupational therapy practice model, the Vona du Toit Model of Creative Ability, integrating principles of the Allens' Cognitive Disability Model and Sensory Modulation.

Advanced clinical assessment and interpretation of patient presentation guides this multi-disciplinary approach. Strategies are aimed at supporting increased participation in personal cares and active engagement in meaningful activities presented at the appropriate level of cognitive and physical demand. Individualised strategies are captured within a Personalised Support Plan (PSP). An education framework supported implementation and integration into acute care plans through modelling and point of care support by the occupational therapist. PSPs are used as a direct handover tool to families and residential aged care facilities to support transitions and care in the community with the additional aim to reduce representation to hospital.

With the provision of this approach there has been a significant reduction in the need for security staff intervention, reduced pharmacological intervention, increased engagement and participation in meaningful activities and an improvement in sustainable transitions.

Partnering with patients and their carers to support active participation and engagement, growing staff skills, knowledge and confidence to support people living with dementia and working with residential aged care facilities to support transitions are all contributing to enhanced care for people living with dementia accessing this acute hospital setting.

Poster Presentation Abstracts

ID: 320

Abstract Topic: Well being and quality of life

Keywords: Alzheimer's disease, MMSE, Activities of Daily Living, IADL, Vietnam

Cognition and activities of daily living in people with dementia in Vietnam : a correlational study

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Abstract:

Objective: Alzheimer's disease (AD) is characterized by its inevitable progressive nature, with cognition and daily functioning among the most essential evaluation. This study aims to investigate the correlation between cognition and informant-based functional scales in people with AD in Vietnam.

Method: A total of 31 AD patients aged 51 to 85 (67% female) from two hospitals in Vietnam was included in a cross-sectional analysis. The mean duration with memory loss was 28 months. Patients with memory complaint were screening for cognitive impairment by Mini-Mental State Examination (MMSE) test. Functions were measured with the Katz Index of Independence in Activities of Daily Living (ADL) and the Lawton Instrumental Activities of Daily Living (IADL), completed by a caregiver. Data were analyzed with Spearman rank correlations.

Result: MMSE showed significant statistical correlation with both functional measures, with IADL (female: $R = 0.65$, $p = 0.0012$; male: $R = 0.66$, $p = 0.035$) more strongly correlated than ADL ($R = 0.55$, $p = 0.0012$). A critical shift where patients began to lose independence of ADL items were observed at an MMSE score of 17-18.

Conclusion: Cognition appears to be a valuable contributing factor to foreseeing impairment of daily functioning. Recognizing the arrival and progression of impairment in cognition and everyday abilities is of paramount importance to anyone involved in the care of people with AD.

Poster Presentation Abstracts

ID: 323

Abstract Topic: Diagnosis

Keywords: Alzheimer's disease; Diagnosis; Mini-mental state Examination; Abbreviated Mental Test Score; Functional Assessment Staging tool

Comparison of diagnostic value of four dementia tests

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¹Iranian Alzheimer's Association; ²Iranian State Welfare Organization (ISWO)

Abstract:

Objective: This study aimed to compare the diagnostic value of four questionnaires for the diagnosis of neurocognitive disorders (NCDs) in older adults.

Methodology: the participants of this study were selected from 720 literate community-dwelling older adults lived in Tehran metropolitan that were cognitively evaluated. Finally, 99 subjects with age ≥ 60 in this project, people older than 60 years who willing to participate were enrolled in this study. Four questionnaires; Functional Assessment Staging Tool (FAST), Abbreviated Mental test Score (AMTS), Mini-Mental State Examination (MMSE), and modified Persian Test of Elderly for Assessment of Cognition and Executive function (PEACE) were administered for them. They were then referred to a neuropsychiatrist, and the status of their cognition and neurobehavior was determined. The specialists were blinded to the results of the tests.

Findings: Of the 99 participants, 39 were healthy, eight had mild Alzheimer's disease, 38 had amnesic MCI, five had secondary dementia, and nine had mixed dementia. The area under the Receiver Operating Characteristic (ROC) curve for distinguishing the healthy group the population with cognitive impairment for FAST, AMTS, MMSE, and PEACE tools were 0.692, 0.629, 0.734, and 0.751, respectively.

Conclusion: MMSE and PEACE had better diagnostic power than the other two tests to distinguish the healthy group from the subjects with cognitive impairment.

Poster Presentation Abstracts

ID: 324

Abstract Topic: End of life and palliative care

Keywords: Advance Care Planning, Dementia, End-of-Life, Decision-Making Conflicts

The impact of advance care planning information intervention for persons with mild dementia and their family caregivers on decision-making conflicts of end-of-life care

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¹National Taipei University of Nursing and Health Sciences and Sijhih Cathay General Hospital, Taiwan; ²National Taipei University of Nursing and Health Sciences, Taiwan; ³Taipei City Hospital, Dementia Center, Taiwan

Abstract:

"背景和目標：患有癡呆症的患者的家庭成員通常在臨終關懷護理決策中面臨各種衝突。預先護理計劃（ACP）是輕度癡呆患者的重要溝通方式。在台灣，關鍵的醫療決策主要集中在家庭。本研究探討了ACP信息干預對輕度癡呆患者臨終決策衝突的影響（包括是否進行心肺復蘇[CPR]，人工呼吸機，人工營養和水合）

方法：採用一組預測後測試前實驗設計。在進行以家庭為中心的ACP干預之前，對乾預執行者（經驗豐富的護士）進行ACP培訓以及ACP手冊的製作和驗證。參與者的入選標準是來自記憶診所及其家庭照顧者的輕度癡呆（臨床癡呆評分[CDR] = 0.5-1）的患者。決策衝突量表用於收集數據；

規模包括五個維度，即知情選擇，價值清晰度，支持，不確定性和有效決策，總得分高表明高決策衝突。非參數Wilcoxon檢驗用於統計分析。

結果：共招募了20對患有癡呆症和家庭照顧者的人。患者的平均年齡為79±7.82歲，包括12名男性（60%）和8名女性（40%）。每日生活活動得分平均為95±10.57；13名患者（65%）的CDR評分為1分，7名（35%）患者的評分為0.5分。家庭照顧者平均年齡為60±11.43歲，其中16名女性（80%）和4名男性（20%）。其中12人（60%）與病人一起生活；

大多數照顧者是患者的孩子（13人[65%]），其次是配偶（7人，[35%]）。平均花在護理上的時間是每天14.16±9.2小時。結果顯示，在結構化ACP干預後，輕度癡呆患者臨終決策的決策衝突得分顯著降低（45.4→37.3，Z = -2.464，p = 0.014），特別是在支持的維度（Z = -2.301，p = 0.021），不確定性（Z = -2.863，p = 0.004）和有效決定（Z = -2.797，p = 0.005）。家庭照顧者的總衝突分數也減少了，但減少不顯著（40.35→36.2，Z = -1.571，p = 0.116）。

結論：以家庭為中心的ACP干預確實有效地減少了癡呆症患者面臨的臨終決策的決策衝突。結果表明，醫療服務提供者應強調ACP教育對癡呆症患者及其照顧者的作用，促進家庭成員之間的溝通和支持。

Poster Presentation Abstracts

ID: 329

Abstract Topic: Well being and quality of life

Keywords: Dementia, Sleep disturbances, Care homes, Actigraphy, Questionnaires

Measuring the prevalence of sleep disturbances in people with dementia living in care homes: a systematic review and meta-analysis

Lucy Anne Webster¹, Sergi Costafreda Gonzalez¹, Aisling Stringer¹, Amy Lineham², Jessica Budgett¹, Simon Kyle³, Julie Barber⁴, Gill Livingston¹

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³Sleep and Circadian Neuroscience Institute, University of Oxford, Oxford, United Kingdom;

⁴Department of Statistical Science, UCL, London, United Kingdom

Abstract:

Background and objectives:

Sleep disturbances are a feature in people living with dementia, including getting up during the night, difficulty falling asleep, and excessive daytime sleepiness. These disturbances may not only affect the wellbeing of individuals, but increase carer burden and depression, and therefore may be a reason why people with dementia move into residential care. There are varying estimates of the frequency of sleep disturbances in people with dementia living care homes and different ways of measuring them. Thus, we conducted the first systematic review and meta-analysis on the prevalence and associated factors of sleep disturbances in the care home population with dementia.

Methods:

We searched Embase, MEDLINE, and PsycINFO from database inception to 29th April 2019 for quantitative studies of the prevalence or associated factors of sleep disturbances in people with dementia living in care homes (PROSPERO CRD42017080312). We searched reference lists and emailed authors of included papers for additional data and papers. Two raters completed a standardised study quality checklist. We meta-analysed estimates of prevalence of sleep disturbances, and used meta-regression to investigate effects of method of measurement, demographics and study characteristics. We separated prevalence data by method of measurement into: validated proxy questionnaires for clinically significant cases of sleep disturbances, validated proxy questionnaires for any symptoms of sleep disturbances, and actigraphy measured sleep disturbances. We conducted a narrative synthesis of associated factors reported across individual studies.

Results:

We screened 7901 references of which 58 papers comprising 55 studies were included. Studies included a total of 22,780 participants. On informant questionnaires the pooled prevalence of clinically significant sleep disturbance was 20% (95% Confidence Interval, (CI) 16-24%; $I^2 = 95%$) and of symptoms of sleep disturbance was 38% (CI 33%-45%; $I^2 = 98%$). The pooled prevalence of sleep efficiency <85% on actigraphy was 70% (CI 55-85%; $I^2 = 84%$). Meta-regressions showed that the method of measurement was a statistically significant moderator of prevalence, and that studies with a higher percentage of males were associated with higher estimates of prevalence of sleep disturbances. Sleep disturbances reported on questionnaires across individual studies were consistently associated with staff distress, resident agitation and prescription of psychotropic medication.

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Conclusions:

Clinically significant sleep disturbances are less common than those measured on actigraphy, and actigraphy appears to be measuring a different construct from questionnaires. Sleep disturbances on questionnaires are associated with resident agitation and staff distress, and increased prescription of psychotropics, indicating that sleep disturbances have an impact on the wellbeing of both people with dementia and the staff who care for them.

Poster Presentation Abstracts

ID: 335

Abstract Topic: Registries

Keywords: Dementia, Registries, Information System, Statistics, Public services

The Korean dementia registry and management system (K-DREAMS)

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the National Institute of Dementia in South Korea, Korea, Republic of (South Korea)

Abstract:

Registry for dementia provides important resource for tools for public health surveillance and improvement of quality of care as well as research. In South Korea, the Korean Dementia Registry and Management System (K-DREAMS) was initiated in December 2017 to register and manage people with dementia and older adults who are concerned of the future risks of having dementia by providing them customized services. K-DREAMS was developed based on "Dementia Management Act" of South Korea and it has been operated by the Ministry of Health and welfare and the National Institute of Dementia. In South Korea, 256 local dementia centers were installed between 2017 and 2019 and provide public services for dementia such as counseling, dementia screening, diagnostic assessment, case management, cognitive enhancement program and dementia prevention program. Using K-DREAMS, service providers in local dementia center register people with dementia and their caregiver and non-demented elderly who needs services of local dementia center.

Based on diagnosis and current situation, K-DREAMS offers optimized services for registrants. In August 2019, 2,724,828 people registered in K-DREAMS and 423,935 individuals have diagnosis of dementia and 82,821 were their caregiver. It was estimated that about 53.6% of dementia patients in South Korea were registered in K-DREAMS. From the registered data, K-DREAMS provides current statistics for registered people and uses of service in local dementia centers. Since December 2017, total of 3,147,531 screening tests, 196,903 diagnostic assessments and 55,475 case managements were estimated to be performed in local dementia center. Through K-DREAMS, central and local governments and dementia centers can easily access the statistics of registrants and their uses of service. K-DREAMS will help to manage dementia patients efficiently and provide public service for dementia effectively. In addition, the data in K-DREAMS is expected to be essential sources of evidence for policy making.

Poster Presentation Abstracts

ID: 337

Abstract Topic: Attitudes, awareness and stigma

Keywords: dementia; disability; volunteerism; community; students

Community awareness programmes by medical students for dementia, disability and volunteerism

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¹Universiti Brunei Darussalam; ²RIPAS Hospital, Brunei Darussalam

Abstract:

The local undergraduate medicine course requires third year medical students to complete a community awareness programme for public education on a relevant medical topic. In this presentation, three public awareness campaigns on dementia, disability and volunteerism by medical students are described.

The campaign on dementia involved activities and educational sessions for older people at several venues: the weekend City Car-Free Initiative (Bandarku Ceria), Senior Citizen Activity Centres and the local Dementia Support Group. A dementia forum was organised for university staff and students. An informative session was also given to a Cardiac Rehabilitation group, as cardiac risk factors are associated with increased dementia risk.

The campaign on disability awareness was held at a mall, consisting of informative booths on disability and experiential activities, including use of adaptive equipment and aids. A person with disability shared their life experience in an open dialogue. The students also developed a video showcasing lives of people with disability locally.

The awareness campaign on volunteerism involved an exhibition at the local university on health issues in older people. Older people from the Senior Citizen Activity Centres were invited to the City Car-Free Initiative to participate in aerobic activities and learn from displayed materials regarding healthy ageing. A one-day training programme was also organised and delivered by the students to volunteers from a local association using a reference volunteer training guide.

These campaigns were initiated by students in collaboration with other relevant partners to raise awareness among the public. The students immersed themselves in learning, while providing civic engagement in a useful service to the community. This mutually benefits the students, academic institution and the community. Students are a useful human resource for raising awareness among the public and to reduce stigma associated with dementia and disability.

Poster Presentation Abstracts

ID: 339

Abstract Topic: Dementia friendliness

Keywords: dementia-friendly, engagement, processes, consultation

Defining dementia-friendly research: engaging people with lived experience as collaborators and advisors

Maria K Howard

Alzheimer Society of B.C

Abstract:

There is a shift occurring in health research. In 2011, the Canadian Institutes of Health Research launched the Strategy for Patient-Oriented Research grounded in the view that patients should be proactive partners engaged in the research process.

People living with dementia have historically been excluded from research and are largely still excluded. This is a result of the belief that people living with dementia are unable to understand research processes or give proper consent. This is untrue. People living with dementia and their care partners are experts in the lived experience of dementia and can contribute greatly to research.

The Alzheimer Society of B.C. is committed to defining and promoting a model of research that engages and partners with people living with dementia and their care partners as participants, collaborators and advisors: dementia-friendly research.

In October 2018, the Society hosted a pre-conference workshop at Canadian Association on Gerontology's annual conference: "Strategies for engaging people living with dementia in research: Facilitating a national conversation" in partnership with the University of British Columbia's Centre for Research on Personhood in Dementia. The event brought together researchers, people living with dementia, care partners, health leaders and other key stakeholders from across Canada to start defining what dementia-friendly research could look like and to identify the barriers that exist in moving towards this model.

The following key points arose from participants' moderated discussions:

Research is dementia-friendly when it:

- Meaningfully engages people affected by dementia **before the study begins** to develop research questions.
- Invites people with lived experience to take on advisory and co-researcher roles **during the study**.
- Commits to accessible knowledge mobilization **after the study is completed**.

To overcome barriers, researchers must:

- Combat the stigma by examining their own beliefs and taking part in efforts like education sessions and awareness campaigns.
- Educate ethics boards on the unique needs and abilities of people living with dementia.
- Create flexible research designs to meet the changing realities of people living with dementia and allow for their participation throughout the study. This includes using methods that don't solely depend on written or verbal communication and scheduling activities around the person.

The Alzheimer Society of B.C.'s vision is a world without dementia and this begins with a world where people affected by dementia are acknowledged, supported and included. Research is key to creating this future. However, for this world to become a reality, research must be as effective as possible and

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this can only be achieved by understanding that people affected by dementia and their care partners are essential to the research process.

By embracing dementia-friendly research we can create a dementia-friendly future.

Poster Presentation Abstracts

ID: 340

Abstract Topic: Psychosocial interventions

Keywords: Psychotherapy, Cognitive-behavioral therapy, psychosocial intervention, randomized controlled trial, caregiver

An integrative, cognitive-behavioral treatment for persons living with mild Alzheimer's dementia: results of an RCT

Simon Forstmeier¹, Tanja Roth², Egemen Savaskan³, Andreas Maercker²

¹University of Siegen, Germany; ²University of Zurich, Switzerland; ³Psychiatric University Hospital Zurich, Switzerland

Abstract:

Background and objectives of the study: About 90% of all persons with mild Alzheimer dementia (AD) experience affective and behavioral symptoms. Although some research has supported the effectiveness of specific psychotherapeutic approaches for mild AD, there are only few attempts to evaluate a multi-component treatment programme. This randomized controlled trial evaluates the effect of an integrative cognitive-behavioral treatment on the health of persons with mild AD and their caregivers (CBTAC).

Methods: The CBTAC treatment programme consists of 25 weekly sessions, including eight modules: goal setting; psychoeducation; engagement in pleasant activities; cognitive restructuring; live review; behavior management; interventions for the caregiver; and couples counselling. 50 persons with mild AD and their caregivers have been randomized to either the CBT-based intervention group (CBT) or to the control group, which received treatment-as-usual (TAU). Before and after the treatment phase, participants have been assessed. Follow-ups took place at 6, and 12 months post-treatment. The primary outcome was depression in the person with AD. The secondary outcome measures were apathy, other neuropsychiatric symptoms, functional abilities, quality of life, and quality of the relationship to the caregiver.

Results: CBT reduced depression significantly more than TAU (interaction: $F = 5.3$, $p < .05$), with a moderate-to-large effect size ($d = 0.76$). There was also a significant advantage for CBT with regard to apathy ($F = 4.7$, $p < .05$; $d = 0.71$) and quality of the relationship to the caregiver ($F = 4.3$, $p < .05$; $d = 0.77$). There was no advantage with regard to other neuropsychiatric symptoms, functional abilities, and quality of life.

Conclusions: The results are very encouraging and stimulate an adequately powered multi-center-study.

Poster Presentation Abstracts

ID: 342

Abstract Topic: Consumer empowerment

Keywords: Air Travel, Dementia Friendly, Collaboration, Journey Mapping, Canada

Dementia-friendly air travel in Canada

Maria K Howard¹, Heather C Cowie¹, Linda Garcia², Michael Mulvey²

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Abstract:

In our increasingly fast-paced world, air travel is an essential part of many Canadians' lives. However, barriers in the built and social environments of airports and airplanes can lead to stressful and overwhelming situations for people affected by dementia. Bustling airports that lack signage can cause disorientation – making navigating the environment difficult –and airline staff who lack dementia-specific training can contribute to anxiety and frustration.

While the search for a cure for dementia is ongoing, the reality is that air travel needs to evolve to better support, acknowledge and include people affected by dementia through the application of “dementia-friendly” principles. There are more than 564,000 people living with dementia in Canada now and that number is growing – the need for a dementia-friendly approach is becoming increasingly relevant.

In Canada, the work to change the experience of air travel is being led by the Alzheimer Society of B.C. and the University of Ottawa, members of the International Dementia Air Travel working group (I-D-Air).

This session highlights work that has been done in the provinces of British Columbia and Ontario, focusing on the importance of involvement of and collaboration with people with lived experience. It will speak to the process of journey mapping and how it can be applied to air travel, identifying gaps and challenges in booking flights, navigating security and finally arriving to determine how to make the experience for people affected by dementia as smooth and safe as possible.

Poster Presentation Abstracts

ID: 343

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Intergenerational relations, social inclusion, elderly-children

Crossing social and intergenerational barriers in social inclusion.

Jacqueline Arabia

FUNDACION ALZHEIMER, Colombia

Abstract:

Introduction

The experience that we are going to present promotes reflection and dialogue of knowledge around actions that make social inclusion possible, the strengthening of capacities and the development of opportunities within both the school community as well as the environment of elderly people with dementia. Fostering, through the implementation of social service in primary school, reflections with older adults and caregivers on the role played by various community representatives in building an inclusive and intergenerational culture of peace through education. The classroom is understood as that political and public scenario, ready for collaborative learning, together, in community in front of life and with others. In a society like ours, in which a culture of violence has predominated, which affects the way we think, and that way brings more violence, it is crucial to include imaginaries, or representations about the being and the duty to be of the society in which we live. "Education is the key to peace". Our aim has been to promote actions that favor a culture and education for peace, that contribute to the transformation of those forms and ways of relating, seeing and considering the other. A form of relationship that makes the difference of interacting inside the school and in the future of the children with their elders. People with dementia need greater integration and community participation, which is closely aligned with what should happen in a society for all ages.

Objective: Crossing social barriers between inclusive institutions such as the Alzheimer's Foundation and students of the Liceo este Alpes del Cali Colombia elementary school through the implementation of the service and social responsibility to the community

Method: From a service-learning approach, with intentional learning activities, members of both institutions work collaboratively to achieve mutually beneficial outcomes for both parties. We work 3 dimensions: Understand what it means to live in society Promote democratic participation and accountability. Guarantee participation, peaceful coexistence, valuing difference within a framework of plurality, identity and valuing coexistence.

Results: In both contexts, the positive impact of the program can be seen in the increase of curiosity and the discovery of new realities. In the elderly, there is an improvement in their state of mind, integration into organized activities, improvements in their social skills, interest in remaining active, family interaction among others. In children, improvement in their socio-affective skills, cognitive mastery, awareness and empathy for others.

Conclusions

The generational exchange and the actions generated in it, do not act as mere recreational activity, but have a therapeutic and rehabilitative function that improves the quality of life of people with dementia. The change in attitude that occurs in children after experience with respect to the figure of the elder is revealing.

Poster Presentation Abstracts

ID: 344

Abstract Topic: Economics of dementia

Keywords: cost of informal care, dementia in the United States

Estimating the costs of informal care for Alzheimer's and related dementias in the us

Joseph Dieleman, Adrien Allorant

Institute for Health Metrics and Evaluation (IHME), University of Washington, United States of America

Abstract:

Background:

Dementia is the health conditions with the third largest direct medical spending in the US in 2015, with \$93.5 billion. This estimate is nevertheless an underestimate of the true costs associated with dementia, as a major portion of the costs of dementia is borne by unpaid caregivers. Persons living with dementia tend to rely heavily on informal care for assistance with activities of daily living (ADLs), instrumental ADLs (IADLs), and/or simply monitoring. Ignoring the costs of informal care for persons living with dementia minimizes the real cost associated with dementia and disregards the true burden on families. To fill this knowledge gap we measured the cost of informal care by age, sex, and severity for dementia patients for 1996-2015.

Methods:

We used the Aging Demographic and Memory Study informant caregiving questionnaire to estimate the average annual cost of informal care for dementia stratified by age, sex, severity and year. We used additional data sources, such as the Behavioral Risk Factor Surveillance System's Caregiver Module and Global Burden of Disease 2017 Study. We estimated the volume of informal care using the number of hours of active helping and supervision. The unit cost of an hour of informal care varied with the content of care provided and the characteristics of the patient and caregiver. For intensive help such as assisting with ADLs, we used a replacement cost approach. For care activities such as IADLs and monitoring we adopted an opportunity cost approach – using all available information to impute the foregone wages of the caregiver. The annual cost of informal care per individual was obtained by multiplying the estimate of the annual volume of informal care with the estimate of the unit cost for each hour of informal care. We adjusted on demographics and comorbidities to get estimates of the average annual cost by age, sex, severity and year. We multiplied these estimates by the prevalence of dementia stratified by age, sex, severity and year to obtain our estimate of the total cost of informal care for dementia in the US.

Results:

This is on-going research although preliminary estimates show that informal care represents a significant share of the total costs associated with dementia in the US. However, drawing on both the opportunity and the replacement cost approaches to impute closely the cost of informal care for caregivers, we found estimates at the low end of the ranges of estimates published in the literature. We compared the results obtained with opportunity cost, replacement cost, and a mix of the two approaches, and found that final estimates of costs vary significantly with the approach chosen.

Conclusion:

Informal care makes up a major portion of the costs of dementia care. Ignoring informal care significantly underestimates the total cost of dementia, and lessens the true extent of the burden that affects families with a relative with dementia.

Poster Presentation Abstracts

ID: 348

Abstract Topic: Attitudes, awareness and stigma

Keywords: awareness, stigma, dementia literacy, knowledge, attitudes

The effect of dementia friends on attitudes towards dementia in adolescents: a pilot study

Nicolas Farina¹, Laura Hughes¹, Parveen Sahdia², Griffiths Alys³, Banerjee Sube¹

¹Brighton and Sussex Medical School, United Kingdom; ²University of Bradford, United Kingdom;

³Leeds Beckett University, United Kingdom

Abstract:

Introduction: Reducing stigma towards dementia is seen as a key policy priority internationally. Current evidence suggests that negative and stigmatising attitudes towards dementia may form at a young age, and therefore we need to ensure that we try to address this as early as possible. There are a number of dementia education and awareness sessions aimed at adolescents. One of the most widely utilised dementia awareness initiatives in the UK is Dementia Friends. However, as with many dementia awareness initiatives they have not been robustly evaluated in relation to effect on dementia attitudes or whether it is tailored to an adolescent population. This is a pilot study to explore the efficacy of Dementia Friends in a British adolescent sample.

Methods: 311 adolescents were assigned into either receive Dementia Friends (a one-off 60-minute interactive class that teaches about dementia and how it can affect people's lives) or education as usual. All participants completed a series of questionnaires pre and post, related to dementia attitudes (A-ADS and KIDS). A sub study of 30 adolescents also participated in focus group discussions exploring their perceptions of the session.

Results: Adolescents in the dementia awareness group only showed small improvements between time points. Qualitative feedback was generally positive, with adolescents believing that their attitudes and knowledge improved because of the session.

Conclusions: Dementia Friends is a great success in terms of numbers, though this pilot study suggests that it may not achieve its goal of reducing stigma. Importantly, Dementia Friends did not have a negative effect on attitudes, and most participants enjoyed the sessions. It is important that these findings are replicated in a larger randomised-controlled study.

Poster Presentation Abstracts

ID: 350

Abstract Topic: Formal carers education and training

Keywords: Dementia, Health Personnel, Caregivers, Education, Comparative Study

An international comparative study of dementia workforce education and training

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Abstract:

Ensuring informed and skilled workforces for people with dementia (PWD) is of international concern to meet the quality-of-life and care needs of PWD and their caregivers. However, dementia workforces and the training programs for them vary considerably between countries. By comparing the 83 dementia workforce education programs (13 from the United States, 34 from the United Kingdom, 7 from France, 15 from Japan, and 14 from South Korea) between countries, we tried to find the essential contents and effective operation of dementia workforce training. We found that all countries had a management system on workforce education programs. In the United Kingdom and Japan, governments provided the standard guideline for developing the education program.

In addition, the United Kingdom and Japan had a control tower for developing standard guidelines, coordinating education curriculums, and managing education records. Most countries provided the workforces with the education programs tailored to their capacity and role in care settings. Usually, the education programs consisted of basic and advanced courses, and the advanced courses were usually longer and more practices than the basic courses. In particular, the United Kingdom put more emphasis on the patient-centered approach and the end of life care than other countries. In all countries, the multidisciplinary team approach was emphasized.

Poster Presentation Abstracts

ID: 354

Abstract Topic: Informal carers support – pre, during and post

Keywords: Dementia, Carer, Support, Collaboration, Carer Centred

Carer support clinics-plugging the gaps in the care we give our carers!

Karen Shepherd

Illawarra Shoalhaven Local Health District, Australia

Background and Objective:

The demand for dementia assessment services within our local health district is extremely high- we have long waiting lists and diagnostic clinics are run at maximum capacity. Therefore, the time we get to spend with stressed carers is minimum. This was leading to increased carer burden and potentially affecting outcomes for the patients living with dementia.

A Dementia Specialist Nurse lead clinic aimed at carer support has been developed. Carers are able to attend to seek support and advice on a range of issues relating to dementia.

Proposed Benefits:

Carers-

Improved access to expert advice

A regular point of Contact

Will allow carers a "voice"

More patient/carers centred

The Service-

The potential to ease the Geriatric Wait List

An opportunity to provide a best practice patient/carers centred approach

An opportunity to have a more non medicinal approach to dementia management

The potential for transferability to other groups of carers managing other disease groups

The Dementia Nurse Specialist

An opportunity to work with an autonomous approach

An opportunity to improve outcomes for patients/carers

Methods for the Establishment of Carer Support Clinics

The carer support clinic was developed on the back of a collaborative research project that the Dementia Nurse Specialist is participating in that is being conducted by the Deakin University in Queensland, Australia titled: "Agents of Change"- Creating National Quality Collaboratives to improve dementia care.

Through a MOOC Learning Module gaps were identified and a final plan was developed based on findings for Carer Support Clinic

Poster Presentation Abstracts

Methods for the evaluation of Carer Support Clinic

Database developed

Carer Satisfaction Surveys

Colleague Satisfaction Surveys

Wait list numbers monitored pre and post clinic

Dementia Nurse Specialist attends monthly meetings with Deakin University Collaborative Research Team to discuss data findings to date

Conclusions

Evaluation of the Carer Support Clinics is ongoing and due for completion in December 2019

Initial data and anecdotal evidence to date is extremely positive.

A *snapshot* of data to date include:

- 27 carers seen via the Carer Support Clinic
- 22 carers referred to further education- such as "Understanding Dementia Workshop" and the "Living with Memory Loss Program"
- 15 referrals made to My Aged Care on behalf of the carers to access community services
- 21 carers requested to attend another carer support clinic
- Attendance by carers has been 100 %
- 12 referrals to the Dementia Advisory Service
- 7 referrals to the Dementia Behaviour Advisory Service
- 2 referrals to the Continence Advisor
- 27 discussions on carer "self Care"

The "project" phase of the Carer Support Clinic is due for completion in December 2019 and we look forward to final evaluation.

Local administration in the area health service are pleased to continue the Carer Support Clinic on an ongoing basis and are keen to trial this model of care for carers in other health groups.

Poster Presentation Abstracts

ID: 355

Abstract Topic: Informal carers support – pre, during and post

Keywords: dementia carers, spousal carers, carer support, communication, grief

'Til dementia do us part': caring and grieving for an intimate partner with dementia.

Jane Forbes Thompson¹, Gaynor Macdonald²

¹Member of the public; ²University of Sydney

Abstract:

Caring in the context of dementia is especially demanding. Caring for an intimate partner with dementia highlights these distinctive demands as they are experienced so acutely: the impact for carers continues long after the death of the person with dementia. Awareness of these impacts is needed if carers are to be cared for themselves. Lack of insight means that strategies designed to support them may be inadequate, compounding their emotional stress.

The primary focus on living well with dementia is the person with dementia. But living well also needs to encompass carers. In the absence of cure or effective medical treatment, the best treatment we can offer a person with dementia is a good carer. Over 70% of dementia care is provided at home by informal carers. Predominantly partners or adult children, they are untrained, unpaid, undervalued and often unsupported.

Our inspirations for this paper are our husbands who died with Alzheimer's disease. We tried to live well and be good carers, but faced huge challenges requiring enormous resilience - accompanied by enormous grief. We have sought to find meaning in our caring experiences and understand that grief. Our work draws on our professional and personal experiences and that of our network of experienced carers.

Dementia impacts significantly on the ways people connect with each other. As humans our connections with others are fundamental but dementia demands new ways of understanding what it means to be 'in connection'. Dementia is commonly understood as coinciding with a diminishing even eventual loss of self for the person with dementia. But what makes dementia care distinctive is that, as the person with dementia changes, the person of the carer must also change. These are not just changes in lifestyle or lost intimacies – they are more profound. They involve becoming part of a different relationship that requires a different sense of one's self.

It is challenging for any carer to understand how to respond appropriately to and communicate with a person who is changing, towards whom they must change. There is no greater impact than that on the relationship between intimate partners. A good carer may be able to hold their partner with dementia in their identity so that more of the old self remains. But what is happening to the self of the carer? What are the implications of changes in physical and emotional intimacy? Why do impacts continue long after the death of their partner? Much of the grief associated with seeing a loved one change is a grieving for the loss of one's own self as one adjusts. It is a complex grief, for the self and other of a pre-dementia relationship, for a loved one who has died, and then the loss of one's new carer-self.

Addressing these issues is critical to providing better support for carers. The insights from a focus on intimate partner carers provide an important window into the demands of dementia care more broadly, and the need to develop a more caring society.

Poster Presentation Abstracts

ID: 356

Abstract Topic: Models of care

Keywords: Nursing homes, care workers, professional role, dementia knowledge, qualitative research

A new role in aged care: the dementia care support worker

Emma J. Lea, Andrew L. Robinson, Kathleen V. Doherty

University of Tasmania, Australia

Abstract:

Introduction

Over half of Australian aged care (nursing) home residents have a dementia diagnosis, like many other countries. People living with dementia have high care needs in domains of daily living and behavioural support. It is vital that aged care home staff can meet these complex needs, yet gaps have been found in staff dementia knowledge. To address this, the University of Tasmania's Wicking Centre created the Bachelor of Dementia Care. A 2-year project across three care homes of one Australian aged care organisation developed and evaluated a new Dementia Care Support Worker role for a care worker with this degree. The study aims to examine staff perceptions of this role, to produce a model of the key considerations for its establishment.

Methods

Eleven interviews were held toward project end (early 2019) with people in middle-senior management (e.g. clinical nurse) and other key roles across the three sites, when data saturation was reached. The semi-structured interview schedule included questions on role usefulness and challenges and how to best prepare a Bachelor of Dementia Care graduate for this role. Interviews were audio-recorded and analysed thematically.

Results

Interviewees raised five key challenges to best support the establishment of the Dementia Care Support Worker role: 1) Role promotion; 2) Communication - infrastructure, skills, pathways; 3) Working across multiple sites; 4) Knowledge translation; and 5) Organisational culture. Four main benefits of the role emerged: 1) New approaches to care for residents with dementia; 2) Increased staff awareness and knowledge of dementia; 3) Support provided for staff; and 4) Support provided for family. Interviewees supported role continuation and expansion, recommending six key areas to consider when establishing the role: 1) Role structure; 2) Communication, teamwork and leadership to effectively engage with staff and residents; 3) Clarity of scope and management of role; 4) Role promotion; 5) Knowledge about dementia; and 6) Documentation skills. A model was developed from these themes, highlighting the need for clear support structures to be in place, including role definition, role promotion and training, in order to maximise the benefits of the role, which include staff training and education about dementia, trialling new approaches to care and supporting family.

Conclusions

In the context of the need in residential aged care for improved dementia knowledge and evidence-based practice in dementia care, the Dementia Care Support Worker role can improve staff and family awareness of dementia and resident care. The study suggests that this role should be modelled in other care homes, which can be assisted by utilising the developed model as a guide to ensure adequate support structures are in place.

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10-12 December 2020



Poster Presentation Abstracts

ID: 357

Abstract Topic: Education and training in hospitals – NEW

Keywords: dementia, falls, inpatients, multidisciplinary interventions

Multidisciplinary fall risk interventions in dementia ward

Si Ching LIM

CGH, Singapore

Abstract:

inpatient falls are common among the elderly with dementia. There are multiple factors which contribute to falls in the hospital among the elderly with dementia. Falls in the hospital is considered a serious reportable event, especially so if there are serious injuries involved. The elderly patients with dementia are 4 times more likely to fall and sustain injuries during falls, compared to their peers without dementia. The authors developed a Quality Improvement project targeting factors such as medication management, postural blood pressure monitor with interventions, physiotherapy referrals for gait assessment with intervention and routine screening for and management of urinary incontinence. Sharing the outcomes of these interventions.

Poster Presentation Abstracts

ID: 364

Abstract Topic: Models of care

Keywords: Nursing homes, nutrition knowledge, nutrition care practices, action planning, mixed methods

Meaningful engagement in nutritional understanding (menu) project: developing effective nutrition and hydration action plans for people with dementia in residential aged care

Emma Lea¹, Lynette Goldberg¹, Andrea Price¹, Fran McInerney¹, Kathleen Doherty¹, Amber Johnstone¹, Jane McDougall¹, Elizabeth Beattie², Liz Isenring³

¹University of Tasmania, Australia; ²Queensland University of Technology; ³Bond University

Abstract:

Introduction

Dementia increases malnutrition risk. Malnutrition rates for people living with dementia in residential aged care are high world-wide, often 50% or over. Malnutrition increases ill health and decreases quality of life. This presentation outlines the collaborative development of action plans to improve care for people with dementia in residential aged care in an Australian study: Meaningful Engagement in Nutritional Understanding (MENU).

Methods

The MENU participatory, whole-of-organisation intervention study involves residents, family members and staff collaboratively selecting and implementing customised and best-evidence nutrition care strategies for people living with dementia. Baseline mixed methods data were collected from two participating aged care homes (October 2018 - January 2019). Nutrition knowledge, attitudes and organisational practices were measured via a survey (49 staff & family members), qualitative data from workshops (47 staff, residents & family members), and nutritional screening and ethnographic observations (18 residents living with dementia). Data were analysed using descriptive and thematic approaches and shared with staff, residents and family members at workshops, along with education on best-evidence nutritional care to assist in identification of key intervention areas. Nutrition Champions at each home guided the chosen intervention strategies.

Results

Staff nutrition knowledge was moderate (mean score 6/11 on the survey), with a third having undertaken nutrition education. Observations suggested areas for improvement focused on strategies to increase hydration, maintaining adequate snacks between meals, and enhancing the mealtime environment – including staff and residents eating together and decreasing noise levels in dining rooms. Workshop attendance was challenging as attending to work activities was prioritised over participating in educational research. Despite this, workshop participants, Nutrition Champions, and researchers successfully worked together to consider the data and develop and implement a customised action plan for each care home.

Conclusions

Early findings show the positive impact of customised and evidence-based nutritional care for people with dementia in residential care, supported by tailored nutrition education. Implementing the adaptable and transferable MENU model assisted staff to focus on what worked best for the residents in their care and in their unique setting. This may enhance staff capacity to practice best evidence care, reduce nutrition-related ill health and optimise quality of life for people with dementia in residential aged care.

Poster Presentation Abstracts

ID: 365

Abstract Topic: Models of care

Keywords: Ability Centred Care, Enrich Model of Dementia Care, rich tasks, hierarchy of needs, Spirituality

Ability centred care model: a case illustration for implementing rich tasks for persons with dementia

Shi Fang Gay¹, Mee Choo Soh¹, Wei Ling Elaine Koh², Hwan Jing Koh², Eileen Yong¹

¹Apex Harmony Lodge, Singapore; ²Alzheimer's Disease Association (ADA), Singapore

Abstract:

Introduction: The Ability Centred Care (ACC) Model is a ground up living model conceptualised and being practised by Apex Harmony Lodge to guide care planning and implementation of rich tasks to enable persons with dementia to achieve their fullest potential. Built upon the Enriched Model of Dementia Care, the ACC Model helps to deepen the understanding of the interaction between the person's abilities and strengths, the physical and social environment and the provision of rich tasks that can cater to the various needs of persons with dementia to optimise participation.

Methods: A case report is used to describe the application of the ACC Model to allow the pitching and readjusting of the care provision to be of "just-right" challenge. Rick, a 69-year old Czechoslovakian entrepreneur has mixed dementia of Lewy body and Parkinson's disease. He participated in a Grand Prix and did paragliding, windsurfing and scuba diving. He is also an instructor for a self-established flying club. He takes pride in his role as a drummer in a rock and roll band during his younger days. He is self-ambulant in the home environment with low safety awareness. He engages in Gym Tonic, garden walk, playing darts games and watching music videos on iPad. Sometimes, staff plays oldies for him to reminisce.

Results: Guided by ACC Model, the improvised care plan and environment serve to enrich Rick's current engagement. As his basic Sensorimotor needs are fulfilled, Cognitive and Spirituality needs were prioritised out of the four level of needs and integrated into the plans to better engage him. When the environment offers only one stimulus each time, Rick attends better. His task engagement is also better when music is played in the background. Rick's Spirituality needs was observed in his consistent seeking to have meaningful conversation about music. He is also seen to be having an enjoyable time when he walks freely around the home. With the understanding that Rick takes pride in his physical abilities, activities are planned to help maintain and combat the degenerative nature of Parkinson's disease on him, while engaging his various senses. Tailoring to his short attention span, Rick is now empowered to move within the Gym Tonic to express his movements freely. Background music is deliberately played during the exercise to bring more enjoyment for him. The ad-hoc engagement with staff for reminiscence was replaced with regular individual music therapy session, for more profound interaction to reflect his life as a musician and creative expression. He has demonstrated positive affect while having music joint-making session with the music therapist.

Conclusion: The ACC Model highlighted a holistic view of the person with dementia and aided the care team to prioritise needs and formulate goals for the persons with dementia, enabling the care team to uncover hidden talents and unleash the potential of the individuals for purposeful and meaningful participation.

Poster Presentation Abstracts

ID: 368

Abstract Topic: Psychosocial interventions

Keywords: dementia, challenging behavior, caregivers, psychosocial support

Psychosocial support for people with dementia with challenging behavior and their carers living in the community: two interventions in the Netherlands

Marleen Prins^{1,2}, Iris van Asch¹, Bernadette Willemse¹, Anne Margriet Pot^{2,3,4,5}

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Abstract:

Behavior of people with dementia living in the community changes over time. These behavior changes can be difficult to cope with for people with dementia themselves and their family carers. Research has shown negative effects on quality of life of the people with dementia, their family carer and their relationship. Changes in behavior that are difficult to cope with accelerates the placement of the people with dementia in a care home. Apart from the fact that people prefer to stay in their own environment as long as possible, placement in a care home also has a substantial impact on the already high costs of long-term care. Therefore, the availability of psychosocial interventions for managing challenging behaviors is important and currently lacking in the community. Psychosocial interventions for managing challenging behaviors should use a person-centered approach and try to discover underlying causes of behavior and try to influence them, in line with the theory of Tom Kitwood. Two interventions have been developed and evaluated. These interventions focus on discovering underlying causes for the behavior and formulate individualized plans. The first intervention is an e-learning that consists of six films with different types of behavior that are freely available on a national dementia platform for family carers (dementie.nl). In these films, family carers and professionals explain what the behavior entails, what common causes are and how they coped with the behavior in the past. The second intervention is aimed at dementia case managers. They learn to follow a six step method in helping people with dementia and their family carers to manage challenging behavior. Important elements are: using a multidisciplinary approach, involving family carers in discovering causes and evaluating the individualized plan. These interventions improve psychosocial care for people with dementia and their carers dealing with challenging behavior living in the community. The development and content of and experiences with both interventions will be presented.

Poster Presentation Abstracts

ID: 369

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, caregivers, intervention, post-diagnostic, dyadic

Dyadic intervention for people with dementia and their family carers in an early stage after the diagnosis

Marleen Prins, Marjolein Veerbeek, Elsemieke van Belzen, Bernadette Willemse

Netherlands Institute of Mental Health and Addiction (Trimbos-institute), Netherlands, The

Abstract:

Background and objectives Adaptation to and coping with the diagnosis dementia is a complex process. The right support in this phase is important to find the right care and to (self-)manage future care wishes. However, people with dementia and their family carers often experience support directly after the diagnosis as inadequate. Support is not provided until problems start to accumulate and available support is not focused on continuation of their life and the emotional impact of the diagnosis. Therefore, the intervention SHARE [Support, Health, Activities, Resources, Education] was developed and studied in the US and adjusted to and pilot-tested in the Netherlands with positive results. SHARE is innovative because it is designed for dyads dealing with early-stage dementia to enhance communication between people with dementia and their family carers and to prepare them for the future. In this study, the (cost)effectiveness of the Dutch SHARE is evaluated.

Methods The intervention is designed for dyads dealing with early-stage dementia to enhance skills of the dyad to cope with changes and stressors that might be expected in the future due to the dementia. The intervention consists of a pre-session and four or five sessions. The intervention is performed by healthcare psychologists when the person with dementia is still able to participate actively and before the family carer is overwhelmed by care-related stress. The primary outcome measurement for the people with dementia is quality of life and self-efficacy for the family carers. Secondary outcomes are stress, communication in the relationship and perspective taking (only family carers). The design and procedures of the RCT will be presented in this poster session as well as the demographic characteristics of participating dyads.

Positive impact and perspectives This study contributes to knowledge about psychosocial interventions for people with dementia and family carers with special attention for preventive empowerment of the ability to cope with the disease and the capacity to deal with the situation.

Poster Presentation Abstracts

ID: 370

Abstract Topic: Non-pharmacological interventions

Keywords: Therapeutic cooking, Mild cognitive impairment, quality of life, dementia, confectionery

Effect of therapeutic cooking for the elderly with mild dementia and mild cognitive impairment (MCI). - from a practical research at a " confectionery cooking club " in a nursing home in Japan-

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¹Kyoto University of Education, Japan; ²Saintpaulia Ainosato; ³Kindai University; ⁴Elegano Konan

Abstract:

Introduction Cooking activities can be expected to have various therapeutic effects such as alleviating behavioral and psychological symptoms of dementia (BPSD) and improving quality of life (QOL). We defined this as "therapeutic cooking", and the purpose of this study is to clarify the effects of regular therapeutic cooking for the elderly with mild dementia and mild cognitive impairment (MCI).

Methods From July to December 2016, the "Confectionery Cooking Club" was held twice a month for residents in a private nursing home. One class was a practice class and it was conducted with 3 participants and 2 staff members. 2 weeks later, we conducted a improved version as the regular class with 7-9 participants and 3-5 staff per session. Before and after the course, the degree of dementia was evaluated by Clinical Dementia Rating (CDR) and the "Forgetfulness Consultation Program", and the QOL evaluation was evaluated by the Multi-dimensional Observation Scale for Elderly Subjects (MOSES). In addition to the overall evaluation (support method, etc.) of each regular class by the staff, observational surveys were conducted.

Our study was approved by the Research Ethics Committee of Kyoto University of Education. We explained the purpose, contents, and ethical considerations of this study verbally and in writing to the participants and the facility manager and obtained their consent.

Results After interviewing participants, we created a recipe that introduced western confectionery. After the practice class, we gathered feedback from participants and modified the class to introduce western confectionery.

In the first regular class, the overall evaluation of preparation and support methods was low, but it increased after the second regular class. As for the effect on participants, 5 out of 7 participants who participated continuously showed improvements in the degree of dementia. In particular, one person who participated in all the classes, including the practice classes, recovered from MCI to a healthy state, improved quality of life with MOSES, increased communication with staff and participants, and demonstrated changes in facial expressions. For the other four, MOSES and observational evaluation improved, and participation in other activities also increased. In addition, there was a participant who increased their amount of time spent cooking in their free time, which was also effective in improving the quality of their daily life.

Poster Presentation Abstracts

ID: 371

Abstract Topic: Models of care

Keywords: communication, nursing staff, people with dementia, person centered care, caregivers

Enhancing communication between nursing staff and people with dementia and their formal and informal carers: development of tools

Claudia van der Velden, Marjolein Veerbeek, Bernadette Willemse

Netherlands Institute of Mental Health and Addiction, Netherlands, The

Abstract:

Background Nursing staff play an important role in the care of people with dementia, both at home and in residential care. Communication is essential in providing person centered care to people with dementia. However, symptoms of the disease, such as deterioration in memory, concentration, thought and speech, make communication with people with dementia more challenging. Therefore, at the request of nursing staff themselves, we developed tools to support nursing staff to better communicate with people with dementia in daily care.

Methods First, we identified bottlenecks in communication experienced by nursing staff, informal carers and people with dementia through online questionnaires among nursing staff (1.070) and informal caregivers (n = 446) and face-to-face interviews with informal carers (n = 7) and people with dementia (n = 5). Next, we set up a working group consisting of nurses, nurse practitioners, caregivers, psychologist, elderly care physician and a representative of the Dutch Alzheimer's Association (n = 15) to support us with the development of the tools. Besides scientific literature, their practical experience form the basis of the tools. Finally, there is a field-test, in which nursing staff (n = 45) uses the developed tools for three month in daily practice, to help improve the tools even more and learn about enhancing and hampering factors in using them. All this is done to match the tools with the needs in practice as good as possible.

Results Identification of the bottlenecks showed that for person centered care, not only communication between nursing staff and people with dementia themselves needed to improve, but also communication between nursing staff and the informal carers and other professionals involved. Therefore, the tools serve as a handle for enhancing communication with all three groups. A guide incorporates recommendations how to communicate with all three groups. It is specified whether the recommendations are based on literature, or practical experience by the working group. The recommendations are enriched with practical examples, to make the recommendations more tangible for the nursing staff. Furthermore, reflection tools and short videos are developed to enhance practical use even more. In this poster session the steps in development and the tools themselves will be presented.

Perspectives The Dutch professional nurses organization, called V&VN, is owner of the tools and they will implement them on a nationwide level.

Poster Presentation Abstracts

ID: 375

Abstract Topic: Non-pharmacological interventions

Keywords: project, horizon, bpsd, trial, intervention

Recage project – respectful caring for agitated elderly - horizon 2020

Carlo Alberto Defanti¹, Sara Fascendini¹, Mario Possenti²

¹Centro Alzheimer FERB, Gazzaniga, Italy; ²Federazione Alzheimer Italia, Milano, Italy

Abstract:

Introduction

The current state-of-the-art of the treatment of one of the most challenging problem arising during dementia the so-called Behavioral and Psychological Symptoms of Dementia (BPSD) is still unsatisfactory. Some European countries have implemented a residential medical structure- called SCU-B- lying outside of a nursing home, in a general hospital or elsewhere, where person with dementia (PwD) are temporarily admitted when their behavioral disturbances are not amenable to control at home. The major objective of the Recage project who has received funding from the European Union's Horizon 2020, will be to assess the effectiveness of the intervention in SCU-B.

Methods

The consortium of RECAGE consists of 17 organisations, covering all the necessary components of the ecosystem and of the innovation chain, to reach the project objectives. 11 clinical partners have been involved to perform the clinical study, five of these with a SCU-B (Gazzaniga, Modena, Ottestad, Genève, Mannheim) and the other centres lacking this structure (Thessaloniki, Mantova, Bergamo, Perugia, Paris, Berlin). The study will have a recruitment phase of nine months, followed by the clinical observation during 36 months. So, the total duration of the study will be 52 months. In a first phase 500 patients with moderate dementia and severe BPSD (NPI >32) age <82, in two cohorts of 250, will be recruited by five clinical centres endowed with a SCU-B (first cohort) and six centres lacking this structure (second cohort). The follow-up will last three years and patients will be visited every 6 months and submitted to a battery exploring the severity of the BPSD.

The study will allow us:

- To assess the short and long-term clinical effectiveness of SCU-B on BPSD
- To measure the changes of the quality of life of the pwd/carers over time
- To explore if the SCU-B is effective in delaying institutionalisation
- To performe the cost-effectiveness analysis comparing the cohorts.
- To evaluate the ethical aspects of care in the SCU-B (use of restraints, attitude of the staff/relatives to the pwd, the quality of life of the primary caregivers etc.)

The second phase will be devoted to adapting the model according to the results of the cohort study. The third phase is a plan for scaling up the intervention in the countries who take part in the study, primarily in countries where SCU-B are absent or not widespread (Italy, Greece).

Results

We choose to split the different actions we are going to undertake in seven main work packages. Now completed the WP1. WP2 is the core of the project and is made of two moments: the enrolment, lasting 9 months (completed), and the three year follow-up (in course).

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Poster Presentation Abstracts

Conclusions

Our working hypothesis is the superiority of the pathways comprising a SCU-B over the other one lacking it both for its short term efficacy (alleviating BPSD and improving quality of life of PwD) and possibly for its long term efficacy, measured as delay of NHP.

Poster Presentation Abstracts

ID: 378

Abstract Topic: Dementia friendliness

Keywords: friendly, community, network, italy, indicators

Strengths and weaknesses of dementia friendly program in Italy. A network of 25 community.

Mario Possenti, Gabriella Salvini Porro, Francesca Arosio

Federazione Alzheimer Italia, Italy

Abstract:

At the beginning of 2016 the Italian Dementia Friendly Community program was started by Federazione Alzheimer Italia on the basis of a protocol developed in Great Britain by Alzheimer's Society, with a pilot project in Abbiategrasso, a 30,000 inhabitant town in northern Italy.

The basic idea was to evaluate the feasibility of a large-scale dissemination of these communities while always keeping in mind the peculiarities of Italian society. For the realization of a Dementia Friendly Community, the steps to be taken are first of all the formation of a promoter group, the creator and engine of initiatives that monitors over time how much is being done and the needs of people with dementia and their families. Federazione Alzheimer Italia, working alongside local organizations, provides official guidelines, materials for the implementation of customized activities, suggestions and recommendations as well as tools for assessing consistency and effectiveness of all interventions.

Federazione Alzheimer Italia, with the pilot site in Abbiategrasso, is involved together with other partners in the Work Package 7 of the Joint Action, dedicated to Dementia Friendly Communities, with the aim of validating a series of indicators and providing indications for a shared model.

To date in Italy there are 25 Communities: towns and portions of cities, which have accepted the challenge of Federazione Alzheimer Italia with commitment to launch a path on their territory where citizens have the opportunity to welcome and involve people with dementia. This path is made up of informative meetings, recreational, cultural and sports events aimed at the participation of citizens, never forgetting the active involvement of people with dementia.

The project continues to spread and grow because more and more communities have perceived the importance of initiatives like these to make dementia known but above all to fight the stigma towards people who live with dementia. However, it is necessary to monitor and evaluate these initiatives over time as it is essential to have data to be able to know, in the long term, the impact on the population and to be able to overcome those difficulties that may arise, for example, from different social contexts.

Evaluation and monitoring are quality marks of the initiatives taken in place for a Dementia Friendly Community: precisely because each reality is different from the others and there is no uniform path to the social change, it is crucial to identify indicators, modality and timing for the evaluation of the initiatives.

For this reason a working group was created for the study of appropriate indicators and, thanks to a series of self-assessment tools, collected and identified the strengths and weaknesses of each community. Through these measurements it was possible to create and share with all the communities a series of useful recommendations in order start a path toward the inclusion of people with dementia.

Poster Presentation Abstracts

ID: 380

Abstract Topic: Environment and architecture for dementia

Keywords: architecture, design, dementia, research, caretime

“Come to your senses - dementia-sensitive design saves money!”

Dr. Birgit Maria Dietz

BIfadA Bavarian Institute of Architecture for the elderly and cognitively Impaired, Germany

Abstract:

As we age, we must all adjust to the increasing functional limitations of our bodies, our senses and our mind. As long as we are still able to understand what is happening to us, we are able to develop our own individual strategies to compensate. For example, we put on glasses and seek a place with good illumination to read.

However, when the normal aging process is accompanied by dementia, architects and designers must strive to offset the limitations of our bodies by designing surroundings that offer practical solutions. A decline in abilities should trigger efforts to make that person's surroundings safe and understandable. Our goal as architects should be to maintain as much balance for as long as possible.

If such efforts are not made, a loss of competence becomes evident, a feeling that the living space no longer serves the person's needs in the way that they would wish. This leads to feelings of anger or sadness, while loss of competence leads to fear especially in unfamiliar environments like for example a hospital. Fear in turn results in actions such as running away or hiding, and ultimately to social isolation.

Thus, it is crucial to minimise this feeling of incompetence and uncertainty. But, as architects, what exactly can we do? Building for the elderly means thinking about acoustics, colours, orientation aids, lighting and additional practical details. Often even small interventions do have big impact.

So we set up a pilot study to find out how long it takes staff in a care facility and in a hospital to help patients get to and use the toilet:

The reliability of the recorded times at care homes was open to question because nursing home residents were given incontinence pads at the first sign of wetting regardless of the cause for that being urinary or cognitive. Furthermore staff took residents to the toilet, but then completed other tasks before collecting the residents some time later.

The pilot study has therefore been limited to patients at hospitals. We timed care time for taking patients to the toilet in different departments. On average the recorded time was 15 minutes.

We then examined whether architectural measures can promote the independent use of the toilet and thus save nursing time. An intervention in the hospital that is both easy to carry out and to control is the use of a sticker placed above the door handle on the washroom door. The evaluation of questionnaires filled out by the hospital staff showed that washing rooms with stickers tended to be found by patients more often than the rooms without stickers. In addition no incidents of patients wetting themselves occurred in the rooms with bathroom stickers. Taking on average those 15 minutes for assisted toilet visits and those 15 minutes for washing and changing clothes in the course of urination, these minor modifications demonstrate that dementia-sensitive design can markedly reduce care time.

Poster Presentation Abstracts

ID: 381

Abstract Topic: Psychosocial interventions

Keywords: Needs of people with dementia, diagnosis, family carers, psychosocial

Examining the needs of people with dementia and family carers directly after the diagnosis dementia

Claudia van der Velden, Elsemieke van Belzen, Bernadette Willemse

Netherlands Institute of Mental Health and Addiction, Netherlands, The

Abstract:

Introduction

Most often the diagnosis dementia gives people clarification, but at the same time it raises questions and causes a range of emotions. According to professionals, support for people with dementia and family carers (client pairs) nowadays is mainly focused on later-stage-dementia instead on early-stage. Besides, this support is mostly about practical/medical topics and less about emotional/psychological or social topics. Studies show that it is a complex process for people with dementia and family carers to cope with the diagnosis in their daily life directly after diagnosis.

Aim

The aim of the present study was to examine the specific needs of client pairs in order to support them in the early-stages after diagnosis .

Methods

Focus groups, interviews and a literature-review were performed to determine these needs. Together with professionals, findings were translated into a conversation guide, which helps professionals to have a structured dialogue on practical/medical, emotional/psychological and social topics with client pairs in the early stage after the diagnosis. An evaluation is conducted by observations and interviews with client pairs (n=5) and a work session with professionals.

Results

People with dementia, their caregiver(s) and professionals experience these conversations as very positive. Client pairs indicated that the power of the conversations is mainly in the type of counsellor (accessibility, warm and giving a comfortable feeling). Also, timing of the conversation is crucial to prevent falling into a 'gap' after diagnosis. According to client pairs, most important themes were focusing on 'not making the diagnosis too heavy' and 'sharing the diagnosis with friends/family'. The professionals were also very positive about the conversation. Important themes for them were focusing on the more personal, holistic and preventive approach in the conversations.

Conclusion

In order to accommodate the needs of the client pairs, the conversation in early-stage after diagnosis should be carried out in a personal, holistic manner and should address themes that include coping and sharing the diagnosis with others. Above all, the counsellors leading such conversations should do so in a warm and accessible manner.

Poster Presentation Abstracts

ID: 382

Abstract Topic: Formal carers education and training

Keywords: e-learning, person-centered-care, health care professionals

Evaluation of an e-learning aiming to improve person-centered attitude in healthcare professionals working with people with dementia

Claudia van der Velden, Bernadette Willemse

Netherlands Institute of Mental Health and Addiction, Netherlands, The

Abstract:

Introduction Healthcare professionals working with people with dementia (PwD) have increasingly been moving away from task-oriented models of healthcare towards a more person-centered care (PCC) model. Several studies have showed positive results of PCC on quality of life of PwD. Also, it shows positive effects on self-esteem and work satisfaction of healthcare professionals. An effective way to educate professionals in PCC and improve their knowledge and person-centered attitude is by using online learning tools.

We developed an e-learning in co-creation with end users focusing on well-being and (changing) behavior of PwD. The interactive e-learning supports healthcare professionals in developing a person-centered attitude, using practical videos and exercises.

Methods In the current pilot study, the e-learning is evaluated. To date, 33 healthcare professionals working in Dutch care homes from different care organizations participated in the study and completed the e-learning. In addition, they filled in online questionnaires before and after completing the e-learning. The questionnaires include the Approach to Dementia Questionnaire, Dementia Knowledge, Person Centered Care, Sense of Competence in Dementia Care Questionnaire. Post-measurement also included questions about satisfaction with the e-learning and user-friendliness.

Results The final participants are currently completing their post-measurement questionnaires and final results are expected in September 2019. Preliminary data-analysis shows promising results. Positive effects on knowledge about dementia, person-centered attitude and sense of competence are expected. Also, user-friendliness, especially the flexibility of the e-learning (being able to follow the e-learning at home or at work and being able to stop and continue at any time) and the practice-oriented videos are positively evaluated.

Conclusion Preliminary results of this pilot study suggest that the e-learning might contribute to developing a more person-centered attitude in healthcare professionals and indicate that participants have positive experiences with the e-learning module.

Poster Presentation Abstracts

ID: 384

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: motor-cognition rehabilitation, multidisciplinary group exercises, Short Physical Performance Battery (SPPB) test, muscle flexibility, community-based

The effect of motor-cognition rehabilitation programs at support center for people with dementia and their families (SPDF)

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Abstract:

Background

To facing an aging society and the increasing cost of dementia care, the government of Taiwan developed the long-term care program of dementia prevention and care policy and action plan v2.0 to setup the Integrated Dementia Care Center (IDCC) and Support Center for People with Dementia and their Families (SPDF) to supporting a dementia friendly community. According to evidence based medicine we designed a 12-week multidisciplinary program with motor-cognitive interventions combining cognitive games and physical activities in one SPDF. In this study we will share the effect of motor-cognition rehabilitation programs on the physical functions and emotion of these participants.

Methods

From 2019/4/3 to 6/26, there are twelve elders participated this multidisciplinary motor-cognitive training program. The content of cognitive program included color matching vegetable and fruit names, building block game, 0-10 numbers writing with body part, singing with the cross midline physical exercise combine with muscle strengthening, muscle stretching, sensory stimulation, balance training group exercises. All the participants has mild to moderate dementia and aging more than 80 y/o. They participated this program 2 hours a week for 12 consecutive weeks and received evaluations before and after training program. We evaluate their physical conditions including the muscle strength, muscle flexibility and the Short Physical Performance Battery (SPPB) test. We also used the emotional face picture from 0-10 scale to evaluate mood, and the Kihon Checklist to evaluate general frailty.

Results

The average attendance rate was 93.75%. The average improvement rates were 24.5% in the Short Physical Performance Battery (SPPB) test, 29.8% in the lower extremity muscle strength, and 30.8% in grasp strength. The average improvement rates of flexibility of lower extremity is 4.5cm and upper extremity is 6.7cm. All the participants with dementia showed happy mood during the training course and the Kihon Checklist average improvement rate is 10.2%.

Conclusion

This study reveals the positive effect of cognitive-motor rehabilitation programs on physical functions of elderly with mild to moderate dementia. They got improvement in strength and flexibility and the walking performance. This "community-based" service system with good support of each family, good country policy and friendly community follow by the group exercise combine cognitive activity will improve physical function, emotional stability and reduce anxiety for the elderly with mild to moderate dementia.

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The limitation of our study is the small sample size and no control group. Future research with a randomized control design and larger sample size is needed.

Poster Presentation Abstracts

ID: 386

Abstract Topic: Well being and quality of life

Keywords: Quality of life, care homes, instrument development, routine outcome assessment

Quality of life measurement in care homes: reliability and validity of the demqol-ch instrument

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Abstract:

Background and aims: In the UK a third of people with dementia live in care homes. The quality of care has been questioned, with calls to improve services provided to older adults. One problem in understanding care in homes is that we do not collect information on the quality of life (QoL) of residents as a part of normal care. QoL measurement captures the overall effect on an individual of the care they receive and the illnesses and problems they have. Obtaining routine measurements such as QoL could be beneficial and feasible in improving resident outcomes. However, the routine use of QoL instruments in care homes in the UK has not been investigated. This is likely due to a lack of suitable instruments for routine use in care homes by care staff. The aim of this study was to investigate the routine use of a measure of QoL in care homes and assess its psychometric properties when used by care staff.

Method: A two-phase study was carried out. Phase 1: The ability of care staff from two care homes to use the DEMQOL-Proxy without interviewer-administration was assessed using agreement analysis between a self-administered and interviewer-administered (the standard method of administration) version of the instrument. Based on these findings, DEMQOL-Proxy was adapted into a new version, DEMQOL-CH, for use as a self-administered instrument in care homes. We assessed agreement between the new DEMQOL-CH and DEMQOL-Proxy to ensure DEMQOL-CH was used correctly. Phase 2: A preliminary assessment of the psychometric properties of DEMQOL-CH when used routinely was completed in a further five care homes.

Results: Phase 1: Nineteen care staff from two care homes completed QoL measurements for residents. Systematic error was identified when staff self-completed the DEMQOL-Proxy without an interviewer. We modified the DEMQOL-Proxy to create DEMQOL-CH; this reduced the error, producing a version that could be used more accurately by care staff. Phase 2: Eleven care staff from five care homes rated resident QoL routinely. DEMQOL-CH showed acceptable psychometric properties with satisfactory reliability and validity and a clear factor structure.

Conclusion: The research presents positive preliminary data on the acceptability, feasibility and performance of routine QoL measurement in care homes using an adapted version of DEMQOL-Proxy, the DEMQOL-CH. Results provide evidence to support the concept that routine measurement of QoL may be possible in care homes. Research is needed to refine and test the instrument further, and to explore the potential for benefits to residents, staff, and care homes in larger and more representative populations.

Poster Presentation Abstracts

ID: 388

Abstract Topic: Attitudes, awareness and stigma

Keywords: education; stigma; healthcare students

Perceptions and attitudes towards dementia among university students in Malaysia

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Abstract:

One of the major challenges worldwide is the stigma associated with dementia. There is limited dementia awareness within Malaysian communities, including levels of confusion regarding the differences between dementia and the usual ageing progress, which can lead to delays in support seeking. The need for additional training and education for healthcare professionals has been highlighted. The present study aimed to evaluate the benefits of a one-hour dementia education session (Dementia Detectives workshop) for pharmacy undergraduate students at a Malaysian university. This workshop aims to increase understanding of dementia and develop positive person-centred attitudes towards those living with dementia. A total of 97 participants attended the workshop and completed pre- (Time 1) and post-workshop (Time 2) questionnaires consisting of validated measures exploring attitudes towards dementia and older people more broadly. Attitudes towards people with dementia showed significant positive changes between Time 1 and Time 2, whereas no differences were found for attitudes towards older people. Significant increases in perceptions of the length of time dementia affects someone's life, the control someone with dementia has over their illness, level of concern about a person, and how well participants understand dementia were also seen. As medical and pharmacy students develop theoretical knowledge, practical skills and professional attitudes during their undergraduate studies, it is important for students to also learn about the humanistic side of diseases and conditions through workshops such as the one presented here.

Currently there is no National Dementia Strategy in Malaysia. As limited dementia awareness, and negative attitudes and stigma towards people with dementia have been highlighted as issues in Malaysia (Nikmat et al., 2011), the Dementia Detectives workshop offers an opportunity to address these issues in the short term, whilst a strategy is developed. Additionally, a dementia education and training framework should be developed to ensure that future healthcare professionals receive appropriate training to support people living with dementia. Further research should now be conducted to consider how Dementia Detectives can be delivered to non-healthcare students and what the barriers and facilitators to wider delivery are. Furthermore, work should be conducted with young people to establish what they believe the core components of a dementia education workshop should look like, and establish the barriers and facilitators to delivering Dementia Detectives more widely.

Poster Presentation Abstracts

ID: 393

Abstract Topic: Epidemiology

Keywords: subjective cognitive decline, prevalence, epidemiology, preclinical Alzheimer's disease, cross-cohort analysis, harmonization, item response theory, individual participant data, COSMIC

Estimating prevalence of subjective cognitive decline across international cohort studies of ageing: a cosmic study

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Abstract:

INTRODUCTION Subjective cognitive decline (SCD), i.e. a self-experienced decline in cognitive ability in the absence of objective cognitive impairment, is recognized as the first notable cognitive syndrome in the preclinical stage of Alzheimer's disease (AD) and other dementias. However, estimates on the prevalence of SCD are scarce. Therefore, we aimed to estimate SCD prevalence based on consensus research criteria for SCD across international cohort studies of ageing.

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METHODS Analyses were based on the combined baseline data for 16 international cohort studies from 15 countries. All studies were members of COSMIC (Cohort Studies of Memory in an International Consortium). Qualitative/semantic and quantitative (Item Response Theory/IRT) approaches were used to a) harmonize SCD items across studies and b) derive SCD prevalence estimates, applying a uniform operationalization algorithm based on current SCD research criteria and implementation guidelines.

RESULTS Analyses included data from 39,387 cognitively unimpaired individuals at least 60 years of age (mean age: $M = 73.1$ years; $SD = 7.1$ years); 57.7% were women. Variety of SCD items was high between studies; however, qualitative harmonization (QH) and IRT both robustly suggested a total SCD prevalence of around one quarter (QH: 23.8%, 95%CI = 23.3%-24.4%; IRT: 25.6%, 95%CI = 25.1%-26.1%) across uniform criteria. SCD prevalence was lower in a) women compared to men, b) individuals with educational levels above primary, c) high-income countries compared to countries with lower income levels, and d) in White people compared to Asian people.

DISCUSSION SCD occurs relatively frequently in ageing populations around the globe, as estimated across 16 international cohorts. However, SCD measurement techniques vary in the absence of standardized instruments, and therefore, our prevalence estimates may be associated with some inaccuracy. Nevertheless, with almost a quarter of all elderly reporting SCD, further investigation of its significance as the first cognitive syndrome in preclinical AD and other dementia is needed. This may lead to improved strategies for early identification and prevention of dementia.

Poster Presentation Abstracts

ID: 395

Abstract Topic: Dementia and dignity

Keywords: Dignity, validated measures, lifelong learning, experiences, responses

Exploring how the use of validated measures may affect the way people with dementia respond and how their dignity can best be supported

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Abstract:

Introduction: A study in the Northern part of Denmark, explored the potential effect of lifelong learning on people with dementia, compared with people with dementia receiving treatment as usual, using five validated measures (cognitive function, quality of life, problem solving, self-esteem and social engagement). Each participant was video recorded completing the pre and post assessments to understand how people with dementia experience and respond to such measures, and whether this process supports their dignity.

Methods: Participants from a lifelong learning intervention (n=36) and a treatment as usual control group (n=34) carried out pre and post validated measures on cognition (MMSE), quality of life (QOL-AD), self-efficacy (General Self-Efficacy Scale), self-esteem (Rosenberg Self-Esteem Scale), and socialisation (Hawthorn Friendship Scale). Each pre and post assessment was video recorded. A pilot analysis phase identified 10 videos (5 control, 5 intervention) of the pre-assessment stage. These recordings were analysed using a video analysis framework (Ridder 2007; Ward 2019).

Results: The findings show that people with dementia wanted to take part in this study, and showed focus and care in how they responded. Questions could be experienced as challenging and complex, and participants showed signs of distress and loss of concentration at times. However, they could be guided to enhance focus again. They also sought confirmation of the correct response, requiring the researcher to provide reassurance about the meaning of questions. Humour and the use of personal stories were reported as a coping mechanism when faced with a challenging question. The measures were found to miss nuances of the responses, as participants explained and reflected on how they interpreted a question. The role of the researcher in supporting, both verbally and nonverbally, the participants was found to be an important aspect of the processes.

Conclusions: That validated measures may miss the reasons for how people with dementia respond to validated measures, with some variability in their interpretations. Furthermore, the measures may miss important information about how they experience living with dementia, as they often share personal stories to explain why they have responded a certain way. The findings provide learning for the way researchers can support a person with dementia's dignity through an assessment, how to maintain positive relationships and support their identity. Little information is provided by the measures on how to interact with people with dementia, or how to guide researchers when participants seek clarity, without invalidating the measure. However, some of the measures might be relevant as a starting point for a deeper, more meaningful conversation as they may encourage people with dementia to open for their feelings and experiences of living with dementia.

Poster Presentation Abstracts

ID: 401

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: twinning, indonesia, netherlands, partnership, communities

Twinning program Netherlands Indonesia

Amalia Fonk Utomo

Stichting Alzheimer Indonesia Nederland, Netherlands, The

Abstract:

Background & Objective

Alzheimer Indonesia and Alzheimer Netherlands have a strong collaboration under the Twinning Program of Alzheimer's Disease International. This is a three-year collaboration for 2017-2019 and actually a renewal of a previous program.

To exchange information, support and learn from each other and for Alzheimer Indonesia to benefit from the organizational experience from Alzheimer Netherlands to improve quality life of people with dementia and caregivers.

Activities and Impact

The main elements of this projects by mid 2019 are:

- Support (knowledge transfer) for the ADI Asia Pacific conference in 2-7 November 2017 in Jakarta including 7 expert speakers from the Netherlands with result 700 participants including multi disciplinaries: health care workers, chapter leaders, youth community leaders, volunteers, general public and government officials. 45 representatives from 20 countries.
- Capacity building for Alzheimer Indonesia by increasing to 21 chapters, 173 caregiver meetings and 12 home visits.
- Training of Indonesian volunteers in Dementia Care Skills with 7 trainers and 26 caregivers.
- Hope, love and care public event in Malang, Indonesia in 19-21 October 2018 19-21 October: Public Event, Malang Indonesia with more than 700 participants in 3 days (multi disciplinaries: health care workers, chapter leaders, youth community leaders, volunteers, general public and government officials), 6 international speakers (3 from ALZI Netherlands; 1 from University of Rotterdam, Netherlands; 1 from University of Tasmania, Australia; and 1 from ADI Asia Pacific) and 8 national speakers.
- Support for awareness activities for Indonesian in the Netherlands through Stichting Alzheimer Indonesia Nederland.
- Presentation of Twinning results at European Alzheimer conference 2019 in The Hague, Netherlands.

Perspectives

Alzheimer Nederland received a three-year grant from the Ministry of Health to support the program financially in collaboration with Alzheimer Indonesia and Alzheimer Indonesia Nederland. And we hope to extend the Twinning Program for the next couple of years.

Poster Presentation Abstracts

ID: 403

Abstract Topic: Dementia policies and public policy

Keywords: Multi-Stakeholder Groups, Citizen Activities, Advocate

Impact of proposals by liaison committee among dementia stakeholders and supporters groups in japan for the realization of a friendly society where people can live alongside "dementia"

Naoko Hara¹, Atsushi Onodera², Eriko Okuyama³, Reiko Nishino⁴, matsuyo Kamada¹, Sanae Umehara², Kahoru Nagasawa³, Norio Uchiyama⁴, Morio Suzuki¹, Masatoshi Tsudome⁴, Kazuo Miyanaga²

¹Alzheimer's Association Japan; ²National Family Association of Early-Onset Dementia and Supporters Liaison; ³Dementia With Lewy Body Support Network; ⁴The National Network of Male Carers and Supporters

Abstract:

Liaison Committee among Dementia Stakeholders and Supporters Groups in Japan. Subsequent to these discussions, we formulated a proposal for the realization of a friendly society where citizens and governments can live alongside with "dementia", announced in May 2019. The proposals were formulated by a group composed of four nationwide organizations with different focuses and objectives regarding dementia, including comprehensive dementia care, early onset dementia, Lewy body disease, and male caregivers. Our membership consists of people with dementia, their family caregivers, and partners and so on.

Our proposals, therefore, reflect the issues and concerns held by the various groups represented in the discussions. It was important, however, to decide on a common theme as well as more specific points of special interest in the proposal. In addition to introducing this proposal to the public, we made efforts to deliver it to the Ministry of Health, Labor and Welfare, related ministries, and the Diet members. Since the G20 Osaka Summit was held in June, there has been significant media interest and we drafted a news article to promote our proposals.

At the same time, the Japanese government proposed a draft policy for promoting dementia policy through the Ministerial Conference for Promoting Dementia Policy. The government's proposal focused on prevention and community engagement with dementia. Almost all of our members opposed the idea that dementia prevention was a prerequisite. We don't want to deny the importance of dementia prevention, but we were concerned about the prejudice such an idea may cause. Even given a policy of prevention, treatment has not yet been established and we are not in a position where complete prevention is possible. We are concerned that people who develop dementia will suffer greater prejudice because of a perceived failure to prevent dementia's onset. The Japanese government changed the pillars of dementia measures to engagement and prevention because we expressed concerns about prejudice at the same time as the recommendations. Living alongside and engaging with dementia is the foundation of a dementia-friendly society. If society does not have that inclusivity and engagement with dementia at its core, we fear that prejudice against dementia will only grow.

We will continue our regular meetings into the future in our efforts to contribute to the realization of a dementia-friendly society. Ultimately, we would like to see our six recommendation points introduced in Japan. COI: These activities were supported by The Pharmaceutical Research and Manufacturers of America.

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Poster Presentation Abstracts

ID: 406

Abstract Topic: Formal carers education and training

Keywords: Dementia, education, patient voice

Academic programs in dementia care and policy

Michael Splaine, Kate Gordon

Splaine Consulting, United States of America

Abstract:

In 2017 a listing and categorization of academic programs in dementia care and policy was created, sourced from University websites and catalogues as of September 2017 in English speaking countries, 12 programs were identified and categorized, with none available with a focus or course on policy

This information collection process is now being completed and preliminary indications are that number has increased and some courses in dementia policy are becoming available.

This indicates an avenue for public health and practitioner development but also may raise questions of standardization, quality and the role of innovation and the voice of persons with dementia and caregivers in educating about their care needs and wishes.

Poster Presentation Abstracts

ID: 407

Abstract Topic: Epidemiology

Keywords: Cognition, screening, Tanzania, Nigeria, sub-Saharan Africa, low- and middle-income countries

Population normative data for the idea six-item cognitive screen, cerad 10 word list and animal naming test in Tanzania and Nigeria

William Keith Gray¹, Stella-Maria Paddick^{2,3}, Adesola Ogunniyi⁴, Olaide Olakehinde⁴, Catherine Dotchin^{1,2}, John Kissima⁵, Jane Rogathe⁶, Declare Mushi⁶, Louise Robinson², Richard Walker^{1,2}

¹Northumbria Healthcare NHS Foundation Trust, United Kingdom; ²Newcastle University, United Kingdom; ³Northumberland Tyne and Wear NHS Trust, United Kingdom; ⁴University of Ibadan, Nigeria; ⁵Hai District Hospital, Boma ngombe Tanzania; ⁶Kilimanjaro Christian Medical University College, Tanzania

Abstract:

Background/Objectives: Screening for cognitive impairment and dementia in low- and middle-income countries is complicated by educational and cultural differences which may confound performance on cognitive screening tools. In sub-Saharan Africa (SSA) culturally and educationally appropriate population normative values for simple cognitive screening measures are lacking. This results in difficulty in correctly identifying individuals who may have cognitive impairment or dementia.

We aimed to report population normative values for a previously-validated brief cognitive screen (the IDEA six-item screen) and other simple cognitive measures in people aged 60 and over in one East African rural (Kilimanjaro, Tanzania) and one West-African semi-urban site (Lalupon, Nigeria).

Methods: Community-based door to door catchment area screening was conducted in 12 villages selected by stratified random sampling in the Hai District, Kilimanjaro Tanzania and 6 wards of the semi-urban Lalupon district Oyo State Nigeria selected by cluster sampling.

Demographic data (age, gender and educational background) were collected and the IDEA six-item cognitive screen administered to all consenting individuals aged 60 and over. Cognitive scores were extracted for IDEA six-item screen total, CERAD 10 word learning list (immediate and delayed recall) and categorical verbal fluency (animal naming).

Results: Data were available for 3,011 people aged 60 years and over in Tanzania and 1,117 people in Nigeria. Cognitive scores across both sites were similar. Lower scores were seen at higher age, and at lower education levels. Effect of gender resolved when age and education were taken into account. Verbal fluency scores were substantially lower than typically reported in high income countries in those with and without formal education.

Conclusion/Perspective: The IDEA cognitive screen and additional sub-scales appear to work well with similar scores seen in these rural and semi-urban populations in East and West Africa. The lower scores compared to previously published data support the need for population-specific published norms. Cut-off scores may need to be adjusted for education and age but not necessarily for gender.

This research was part funded by the National Institute for Health Research (NIHR) (16/137/62) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care. Grand Challenges Canada is acknowledged for funding the study through Grant # 0086-04

Poster Presentation Abstracts

ID: 408

Abstract Topic: Epidemiology

Keywords: Dementia, epidemiology, Tanzania, sub-Saharan Africa

The prevalence of dementia in rural Tanzania. Community-based prevalence estimates in 2009-2010 and 2018-2019

Stella-Maria Paddick^{1,2}, Marcella Joseph³, Damas Andrea⁴, Sarah Urasa³, Aloyce Kisoli³, John Kissima⁵, Irene Haule⁵, William Keith Gray⁶, Catherine Dotchin^{1,6}, Declare Mushi³, Louise Robinson¹, Richard Walker^{1,6}

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Abstract:

Objectives/Introduction

The majority of people with dementia live in low and middle income countries (LMICS). Current limited epidemiological data on dementia in sub-Saharan Africa indicate that prevalence may be increasing. We previously reported prevalence of dementia of 7.5% (6.4% age-adjusted) in rural Tanzania in 2009-2010 in individuals aged 70 and over. We aimed to repeat a community-based dementia prevalence estimate in the same setting to assess whether prevalence has in fact increased

Methods

This was a two-phase door-to-door community based cross-sectional survey in the Hai district, rural Kilimanjaro Tanzania. In Phase I, trained rural primary health workers screened all consenting individuals aged 60 and older from 12 rural villages using a newly-developed dementia screening App based on previously-validated paper-and-pencil tools (The IDEA six-item cognitive screen and IDEA-Instrumental Activities of Daily Living (IADLs) assessment).

In Phase II, a stratified sample of those identified in Phase I were clinically assessed using the DSM-V criteria by a research doctor and case histories subsequently reviewed by consensus panel to confirm diagnosis. Data were compared to data previously obtained in 2009-2010 using similar methodology within the same region.

Results

Of 3022 people who fulfilled the inclusion criteria, 424 screened positive for probable dementia, and 227 screened positive for possible dementia using the IDEA six-item screen. During clinical assessment in Phase II, 105 cases of dementia were identified according to the DSM-V criteria. The prevalence of dementia was 6.1% in those aged 60 and over (10.2% in those aged 70 and over). Prevalence rates increased significantly with increasing age.

Conclusions/Perspective

The prevalence of dementia in this rural Tanzanian population is similar to that reported in high-income countries, and appears to have increased since 2010. Dementia is likely to become a significant health burden in this population as demographic transition continues. Further research on risk factors for dementia in sub-Saharan Africa is needed to inform policy makers and plan local health services.

This research was funded by the National Institute for Health Research (NIHR) (16/137/62) using UK aid from the UK Government to support global health research. The views expressed in this

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Poster Presentation Abstracts

ID: 409

Abstract Topic: Epidemiology

Keywords: Dementia, subjective memory impairment, screening, Tanzania, sub-Saharan Africa

The prevalence and associations of subjective memory complaints in older adults in Hai, Tanzania

Monty Fricker¹, Robyn Barber¹, Sarah Urasa², Aloyce Kisoli², Catherine Dotchin^{1,3}, Stella-Maria Paddick^{1,4}, John Kissima⁵, Irene Haule⁵, William Keith Gray³, Declare Mushi², Louise Robinson¹, Richard Walker^{1,3}

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Abstract:

Background/Objectives

Older adults with subjective memory complaints (SMCs) have been shown to have a 1.5 to 3 fold increased risk of progression to mild cognitive impairment (MCI) or dementia. Despite the fact that the majority of people with dementia live in low- and middle-income countries, such as Tanzania, little is known about how perceptions of memory problems in these countries relate to objectively assessed cognition.

We aimed to 1) Establish the prevalence and socio-demographic associations of SMC in a cohort of older adults in Hai, Tanzania and (2) determine the relationship between self- and informant-reported cognitive decline and objectively assessed cognition.

Methods: A population-based sample of 407 older adults (aged ≥ 60 years) living in 2 rural villages in Tanzania were screened for cognitive impairment by trained rural primary health care workers using a newly developed App based on previously-validated paper and pencil tools. Subjective memory complaints (SMC) were assessed by self-report in older participants and in a close informant.

A stratified sample of 84 subjects were assessed for dementia based on the gold standard DSM-V criteria, blind to the outcome of SMC assessment on screening. Stage two assessment included clinical history, neurological examination and collateral history from a close informant.

Results: The prevalence of SMC was very high (80.1%) in this cohort. SMC was found to be significantly associated with increasing age, female sex, fewer years in education and illiteracy. Both self- and informant-reported cognitive complaints were associated with significantly poorer cognitive screening scores. Only informant-reported SMC were significantly associated with a provisional diagnosis of DSM-V dementia.

Conclusions: The prevalence of SMC was high in this Tanzanian cohort; one possible reason for which is lower levels of educational attainment. Longitudinal follow-up of this cohort is required to identify risk factors which determine progression from SMC to dementia.

This research was part funded by the National Institute for Health Research (NIHR) (16/137/62) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care.

Poster Presentation Abstracts

ID: 410

Abstract Topic: Epidemiology

Keywords: Dementia, diagnosis, Tanzania, sub-Saharan Africa, epidemiology

Dementia subtypes in rural Tanzania: proportions and community-based screening

Rosie Lyus¹, Marcella Joseph², Sarah Urasa², Damas Andrea³, Catherine Dotchin^{1,4}, Stella-Maria Paddick^{1,5}, John Kissima⁶, Irene Haule⁶, William Keith Gray⁴, Declare Mushi², Louise Robinson¹, Richard Walker¹

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Abstract:

Background/Objectives A high proportion of vascular dementia (VAD) has previously been identified in Hai, Tanzania. A diagnostic tool is required to enable a task shifting approach to dementia subtype diagnosis in sub-Saharan Africa (SSA). The Identification and Intervention for Dementia in Elderly Africans (IDEA) dementia screening tool has been developed for use by non-specialists in SSA. It could potentially differentiate Alzheimer's disease (ADD) and VAD by detecting different patterns of neuropsychological impairment.

We aimed to 1. Estimate the proportions of dementia subtypes in a cohort of dementia cases in Tanzania. 2. Investigate whether the IDEA six-item screen potentially differentiates ADD and VAD.

Methods: 3011 people aged 60 and over in twelve randomly selected villages in Hai were assessed using the IDEA screen. A stratified sample were followed up for DSM-V diagnosis with clinical history neurological examination and collateral history from a close informant. Dementia cases were followed up for further clinical assessment and subtype diagnosis by an expert consensus panel. Subtype diagnostic criteria included the McKeith criteria and DLB Toolkit for Dementia with Lewy Bodies (DLB), NINCDS-AIREN criteria and Hachinski score for vascular dementia and NINCDS-ADRDA for Alzheimer's disease (ADD)

Results: Of 76 dementia cases, 42 (55.30%) were ADD, 14 (18.40%) were mixed ADD and VAD, 13 (17.10%) were VAD and 7 (9.20%) were other subtypes. In 2010, 48.7% were AD and 41.7% were VAD. There were no significant differences in patterns of cognitive impairment on the IDEA screen between subtype groups.

Conclusion: Since 2010, the proportion of ADD has increased and dementia with a vascular component has decreased in Hai. With demographic ageing and potential reductions in hypertension and stroke, this trend may continue. Subtype diagnosis is currently not possible using this task shifting approach. Treatment with subtype-specific pharmacological therapies is not feasible for most dementia patients in SSA. Instead, interventions should focus on prevention and non-pharmacological therapies.

This research was part-funded by the National Institute for Health Research (NIHR) (16/137/62) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care.

Poster Presentation Abstracts

ID: 411

Abstract Topic: Diagnostic tools

Keywords: Dementia, diagnosis, Tanzania, sub-Saharan Africa, task-shifting

Feasibility of app-based dementia screening by rural primary health workers in Tanzania. A potential task-shifting approach to dementia diagnosis

Robyn Barber¹, Aoife Colgan¹, Sarah Urasa², Stella-Maria Paddick^{1,3}, Catherine Dotchin^{1,4}, John Kissima⁵, Irene Haule⁵, William Keith Gray⁴, Louise Robinson¹, Richard Walker^{1,4}

¹Newcastle University, United Kingdom; ²Kilimanjaro Christian Medical University College, Tanzania;

³Northumberland Tyne and Wear NHS Trust, United Kingdom; ⁴Northumbria Healthcare NHS Foundation Trust, United Kingdom; ⁵Hai District Hospital, Boma ngombe Tanzania

Abstract:

Background/Objectives

The majority of people with dementia live in low and middle income countries (LMICS). In sub-Saharan Africa (SSA), human-resource shortages in mental health and geriatric medicine are well recognised. Use of technological solutions may improve access to diagnosis. We aimed to assess feasibility of a dementia screening App for non-specialist workers in rural Kilimanjaro, Tanzania. The App includes two previously-validated culturally appropriate low-literacy screening tools for cognitive (the IDEA six-item screen) and functional impairment (the IDEA-IADL).

Methods

Rural census enumerators were given standardised training in use of the App and operation of the tablet device. Enumerators then carried out a cross-sectional survey of all consenting adults aged 60 and over in 12 rural villages within the Hai demographic surveillance site (DSS) using the App alongside a full door-to-door census. Demographic data (age, gender and educational background) were also collected.

In Phase II of the study those screened were stratified and selected for second-stage assessment based upon App screening score. All those screen positive (probable dementia) 50% of borderline cases (possible dementia) and 10% of screen-negative individuals were selected from two focus villages. Second stage assessment for major cognitive impairment took place blinded to App screening score.

To determine construct validity, App screening scores were compared with factors associated with dementia (age, education, informant-reported functional impairment, and bedside tests of executive function and working memory) as well as provisional DSM-V dementia diagnosis. Census enumerators and participants seen in phase II were given Likert-style questionnaires to explore the acceptability of using the App

Results

Positive screening score on the pilot App was significantly correlated with age, education and informant-reported functional impairment in Phase I and with bedside cognitive tests and provisional dementia diagnosis in Phase II suggesting good construct validity. In terms of acceptability, enumerators reported that the App was simple to use, and useful for future work, but 25% reported difficulties in device-charging due to inconsistent electricity supply. Most participants and enumerators preferred the App to pencil and paper tests.

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Conclusion/Perspective

Using an App to screen for dementia in a rural Tanzanian population appears feasible and may be a future longer-term approach. A potential barrier to large-scale use of the App in this setting is the unreliable electricity supply, which may prevent regular charging of smart-device batteries.

This research was part funded by the National Institute for Health Research (NIHR) (16/137/62) using UK aid from the UK Government to support global health research. The views expressed in this publication are those of the author(s) and not necessarily those of the NIHR or the UK Department of Health and Social Care.

Poster Presentation Abstracts

ID: 412

Abstract Topic: Attitudes, awareness and stigma

Keywords: dementia stigma, people-first approach, microtown, care community, NewDirection Care

Breaking down the stigma of dementia while providing a people-first approach at the world's first residential aged care microtown

Natasha Chadwick

NewDirection Care, Australia

Abstract:

Dementia is one of the biggest health challenges of our time, and cases are predicted to soar as populations age. According to research commissioned for Dementia Australia more than 436,000 Australians are now living with dementia, a number that is projected to increase to 590,000 in just 10 years and almost 1.1 million by 2058. Despite this we are still not doing anywhere near enough as a society to help older Australians and people living with dementia.

While awareness has increased, a diagnosis of dementia, like other mental illnesses carries significant stigma and negative attitudes persist. Consequently, the default model of care is still to shut people away in drab dormitories in impersonal institutions, segregating those with dementia from the rest of society. This is a Dickensian way of doing things, treating people as if they are criminals for no other reason than they have a brain injury or brain disease or because of their advancing years.

Motivated by the need to change the way we care for those living with dementia and the desire to avoid making the elderly a negatively perceived minority, I created NewDirection Care Bellmere. This groundbreaking care community is turning traditional aged and dementia care on its head. Instead of an institutional layout, we have built the world's first microtown, a community of six streets, a town centre and 17 domestic-style homes that each accommodates seven people. Each house features ensuite bedrooms, a shared kitchen, laundry, sitting rooms and a front and back yard.

Our focus is on the individual, recognising that each resident has unique needs, values, interests and aspirations. In their houses, they're encouraged and supported to help with cooking and other household chores. With our model of care residents are more involved in their daily routine and decision making and aren't segregated based on cognitive diagnosis. It is respectful, people-first individualised care where we don't take a person's independence or choices away.

At NewDirection Care residents are not shut away from the rest of the world but socialise and play an active part in the community as they wish. They can come and go freely from their homes, and pop into the corner store, café, cinema, gym or visit other people. Our town centre services are also available to the general community.

Part of my rationale for developing NDC Bellmere is to encourage more positive expectations on the part of all members of society including the young about how they will age. To this end, pupils from local schools join our residents for biweekly intergenerational activities. For our residents, the interactions stimulate the memory and promote physical well-being while for children they conquer negative stereotypes about aging, improve their communication skills and helps them to be more socially aware. At NewDirection Care we help residents lead active, independent, happy and fulfilled lives while breaking down the stigma that surrounds dementia.

Poster Presentation Abstracts

ID: 414

Abstract Topic: Dementia and dignity

Keywords: dementia and dignity, house companion, microtown, community, NewDirection Care

Preserving the dignity of people living with dementia at the world's first residential aged care microtown

Natasha Chadwick

NewDirection Care, Australia

Abstract:

The institutional model of aged and dementia care is broken. Residents often report a lack of meaning in their lives, limited opportunities to make contributions to their communities, poor quality interactions with carers and family members and exasperation with strict regimes. When people feel their identity and value as a human being are not respected they stop enjoying life.

At NewDirection Care Bellmere we have disrupted the way aged and dementia care is delivered by creating an Australian and world first, a microtown™. This \$35 million residential aged care community is located north of Brisbane, Queensland, Australia and features a town centre and 17 domestic-style homes with ensuite bedrooms, a kitchen, laundry, sitting rooms, and front and back yards. It is an inclusive community for the elderly and those living with dementia and complex care needs that recreates life in the real world. There are seven residents per home who are encouraged to live a normal a life as possible with freedom, independence and choice.

We don't have locked doors, and residents are free to roam within their homes and within the community. So they can pop down to the town centre whenever they want to go shopping, watch a blockbuster movie in the cinema, enjoy a beauty treatment or catch up with friends and family over a cup of coffee.

Unlike traditional institutional models, there are no wards, laundries, common areas or a large central kitchen. Neither are there nursing assistants or personal carers responsible for showering, toileting and feeding, and a person's choices are not taken away.

Supporting our residents in their homes are House Companions™, a unique 24/7 role, and another world first in residential aged care. On completion of training and a five-week induction programme, House Companions form part of each home's "family" unit providing assistance as needed with daily activities, such as cleaning, personal care and medication.

There are no shower lists or regimented wake-up and meal times. Instead, House Companions help each resident determine their day-to-day patterns, menus, activities and outings. Our residents can get up in the morning when they want, eat what and when they want to, receive guests and visit friends in the other houses. They are treated as individuals, not one of a crowd, and we respect their right to make their own decisions, just as they have throughout their lives. Residents are more involved in their daily routine and decision making and aren't segregated based on cognitive diagnosis.

In contrast with traditional aged care our goal is to enhance a person's independence and enable them to continue to live the life they did before they needed care. Ensuring people with dementia are treated with dignity is vastly improving their quality of life and helping them to live well for as long as possible.

Poster Presentation Abstracts

ID: 417

Abstract Topic: Dementia and human rights – NEW

Keywords: financial exploitation, financial management strategies, dementia policy

How to protect people with dementia from financial exploitation? Recommendations from multidisciplinary professionals of Taiwan

Su-Yuan Chan¹, Mei-Yin Li^{1,2}, Chia-Hsin Cheng^{1,3}, Yung-Jen Yang^{1,4}, Pei-Ning Wang^{1,5}, Wen-Chuin Hsu^{1,6}, Mei-Mei Niou¹, Chien-Hua Chuang^{1,7}, Huey-Fang Liu¹, Jui-Ying Tang^{1,8}, Hong-Jer Chang^{1,9}, Te-Jen Lai^{1,10}, Huey-Jane Lee¹, LI-YU TANG¹

¹Taiwan Alzheimer's Disease Association, Taiwan; ²Taipei Zhongshan Seniors Housing and Service Center, Taipei, Taiwan; ³Yu-Hao Law Firm, Taipei, Taiwan; ⁴Taiwanese Society of Geriatric Psychiatry, Taichung, Taiwan; ⁵Department of Neurology, Neurological Institute, Taipei Veterans General Hospital, Taipei, Taiwan; ⁶Dementia Center, Chang Gung Memorial Hospital, Taoyuan, Taiwan; ⁷Chuang Yi-Chou Foundation, Taipei, Taiwan; ⁸Bank SinoPac, Taipei, Taiwan; ⁹National Taipei University of Nursing and Health Sciences, Taipei, Taiwan; ¹⁰Chung Shan Medical University, Taichung, Taiwan

Abstract:

Taiwan Alzheimer's Disease Association (TADA) has established the Financial Security Task Force due to the increase of financial exploitation of people with dementia. Members in the task force include a person with mild cognitive impairment, a family caregiver, as well as accountants, lawyers, neurologists, psychiatrists, social workers, and other medical and social welfare professionals. Our goal is to protect people with dementia and their caregivers from financial exploitation, to empower them to manage money and property, and to advocate better supports from government departments and different institutions.

We developed several strategies after a preliminary survey of the real conditions of the financial exploitation of people living with dementia in Taiwan. First of all, promoting the financial warning signs of dementia to professionals from multidisciplinary sectors is recommended for current measures. Future policy advocacy will focus on strengthening multidisciplinary cooperation to protect the property of people with dementia.

Second, we developed strategies for different professionals. Medical professionals should make dementia diagnosis earlier and evaluate patient's financial capacity. Financial professionals ought to design services and commodities, both considering the needs of people with dementia and the incentives of business professionals. If people with dementia agree, it is also recommended that the identities of people with dementia can be recorded in the banking system. The last line of defense is the police and law systems. They should increase the awareness of dementia and improve current policies.

Last but not least, the general public should prepare financial management plans earlier, including trust or reverse mortgage. People can also take precautions, such as setting the upper limit in transferring or withdrawing money. It is also essential to discuss with family members about financial issues. Future policies should focus on the system for contacting emergency persons when needed, and the discussion among people with dementia, family members, and professionals.

However, some controversial issues emerge at the same time. For example, it is hard to distinguish the mental capacities of people with dementia. The balance between self-autonomy and protection needs further efforts to achieve. Also, when trying to establish a notification mechanism, personal data

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is at high risk of improper disclosure. To develop proper strategies in the future, we should notice the potential concerns.

The TADA Financial Security Task Force will continue developing strategies and advocating better policies and services. In the new era of human rights, we hope one day, the dream of avoiding people with dementia from financial exploitation will come true.

Poster Presentation Abstracts

ID: 424

Abstract Topic: Polypharmacy – NEW

Keywords: Behavioural and psychological symptoms of dementia, Delirium, Antipsychotics

Communicating antipsychotic deprescribing advice on discharge in patients with dementia and delirium: a clinical audit in a tertiary hospital

Thisuri Jayawardena, Trent Lee, Julie Lin, Fiona Irwin, Elissa Campbell, Brendan Foo

Department of Rehabilitation and Aged Care, Sir Charles Gairdner Hospital, Australia

Abstract:

Introduction

Antipsychotics are frequently used to manage agitation in patients with behavioural and psychological symptoms of dementia (BPSD) and delirium. Practice guidelines recommend minimising the use of these medications due to significant adverse effects including extrapyramidal side effects, falls, sedation, increased cardiovascular and cerebrovascular risks, polypharmacy, and death.¹

Hospitalisation provides an opportunity to engage and educate patients and their carers on antipsychotic use. Discharge letters documenting deprescribing advice enables general practitioners (GPs) to continue treatment de-escalation and patient education in the community following hospital admissions.

Methods

A clinical audit of discharge letters of patients with BPSD and delirium admitted to an acute geriatric unit in a tertiary hospital in Western Australia, over three separate months in 2018, was conducted. The proportion of discharge letters containing antipsychotic deprescribing advice were identified and analysed with qualitative methods.

Results

Of 90 patients with delirium, 28 (33%) were discharged on antipsychotics. Twenty-three of these patients (82%) had a history of dementia or cognitive impairment. Discharge letters for only five of these patients (18%) contained deprescribing advice to GPs. None included involvement of patients or carers.

Conclusions

The audit identified significant scope for improving adherence with clinical practice guidelines and communication of antipsychotic deprescribing advice in patients discharged from an acute geriatric unit. Several interventions have been initiated locally to address this gap. Staff training has commenced to ensure this becomes standard practice and that advice is transcribed to discharge letters for GPs. Additionally, a discharge information package is being developed for carers of patients with cognitive impairment. A re-audit will be conducted in three months to assess efficacy and identify potential barriers to implementation of these interventions.

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Poster Presentation Abstracts

ID: 425

Abstract Topic: Implementation of risk reduction interventions (Local, regional and national levels)

Keywords: community-based computerised cognitive intervention, community implementation, feasibility, cognitive training

Community-based computerised cognitive training is feasible and benefits older adults cognitively

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Abstract:

We evaluated the implementation of a computerised cognitive training (CCT) programme for seniors in community clubs (CCs) and its efficacy on cognition and gait. CCs provide programmes and facilities for local communities.

The CCT (NeeuroFIT) is a commercially available brain training programme offered at two CCs for a nominal fee of \$20. It consists of 20 biweekly 2-hour instructor-facilitated classes conducted in English and/or Chinese. Community-dwelling seniors ≥ 55 years who signed up for the CCT were randomised into the intervention or control group. Participants used an app (Memorie) comprising games targeting attention, memory, decision-making, spatial ability and cognitive flexibility. Selected games were paired with an EEG headset (Senzeband) which quantified users' attention level into scores tied to their game avatar control or game performance. Participants completed the Colour Trails Test Part 2 (CTT) and Repeatable Battery for the Assessment of Neuropsychological Status (RBANS) at baseline (T1), 10 (T2), and 20 weeks later (T3). Gait was assessed via GAITRite at T1 and T2. The intervention and control group attended the CCT from T1 to T2 and T2 to T3 respectively.

Participants were mainly females (76%), Chinese (97.6%), educated (mean=9.03 years) and 57.6% exercised weekly. It proved difficult to recruit the target population (i.e., seniors who do not exercise weekly) at CCs. 25.6% did not adhere to randomisation (e.g., attended intervention group classes despite being randomised into the control group). Dropout rate was 38.4% (N at T1=125, T3=77) and was higher in the control group (48.2%, $p=.042$), due to loss of interest and busy schedules. Excluding dropouts, all except 4 participants attended ≥ 12 classes. Providers ensured smooth programme implementation, but 1 English CCT class had to be conducted for 3 participants due low enrolment and participants' refusal to join the bilingual class. Classes and app use were well-received despite seniors' relative unfamiliarity with technology. Some experienced fatigue from prolonged screen use and found some games difficult. Time taken to complete CTT decreased from T1 to T2 in the intervention group ($p=.039$) with no change in the control group. From T1 to T2, RBANS Figure Copy ($p=.064$), Coding subtests ($p=.056$), Visuospatial domain ($p=.003$) and Total Score ($p=.078$) deteriorated in the control group. The intervention group maintained their performance in the same tests. Control group's gait speed deteriorated from T1 to T2 under both single ($p=.029$) and dual task conditions ($p=.065$) with no change in the intervention group.

CCT can be implemented with relatively good uptake and adherence in CCs, but at a subsidised rate as with other CC programmes. It improves attention and maintains visuospatial abilities, overall cognitive functioning and gait speed in relatively active community-dwelling seniors. CCT's efficacy should be evaluated in seniors at risk of cognitive impairment.

Poster Presentation Abstracts

ID: 426

Abstract Topic: Well being and quality of life

Keywords: residential care, dementia, quality of life, quality of care, staff

Quality of care and quality of life for people with dementia in residential care: what do staff have to do with it?

Katrina Anderson^{1,2}, Annaliese Blair^{1,2}

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Abstract:

Background: There is intense public interest in why some aged care homes provide excellent, person-centred care while others provide poorer care. This longitudinal project aimed to narrow down the most useful targets for working with staff to improve quality of life and quality of care for residents with dementia (Figure 1).

Method: Older adults in residential care with dementia (n=247), their families/care partners (n=225), managers (n=12) and staff (n=228) of 12 not-for-profit Australian residential aged care facilities were followed at baseline, 6 months and 10 months. Staff surveys, family interviews, resident file audits, organisational audits and live observations were utilised.

Result:

Regression coefficients and effect sizes were used to analyse relationships between staff and facility variables and quality of care and quality of life.

Staff deployment factors:

At baseline, higher levels of care assistant hours per resident predicted better quality of care and quality of life; specifically, less physical restraint, fewer adverse incidents, better staff care, improved overall quality of care, more assistance with and treatment of eating/drinking problems, less depression, less pain and more ease and engagement during staff-resident interactions.

Higher levels of registered nurse hours were associated with higher physical restraint and fewer activities for residents. However they were also associated with less psychotropic medication use, fewer adverse incidents, better overall quality of care, more professional treatment of eating and drinking difficulties, and more access to external health professionals.

Individual staff factors:

The characteristics of the staff themselves such as their experience, qualifications, dementia training and knowledge and time spent in direct resident care were not associated with quality of care at baseline. Only staff concern about residents falling and being in pain and their attitudes to physical restraint were consistently associated with quality of the care provided.

Conclusion:

Baseline results indicate that increased levels of care staff predicts better quality of care and quality of life for people with dementia. Higher levels of registered nurses have mixed results. Staff experience, qualifications and training are less important predictors of care quality than their concern for residents and attitudes to physical restraint. Longitudinal results will have broad implications for funding and models of aged residential dementia care.

Poster Presentation Abstracts

ID: 427

Abstract Topic: Consumer empowerment

Keywords: dementia and driving, decision making, person-centre approach

Development and verification of the Taiwanese version Dementia and Driving Decision Aid (DDDA) from 2017-2019

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Abstract:

Background: Dementia causes cognitive and memory difficulties which can reduce driving safety of the individuals. The decision-making process for driving retirement is challenging and yet limited guidance is available. This study builds on the previous development of the Dementia and Driving Decision Aid (DDDA) booklet and translated into Mandarin version. DDDA promotes a common decision-making approach, by initiating dialogue to guide decision-making that promotes driving retirement, collaboration, and then placing the person central on decision-making. This study aimed to evaluate the effectiveness of the train-the-trainer workshop using the Taiwanese Version DDDA among practitioners in Taiwan.

Methods: Mix-methods approach was used in this study. The first Mandarin version DDDA was translated from original English version. Then we conducted a focus group interview and invited 12 experts who understand the perceptions and opinions of Taiwanese people who are able to make both language and cultural adaptation for DDDA. In addition, we delivered two train-the-trainer workshops with a total of 154 participants using dementia and driving education module to test the effectiveness of Mandarin version DDDA on knowledge, confidence, competence and awareness regarding dementia and driving among consumer, caregiver and practitioner. Paired t test and Wilcoxon rank signed test were used to test the effectiveness of the train-the-trainer workshops.

Results: Most participants were healthcare professionals and college or university educational level. All participants from the focus group found the length and information content of the DDDA to be 'just right'. A large majority described the booklet as balanced (91.7%) with the information presented in a 'good' or 'excellent' manner (93.4%). Most participants (85.3%) felt that the DDDA helped them decide about driving and all would recommend the booklet to others. For the train-the-trainer workshops, four themes were extracted, including barriers of booklet implementation, more education is needed, alternative transport resources and targeted consumer approach. The knowledge, confidence, competence and awareness of using DDDA to address dementia and driving issues increased significantly ($p < 0.001$) after the workshops.

Conclusion: The Taiwan Minister of Transportation and Communications launched a 75-year-old driver cognition test policy in 2017. Aligned with the government policy, this is a very appropriate time to implement the DDDA to assist the older adult in the decision on driving. The Taiwanese version DDDA will be implemented through NGOs to consumers and practitioners to support the complex decisions on when to retire from driving. The DDDA booklets are available through Aged and Dementia Health Education and Research (ADHERE) (www.adhere.org.au) and Taiwan Alzheimer's Disease Association.

Poster Presentation Abstracts

ID: 428

Abstract Topic: Formal carers education and training

Keywords: dementia, competency, Simulation-based learning, Team-based learning

Use and effectiveness of blended simulation and team-based learning in dementia care courses

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¹Department of Gerontology and Health Care Management, Chang Gung University of Science and Technology, Taoyuan, Taiwan; ²School of Nursing, Chang Gung University, Taoyuan, Taiwan;

³Taiwan Alzheimer's Disease Association, Taipei, Taiwan; ⁴Dementia Center, Department of Neurology, Chang Gung University and Memorial Hospital, Taoyuan, Taiwan

Abstract:

Background and objectives of the study

In response to a substantial increase in the demand for dementia care, the training of professional care manpower is an important issue for long-term care in Taiwan. Currently, departments related to elderly care in schools already offer courses on dementia care in Taiwan; however, all of them are based on traditional teaching methods, students are more passive recipients of knowledge. Team-based learning can promote critical thinking and establish teamwork skills in students, thus allowing the knowledge learned from the course to be applied in clinical practice. Simulation teaching allows students to gain hands-on experience and learn problem-solving skills. Therefore, this study aimed to investigate the effectiveness of simulation and team-based innovative teaching methods in dementia care courses.

Methods

The study was conducted at the gerontological health care management department of a science and technology university in Taiwan. Purposive sampling was used, and participants comprised students with backgrounds as care workers who took a course on dementia care. In total, 53 participants were included and divided into the control (n=28) and experimental groups (n=25). The control group was taught using traditional teaching methods, the experimental group was taught using simulations and team-based teaching methods. To assess the effectiveness of the intervention, students evaluated the competencies of dementia care before and after the course using an assessment scale for professional competency in dementia care. In addition, a simulation teaching reflection, feedback form, and a team-based learning mutual evaluation form were used to understand the pedagogical effectiveness and students' perception about the course.

Results

Compare the changes in dementia care competency before and after the intervention between the two groups. The overall change score in competency was 64.08(S.D.=43.96) in the experimental group and 51.43(S.D.=37.37) in the control group, indicating that the overall increase in dementia care competency of the experimental group was higher than that of the control group. In addition, in the simulation reflection and feedback, many students responded to the simulation exercises in the classroom and accumulated experience and gained deeper impression compared to traditional classroom teaching. Furthermore, they discovered their own inadequacies and clarified the problem through exercises, thus reducing situations to which they could not respond when faced with actual clinical care in the future.

Conclusions

This study shows that simulation and team-based innovative teaching could enhance students' professional dementia care competency. This innovative course teaching method can provide a

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reference for future promotion of planning and training models in schools or services providing courses for professional dementia care workers.

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ID: 429

Abstract Topic: Education and training in hospitals – NEW

Keywords: simulation-based education, nurses of general hospital

Assessment of a simulation-based education program designed to improve practical dementia care skills of nurses in acute care hospitals

Nobuko Amaki¹, Yumiko Momose¹, Masako Sato², Mina Obayashi³, Aiko Kojima⁴

¹Aichi Prefectural University; ²Seirei Mikatahara General Hospital; ³University of Human Environments; ⁴Gifu University

Abstract:

Background: Nurses at acute care hospitals often find it difficult to deal with behavioral and psychological symptoms of dementia (BPSD) as these can vary with each elderly dementia patient. As a result, studies have emphasized the importance of education. Simulation-based education (SBE) has been proved to be globally effective in strengthening practical skills as it offers integrated knowledge and techniques.

Purpose: To assess whether a simulation-based dementia care education program helps improve practical dementia care skills of nurses.

Methods: Subjects included nurses at two acute-care hospitals in Japan. The education program included a 30-minute lecture on topics such as basic dementia-related knowledge and communication techniques, and a 60-minute SBE session. Role-playing with simulated dementia patients, group discussions, and debriefings were repeated twice. The education program was assessed based on the Kirkpatrick education assessment model. It included a 24-item test on dementia knowledge, an assessment of practical dementia care skills (20 items) that was conducted before and three months after the program, a test of nurses' degree of satisfaction with SBE during the program, and data (post 3 months) on nurses' utilization of practical skills learned in the program. We report on changes in nurses' dementia knowledge test scores and their utilization of practical skills learned in the program. Dementia test scores were compared using the Wilcoxon signed-rank test. Utilization of practical skills was assessed through a qualitative analysis of descriptive responses.

Results: Subjects included 55 nurses. The mean number of years of nursing experience was 13.5±10.2 years, and that of years of dementia care experience was 7.8±7.0 years.

① **Changes in dementia knowledge test scores:** Compared to the pre-program score, the post-3-month scores were higher. Items with higher scores included those related to symptoms of different types of dementia, such as dementia with Lewy bodies and frontotemporal dementia, and methods of dealing with dementia, such as person-centered care.

② **Utilization of practical skills learned in the program:** Types of dementia care that nurses indicated they wanted to employ and did so three months after the program were: "making efforts to speak in a friendly and easily understood manner that was tailored to suit the pace of the patient," "looking for ways of dealing with patients whose words and actions interfere with the provision of care that do not involve restraining the actions of the patient and do not include negative responses," "understanding [patients'] feelings via their facial expressions and actions," and "understanding the value in exchanging information with family members."

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Conclusion: Simulation-based dementia education is quite effective in improving the dementia-related knowledge of nurses and establishing its practical utilization.

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ID: 430

Abstract Topic: Diagnostic tools

Keywords: mild cognitive impairment, eye movement, eye tracking, early diagnosis

Early diagnosis of mild cognitive impairment based on eye movement parameters

jing nie, Qi Qiu, yuan fang, xia li, shifu xiao

Shanghai Mental Health Center, China, People's Republic of

Abstract:

Background and Aims

The dementia process is mostly initiated secretly many years before clinical onset. Current accurate detecting means for early disease are limited because of the high price and mostly invasive means. Eye movement testing have been demonstrated to have relationships with patients' cognitive functions, such as cognition, memory, attention. As a simple non-invasive biomarker of preclinical process maybe will help us for the development of disease treatments or even preventative strategies.

Aim1: To determine whether eye movement parameters have differences between normal elderly and mild cognitive impairment patients.

Aim2: To investigate the most sensitivity and specificity Eye movement type of a MCI diagnostic biomarker.

Aim3: To find the correlation of eye movement parameters with individual cognitive domains.

Methods

80 patients with mild cognitive impairment, 169 healthy controls were recruited from communities, and completed eye movement tests and global and domain-specific cognitive assessments including Moca (Montreal Cognitive Assessment) and NTB (neuropsychological test battery). The eye tracking system was employed to collect eye movement information, and analyze the parameters among the two groups.

Results

There were no statistically significant differences in gender between two groups participants. The patients with mild cognitive impairment showed older age, shorter years of education, lower cognitive scores, and the differences were all statistically significant (Table 1).

For the visual search task, significantly smaller percentage of searching new things during test time were observed for the disease group of long type in baseline and of short type in retest time (Figure 1).

There were no statistically significant differences in percentage of searching new things during test time between the two groups based on three pairs, LT-ST(A), ST-ST (B), LT-LT(C), (Figure 2)

The eye movement parameters was positively correlated with cognitive scores in verbal fluency, delay recall and abstraction test (Table 2).

Conclusions

(1) The clinical utility of eye movement parameters as an early marker can distinguish between MCI and normal elderly, it also needs further exploration in longitudinal studies.

(2) Eye movement parameters is a stable indicator, which not affected by testing type and learning effect.

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(3)we demonstrated that performance in tests of semantic verbal fluency, delay recall and abstraction are was positively correlated with searching time in a visual search task.

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ID: 431

Abstract Topic: Diagnosis

Keywords: Lean 6 Sigma, dementia diagnosis process, DMAIC

Using lean management to shorten the number of days of dementia diagnosis

kai-shan Kao, yi-hua Chen, ya-ling Shih, Cheuk-Sing Choy, Po-Sheng Chih

En Chu Kong Hospital, Taiwan

Abstract:

Background and objectives of the study / Introduction

International Society for the Dementia (ADI) estimates that the global number of dementia is ten million in 2017. With increasing growth rate of aging population, Taiwan has officially entered the stage of an "aged society" around the end of March in 2018. Older adults with dementia account for approximately 8% (260,000) of total population of elders. Initiating an appropriate treatment regimen and methods at a sufficiently early stage has been shown to be effective in postponing the onset of dementia.

Methods

"Lean 6 Sigma" has been used as the research tool of this study for reducing less waste and unnecessary process from dementia diagnosis procedures. Lean and 6 Sigma will be 2 different advantage and factors for us to reducing unnecessary waste and calculating the differences and improvements. This will be a systematic way to time-shorten, procedure-speed up and quality-upgrade.

Results / Positive impact

With DMAIC analysis of Lean 6 Sigma, we are able to know the changing of product life cycle of dementia diagnosis procedures. And with Process Cycle Efficiency calculating, we can soon find problems and even suitable improvements:

We define the improve targets Then measure and drawing Value Stream Mapping and Loss of Process Cycle Efficiency. By analysis some proper improvements. Finally, by using Process Cycle Efficiency and Process Cycle Time, we conclude a Strategy Pattern which will be able to improve the problems inside of dementia diagnosis procedures.

Conclusions / Perspectives

According to the PCE data we get from measurement index shows that the number of diagnostic days has dropped from 80 days to 52 days, greatly shortened by 28 days. That is because Lean concept helps us reducing NVA and waiting Time of patient, and we can find unnecessary waste and in-time improvements by analysis dementia diagnosis process project with Lean 6 Sigma.

Poster Presentation Abstracts

ID: 433

Abstract Topic: Non-pharmacological interventions

Keywords: Reversal, Alzheimers, cognitive decline

Reversal of cognitive decline: 100 patients

Dale Bredesen¹, Dave Jenkins²

¹UCLA; ²NeuroHub

Abstract:

Background and Objectives

The first examples of reversal of cognitive decline in Alzheimer's disease and the pre-Alzheimer's disease conditions MCI (Mild Cognitive Impairment) and SCI (Subjective Cognitive Impairment) have been published. These two publications described a total of 19 patients showing sustained subjective and objective improvement in cognition, using a comprehensive, precision medicine approach that involves determining the potential contributors to the cognitive decline (e.g., activation of the innate immune system by pathogens or intestinal permeability, reduction in trophic or hormonal support, specific toxin exposure, or other contributors), using a computer-based algorithm to determine subtype and then addressing each contributor using a personalized, targeted, multi-factorial approach dubbed ReCODE for reversal of cognitive decline.

Objectives

An obvious criticism of the initial studies is the small number of patients reported and from just one academic institution. Therefore, the key objectives included

1. To demonstrate that a personalised multifactorial approach that reverses cognitive decline can be taught to, and applied by, appropriately trained practitioners and hence scaled.
2. To provide additional support for a randomized controlled trial of the protocols

Results

The published paper (1) described 100 cases of clear, quantitated and objective improvement of cognitive decline in SCI, MCI and early to late Alzheimer's. Contributing authors included Dale Bredesen, David Jenkins and 19 other Practitioners from 16 different clinics and institutions demonstrating the scalability of the protocols. Over 1000 practitioners now utilise the protocols in multiple countries.

The Abstract oral presentation will include descriptions of both the theoretical model and the multimodal therapeutic program, along with 2 case examples of documented reversals.

Conclusions

This 100 case series paper and others suggests that pre and early Alzheimer's may be treatable with a disease modifying personalised approach.

Bredesen has also described a new model of the underlying pathophysiology of Alzheimer's and it is his view that the clinical description of Alzheimer's is in fact a presentation of three different and reversible subtypes of cognitive decline. Bredesen has demonstrated that the collection and analysis of large patient data sets enables subtyping of Alzheimer's and therefore customisation of interventions. The first approved proof of concept trial of 25 patients has begun and results are expected in mid to late 2020.

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Poster Presentation Abstracts

ID: 434

Abstract Topic: Informal carers training

Keywords: MOOC, English as first language, Dementia knowledge

Is a massive open online course accessible and effective for everyone? Native vs non-native English speakers

Sarang Kim, Maree Farrow, Aidan Bindoff, Jay Borchard, Kathleen Doherty

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Abstract:

Introduction: The Internet is one of the most widely used sources of information and Massive Open Online Courses (MOOCs) are a rapidly growing means of education as they can offer world-class teaching and educational resources beyond geographical and social boundaries. However, the majority of MOOCs are offered in English, even those offered by non-English speaking universities. This may exclude many potential learners who do not speak the language. The current study therefore investigates how accessible and effective a MOOC is for non-native English speakers compared to native English speakers.

Methods: The data were drawn from those who enrolled for the Understanding Dementia MOOC (UDMOOC) in 2017. A total of 6,389 enrollees (age range 18-82 years; 88.4% female) from 67 countries who answered both the sign up survey and the Dementia Knowledge Assessment Scale (DKAS) were included in analyses. Dementia knowledge was measured by the DKAS pre and post the UDMOOC. Completion of the course was recorded by passing the quizzes for all modules. Logistic regression and linear multiple regression were used to examine the association of demographic characteristics, relationship with people with dementia, and dementia knowledge with the completion of the course and with the DKAS score post UDMOOC.

Results: Native English speakers (n=5320) were older, more likely to be female, less likely to be employed, and had lower educational attainment than non-native English speakers (n=1025). Native English speakers were also more likely to have/had and care/cared for a family member or friend with dementia than non-native English speakers. Native English speakers had a significantly higher DKAS score both pre (M=33.01, SD=9.33) and post (M=44.18, SD=5.47) UDMOOC than non-native English speakers (M=31.65, SD=9.07 and M=40.70, SD=7.71 for pre and post respectively). There was no significant difference between these two groups in their likelihood of completing the UD MOOC, with a completion rate of 65.5% and 65.4% for native and non-native English speakers respectively. However, when adjusted for demographic variables, relationship with people with dementia, and dementia knowledge, native English speakers were 1.2 times less likely to complete the UDMOOC. English as a first language ($\beta=0.19$, $p<0.001$) was significantly associated with DKAS score post UDMOOC when adjusted for variables listed above.

Conclusions: Characteristics of UDMOOC enrollees who are native and non-native English speakers are significantly different. It suggests we are attracting non-native English speakers who are highly educated and living in an English-speaking country. Our findings suggest that the UDMOOC is accessible to everyone who understands English but is a more effective tool for native English speakers. This may highlight the need for translation of the course to enhance learners' understanding and to reach additional communities and learners in need of dementia education.

Poster Presentation Abstracts

ID: 436

Abstract Topic: Young onset dementia

Keywords: Younger onset Dementia, Young Onset Dementia, Caregivers, Needs

Caregivers of younger onset dementia: exploring needs, obstacles and service gaps

Chyi En Teoh¹, Sok Hwee Lim¹, Hwan Jing Koh¹, Wan Lin Jolina Chua², Stephen Yew Wei Chan¹, Suqi Cai¹

¹Alzheimer's Disease Association, Singapore; ²National Council of Social Service

Abstract:

Dementia is commonly found to affect older persons above the age of 65. However, dementia could potentially affect anyone below the age of 65, also known as younger onset dementia. In 2017, there is an estimate of about 4000 younger persons living with dementia and the number is expected to double by the 2030 in Singapore.

With the caregiving role primarily taken up by the family members, the caregiver is placed in a stressful situation, facing different challenges while coping with the sense of loss due to the diagnosis of their loved ones. There are few studies conducted in the local context examining the needs of younger onset dementia caregivers.

This study aims to (1) identify the needs of caregivers supporting persons with younger onset dementia; (2) discover service gaps in meeting their needs; and (3) understand the barriers faced by caregivers which prevent them from accessing services.

Family caregivers of persons with younger onset dementia were recruited from the Alzheimer's Disease Association's Caregiver Support Centre and National Neuroscience Institute in Singapore. 29 caregivers participated in the qualitative survey, of which 17 caregivers also took part in focus group discussions (FGDs).

The quantitative survey gathered the caregivers' perception towards local services, caregiving roles, their quality of life and demographics of their loved one and themselves. Each FGD covered four different themes of the caregivers' experiences at different stages of their caregiving journey.

Out of the 29 caregivers, there were 19 female caregivers and 10 male caregivers. There were 20 spousal caregivers, seven offspring caregivers and two sibling caregivers. The caregivers' age ranged from 27 to 70 years old. The preliminary analysis suggested that the top four utilised services were Dementia Day Care, Caregiver Support Group, Casework and Counselling.

Findings from the FGDs revealed that there is lack of awareness of younger onset dementia and the process of getting the dementia diagnosis for their loved ones was long drawn which added stress to caregivers. While some services were helpful for caregivers, there remained low service utilisation, resulting in emotional exhaustion. Caregivers also identified the need to re-design some of the services to better meet both their loved one and their needs.

As caregivers feel lost during service navigation, there is a need for a single platform, providing information on types of financial aid, legal advice, physical and emotional support to meet the needs of caregivers. Service providers can also improve existing day care services to be age-appropriate to better meet the needs of persons with younger onset dementia and provide easier access to counselling and support group services to support the caregivers.

Poster Presentation Abstracts

ID: 439

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Post, Diagnostic, Support, Dementia, Caregivers

Pioneering a multidisciplinary post diagnostic support team for dementia in Singapore

Bridget Goh, Stephen Chan, Eileen Lee, Tricia Tan, Chyi En Teoh, May Yoke Fong

Alzheimer's Disease Association, Singapore

Abstract:

With one of the most rapidly ageing populations and highest life expectancies in the world, Singapore faces the consequences of a silver tsunami. One of the biggest threats to wellbeing in old age is the increasing prevalence of dementia, something Singapore is no stranger to. Statistics from the Institute of Mental Health in Singapore report that one in 10 people aged above 60 in Singapore has dementia, with the condition affecting half of those above 85. This makes dementia a priority for the healthcare system in Singapore due to its pervasiveness.

Despite a proliferation of new services and more healthcare workers, the dementia diagnosis system in Singapore remains stretched, with hospitals bearing the brunt of the load. Given the limited resources and time, hospital staff are therefore more reactive rather than proactive, leaving newly diagnosed persons with dementia and their families to navigate Singapore's complex care system themselves. This leads to the persons with dementia and families coming back to the hospital only when a crisis occurs.

Considering the current gaps in dementia services, post diagnostic support (PDS) for dementia, a pilot programme (by Alzheimer's Disease Association of Singapore) was established to meet the gaps. This target population are those that currently have no presenting issues and do not meet any criterion for support services yet. The multidisciplinary PDS team was commissioned in June 2019 and works with local hospitals to assist the newly diagnosed persons with dementia. PDS places emphasis on pre-emptive action that focuses on psychoeducation and socioemotional support to prepare the persons with dementia and family for the trajectory of dementia.

The key difference between PDS and existing programmes is that the former offers proactive follow-up and interventions with families for a year after a person has been being diagnosed. PDS case workers work with each family over an extended period to draw up personalised care plans, depending on the unique needs and circumstances of each family. This care plan centers on the person with dementia to be their own advocate for the type of care they want to receive while collaborating with their families. It forms a blueprint for action, even years down the road, when the person with dementia's condition declines and he or she needs more assistance.

The gradual, comprehensive and unhurried process is expected to be more beneficial for the persons with dementia and families compared to the current post-diagnosis support at the hospitals. This is supported by testimonials from consenting caregivers and persons with dementia currently under the PDS programme. Overall, this pioneering project hopes to highlight the importance of PDS in creating a more holistic approach to supporting newly diagnosed persons with dementia to transform the way support for dementia is provided.

Poster Presentation Abstracts

ID: 441

Abstract Topic: Dementia policies and public policy

Keywords: dementia literacy, Care Policy and Action Plan, friendly policy, People with dementia, Dementia Prevention

Promoting participatory dementia-friendly policies by learning from people with dementia and their families—the case of new Taipei city’s dementia prevention and care action plan

Ran-Chou Chen, Shu-Chen Kao, Yu-Che Chen, Yu-Feng Wu, Chia-Ling Li

Department of Health New Taipei City Government, Taiwan

Abstract:

Background

Traditional public policy systems, ranging from recognition to action, often adopt a “top-down” and “expert decision-making” approach. Seldom do they directly invite stakeholders relevant to the policy to participate in the policymaking process, making these policies unable to directly respond to people’s needs. Therefore, when the WHO listed dementia as an important issue to be addressed by global health systems, New Taipei City held for two consecutive years the Open Space Conference prior to drafting the city-level “New Taipei City’s Dementia Prevention and Care Action Plan”. Based on the core value of open participation, the conference invited a broad spectrum of dementia policy stakeholders to participate in order to understand the public’s opinions and needs through open dialogs and to integrate the consensus into the core strategies of “New Taipei City’s Dementia Prevention and Care Action Plan”. By doing so, a bottom-up and open-participation action plan can be put into practice, and the public and private sectors can join forces in shaping New Taipei City into a dementia-friendly city.

Methodology

The processes of developing and promoting “New Taipei City’s Dementia Prevention and Care Action Plan” are reviewed. By analyzing secondary data, the researchers systematically review and analyze the action strategies created through the bottom-up, open-participation dementia-friendly policies, as well as their social impact.

Results

Employing design thinking as the framework, six major strategies are extracted from the direct open-participation model:

- 1) Promote the public’s dementia literacy and friendly attitude toward dementia.
- 2) Prevent, delay, and reduce the risk of having dementia.
- 3) Improve the city’s dementia diagnosis rate and network of services.
- 4) Provide ubiquitous support and training for family caregivers of people with dementia.
- 5) Build a comprehensive dementia care management information system.
- 6) Develop oversight and evaluation mechanisms and budget targets for the city’s dementia policies.

Conclusion

Dementia and families affected by it must be accepted. Open participation can create user-centric dementia-friendly policies, allowing the voice of the people with dementia to be heard. It can also facilitate active collaboration with the residents, accelerate the deployment of friendly networks and resources, support caregivers through a friendly environment, reduce their burden, and as a result, shape New Taipei City into a dementia-friendly city.

Poster Presentation Abstracts

ID: 443

Abstract Topic: Models of care

Keywords: Dementia, nursing education, communication, Humanitude, care evaluation

Effect of an educational method that uses role playing for care communication techniques with dementia patients

Hisami AOYAGI¹, Tomiko TAKEUCHI¹, Eri OKAMOTO¹, Hideaki TOUYAMA¹, Miwako HONDA², Atsushi NAKAZAWA³

¹Toyama Prefectural University, Japan; ²Tokyo Medical Center; ³Kyoto University

Abstract:

Purpose

As the number of people with dementia increases, teaching techniques for care of people with dementia is becoming more important in nursing education. In this study, using an informatics approach, we showed the effects of a “care communication technique educational method” that uses role playing for university faculty members.

Methods

Subjects: The subjects were 13 nursing faculty members who teach care communication (course name: Nursing Care and Humanitude) to students of the Faculty of Nursing.

Period: Five days in September 2018.

Ethical considerations: Approval was obtained from our university's Ethics Review Board. Research participants were informed in writing that they could withdraw at any time; that the study would not affect their work; and that the analysis and report would be done using research IDs with individual names deleted so that individuals could not be identified.

Procedures: (1) Prior evaluation: The faculty members playing the role of a nurse, wearing a first-person video camera (eyeglass type), performed care communication with faculty members in the role of a patient with dementia, during a change from a supine position to a left lateral position. (2) They participated in an intensive five-day training program for care techniques. The care technology education was taught by an instructor certified in a comprehensive care technique (Humanitude) that uses the senses, emotions, and language. (3) Ex-post evaluation: Care techniques were performed by the same pairs as in the prior evaluation and filmed with the first-person video camera.

Analysis: The eye contact rate (percentage of time that the nurse looked at the face of the patient during the care time) and the mean mutual facial distance (mean distance between the faces of the patient and nurse) were calculated using the video. The results before and after training were compared. Comparison was also done with the eye contact rate and mean mutual facial distance when the instructor performed the care techniques under the same conditions.

Results

Both eye contact rate and mean mutual facial distance improved from before to after training in 6 of the 13 participants. The average eye contact rate of these 6 participants before training was 35.0% and increased to 52.2% after training. The mean mutual facial distance was 158.2 cm before training and decreased to 38.8 cm after training. The target values were the instructor's eye contact rate of 70.0% and mean mutual facial distance of 32.6 cm. After training, the average eye contact rate of the 13

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participants was 41.7% and the mean mutual facial distance was 43.0 cm. The target achievement rate was 59.6% for the former and 75.8% for the latter.

Discussion

The above results show a certain effect from this educational method. At the same time, they suggested the difficulty of maintaining eye contact (care communication) while providing care such as help with position changes to people with cognitive decline.

Poster Presentation Abstracts

ID: 445

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, Dementia Friends, Support Center for People with Dementia and their Families, SPDF, Taiwan Dementia Plan v 2.0

Promoting public dementia literacy through interdisciplinary collaboration and technology adoption—the case of new Taipei city’s dementia friends

Ran-Chou Chen, Shu-Chen Kao, Yu-Che Chen, Yu-Feng Wu, Hsiao-Chuan Chen

Department of Health New Taipei City Government, Taiwan

Abstract:

Research Background

To build an environment that is supportive and friendly, New Taipei City initiated a bottom-up social response program, including facilitating public literacy and recruiting dementia friends (“Army of Lions”). Through interdisciplinary collaboration and adoption of information and communication technology, the goal is to provide richer and more diverse channels for literacy acquisition and make literacy education more accessible. Moreover, systematically collaborating with entities in various specialized areas will promote public dementia literacy, which leads to the realization of the goal of New Taipei becoming a dementia-friendly city.

Methodology

As action research, this case aims to create more channels for the public to understand dementia through systematic planning and promotion, interdisciplinary collaboration, and physical or digital learning via appropriate platforms. Thereby lay down the infrastructure for the dementia-friendly city.

Results

The traditional way of promoting dementia friends has many time-space constraints, resulting in very slow promotion progress. Therefore, New Taipei City has adopted new strategies to systematically promote public dementia literacy. The related strategies are the following.

Lead interdisciplinary collaboration with policies; increase power by joining public and private sectors: The mayor of New Taipei City leads the representatives of various government departments’ employees, volunteers, etc. to recruit 200,000 dementia friends as the goal.

Adopt digital learning and substantially increase the accessibility of literacy education: Going into the age of digital technology, the city government is making it more convenient for the public to learn about dementia, using multiple channels of digital learning.

Use technology to build friendly mutual aid systems: In addition to building literacy, Currently, new tools are being developed to utilize real-time communication software to match and notify those who are interested in serving people with dementia to report at a Support Center for People with Dementia and their Families for voluntary work and even to search for a missing person with dementia.

Conclusion

Compared with the slow promotion of traditional models, having the correct strategies can better impact people’s lives. Through promotion and advocacy, the public’s understanding of dementia is increased, and the illness is further destigmatized. It is hoped that the public can internalize knowledge and turn it into attitude and action, that after taking the dementia friend training courses, they would be dedicated to volunteer and serve the people with dementia and their families so that a dementia-friendly public can become a reality. This, coupled with expanding community dementia care service resources by linking together different networks, will make New Taipei City the first dementia-friendly city in Taiwan.

Poster Presentation Abstracts

ID: 446

Abstract Topic: Attitudes, awareness and stigma

Keywords: Healthcare students, Career Choice, Preferences, Health Education

Medical and nursing students' preferences for working with people with dementia; a systematic review

Molly Hebditch, Stephanie Daley, Gina Sherlock, James Scott, Sube Banerjee, Juliet Wright
Brighton and Sussex Medical School, United Kingdom

Abstract:

Background

A current issue in workforce planning is ensuring future healthcare professionals are both competent and willing to work with older adults with complex needs. This includes dementia care; which is widely recognised as a priority. Yet research suggests that working with older people is unattractive to undergraduate healthcare students (Garbrah, Valimaki, Palovaara, & Kankkunen, 2017; Meiboom, de Vries, Hertogh, & Scheele, 2015). However how students view a career working with people with dementia is not well understood, in either related specialities (e.g. geriatric medicine) or generalist areas, and no systematic reviews have been conducted on this topic.

Method

The aim of this mixed-methods systematic review is to explore the factors related to medical and nursing student preferences' for working with older people and people with dementia. This studies protocol is registered on PROSPERO [CRD42018104647].

Searches were conducted on five databases (MEDLINE, PsycINFO, CINAL, BNI, ERIC) in September 2018. Screening, data extraction and quality appraisal were conducted by two independent reviewers.

Results

1,024 papers were screened (139 full texts) and 62 papers were included in a narrative synthesis. This presentation will outline the factors that have been found associated with student preferences for working with older people and specifically those related to working with people with dementia. Potential factors for preferences for working with people with dementia include the age and gender of students; the perceptions of the work such as communication and emotional challenges; and educational interventions.

Conclusions

Research looking at preferences associated with working with patients with dementia is limited; while there is a growing literature looking at interventions, knowledge and attitudes within dementia education, preferences for working with this patient group is less explored.

Planned future work following this review, as part of a PhD study, is to be conducted to help conceptualise and build a framework for understanding preferences for working with people with dementia.

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Poster Presentation Abstracts

ID: 447

Abstract Topic: Attitudes, awareness and stigma

Keywords: Nursing students, Career Choice, Preferences, Nursing Education

Student nurses' preferences for working with people with dementia; a longitudinal study

Molly Hebditch¹, Stephanie Daley¹, Wendy Grosvenor², Gina Sherlock¹, Sube Banerjee¹, Juliet Wright¹

¹Brighton and Sussex Medical School, United Kingdom; ²University of Surrey, United Kingdom

Abstract:

Background

Increasing the capacity of the dementia care workforce is an international concern. It is consistently found that working with older people is unattractive to student nurses (Garbrah, Valimaki, Palovaara, & Kankkunen, 2017). However, there is a paucity of research on student preferences for working with people with dementia. The aim of this study is to explore nursing student career preferences for working with people with dementia over their training, and the factors associated with these preferences.

Methods

This is a secondary analysis of data collected from 2014 -2018 as part of the evaluation of the educational programme Time for Dementia (Banerjee et al., 2017). A modified career ranking exercise was used (Stevens & Crouch, 1998) to assess changes in preferences over time and factors related to these preferences (n= 488). A content analysis of open-ended questions was conducted to identify reasons for preferences (n= 110).

Results

Preferences for working with older adults and working with dementia decreased during training and was an unpopular career choice. At the univariate level, students' preferences for working with people with dementia were positively associated with the experience of knowing someone with dementia, knowledge, attitudes and taking part in the Time for Dementia programme. Only attitude scores were significantly associated with preferences after accounting for other variables.

The reasons given for a high preference of working with people with dementia (ranks 1-3) was around enhanced skills and knowledge. In contrast, lack of knowledge and experience was cited as a reason for low preference. The most common category of response, regardless of ranking, was the perceived negative aspects of the work. This included communication difficulties with patients and the challenging nature of the work.

Conclusions

This study adds to the literature by confirming that working with dementia is not a popular career for nursing students and outlines possible ways to promote working with people with dementia.

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Poster Presentation Abstracts

ID: 450

Abstract Topic: Informal carers training

Keywords: Dementia, Zentangle, stress, anxiety, depression

The effect of zentangle training programme on stress, anxiety and depression in caregivers of older adults with dementia

Yuet Ying Wong, Andy Chun Yin Chong

The Open University of Hong Kong, Hong Kong S.A.R. (China)

Abstract:

Introduction

Informal caregivers provide up to 75 % of the care for older adults with dementia and they are at increased risk of stress, anxiety and depression compared to informal caregivers caring for older adults without dementia. Psychoeducational Intervention is crucial to promote their mental health.

Methods

A Zentangle training programme is a patented art therapy method which involves creating images using repetitive patterns in a non-purposeful manner. Moreover, Zentangle is a type of mindfulness-based art therapy which can assist people in expressing their feelings more easily. A quasi-experimental study included an experimental group and a control group with a pretest-posttest design was conducted in 2019. A total of 73 caregivers were recruited. The training programme included five sessions in five consecutive weeks. The first session was a lecture held by a certified Zentangle teacher and supervised practice was performed in the subsequent sessions. The levels of stress, anxiety, and depression were measured at the beginning and the end of the training programme.

Results

Paired sample t-test was used to analyse the effects of the programme. There was a significantly decreased the level in stress ($p < 0.001$), anxiety ($p = 0.003$) and depression ($p < 0.001$) following the Zentangle training programme for caregivers of older adults with dementia.

Conclusion

The result of this study supported that Zentangle training can significantly reduce stress, anxiety and depression among the participants. These benefits have important implications for the development and promotion of Zentangle training programmes in other settings to promote mental health among the caregivers of older adults with dementia.

Poster Presentation Abstracts

ID: 452

Abstract Topic: Informal carers support – pre, during and post

Keywords: family caregiver burden, Support Group, dementia

Be a healthy caregiver- the effect of support group for families caring for demented elderly

po-sheng Chih, kai-shan Kao, yi-hua Chen, ya-ling Shih, cheuk-sing Choy

En Chu Kong Hospital, Taiwan

Abstract:

Background and objectives of the study / Introduction

With increasing growth rate of aging population, Taiwan has officially entered the stage of an "aged society" around the end of March in 2018. The elderly with dementia account for approximately 8% (260,000) of total population of elders. *Caring for someone with dementia can present many challenges and take a significant toll on a caregiver's health* caregivers, how to reduce the load of their burden have become an important issue.

Methods

The purpose of this study was to investigate the efficacy of a specifically designed group support program for relatives of patients with dementia and related disorders. The group program included educational/supportive activities (ex: stress adjustment, insomnia and Chinese medicine acupuncture), and used basic principles of the cognitive-behavioral approach. Twenty-four subjects participated in an 12-session program. A convenience sample of family caregivers of dementia patients were surveyed by the Caregiver Burden Inventory.

Results / Positive impact

According to the results of data analysis, 78% caregivers were female and 64% were the patient's daughter or son. Subjects showed a significant decrease in total family burden ($P = .022$). Results indicated that a relatively short but intensive support experience can have a positive effect in reducing some of the burden associated with the care of a demented relative.

Conclusions / Perspectives

The caregivers for demented elderly frequently report experiencing high levels of stress. It can be overwhelming to take care of a loved one with dementia, but too much stress can be harmful to both of patient and caregiver. This study indicated that a specifically designed group support program *could be useful* to avoid burnout.

Poster Presentation Abstracts

ID: 453

Abstract Topic: Informal carers support – pre, during and post

Keywords: dementia with Lewy bodies, carer, experience, family role, support

Experiences of carers of people with dementia with Lewy bodies at home: after diagnosis

Mari YONEYAMA, Yuka ITO, Tomiko TAKEUCHI

Toyama Prefectural University, Japan

Abstract:

Purpose

Interest is increasing in dementia with Lewy bodies (DLB), which is considered to be the second most common type of dementia after Alzheimer's dementia. In this study we clarified the experiences of carers following a diagnosis of DLB so that support can be provided with an emphasis on the perspective of the family.

Methods

Subjects: Seven carers of people with DLB at home.

Period: From January to August, 2015.

Ethical considerations: The study was approved by the Ethics Committee of the University of Toyama. Research participants were informed in writing that they were free to decide whether to participate in the study and that the analysis and report would be done using research IDs with personal information deleted so that individuals could not be identified.

Analysis: Semi-structured interviews were conducted with carers on their experiences following the diagnosis of DLB, and a qualitative inductive analysis was performed.

Results

Even after diagnosis, the carers did not know how to deal with the hallucinations and delusions of the person with DLB, and described "being at the mercy of the hallucinations and delusions." However, they tried to face the hallucinations and delusions with the understanding that they were symptoms of DLB, and they repeatedly "searched for ways to respond to the various symptoms and felt regret." This caused "accumulation and amplification of daily care fatigue." During this time, "family relationships that changed through care" were seen, in some cases deepening the family relationships and in some cases causing them to worsen. In addition, when they saw inappropriate handling by professionals, they felt "dissatisfaction toward the professionals' inappropriate handling" due to their lack of knowledge about DLB, and the "accumulation and amplification of daily care fatigue" grew even stronger. On the other hand, receiving "supportive cooperation from others," such as appropriate advice from family associations or professionals, gave them clues for reflecting on their "search for ways to respond to the various symptoms and regret." As these experiences repeated, they became able to "prepare mentally for predicted symptoms" based on feelings that they could manage the symptoms with close observations of the person with DLB and appropriate doses of medication. These mental preparations triggered a budding "awareness of the new family roles" so that they could "make a better choice for the individual and family" in deciding whether to put the individual in a facility or continue home care.

Discussion

The results suggest a need for professionals to acquire knowledge about DLB so that they can provide mental support for family members who are repeatedly searching for ways to deal with the person and

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feeling regret while being at the mercy of the various symptoms, and so they can think together with family about what actions to take.

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ID: 457

Abstract Topic: Well being and quality of life

Keywords: dementia, quality of life, preference, health economics, evaluation

Valuing dementia quality of life: a comparative analysis of people with dementia, carers and older Australians.

Kim-Huong Nguyen¹, Brendan Mulhern², Julie Ratcliffe³, Tracy Comans¹

¹The University of Queensland, Australia; ²University of Technology Sydney; ³Flinders University

Abstract:

Background: Involving people with dementia and carers in valuing quality of life offers a wealth of information on the lived experience of dementia. Traditionally, they have been largely excluded from preference elicitation exercises as general population values were considered sufficient. This study compared differences in quality of life preferences of three groups: people with dementia, carers, and older Australians in the general public (aged 55+).

Methods: Five quality of life domains (physical, health, mood, memory, living situation, and ability to do fun things) were defined by the AD5D descriptive system. An efficient design was used to generate a discrete choice experiment incorporating survival with 200 choice sets. People with mild to moderate dementia (N=103) and carers (N=131) completed the experiment via face-to-face interviews. The general public older Australians (N=710) undertook the survey using an online platform. Multinomial logistic regressions were used to estimate the relative weights attributable to the AD5D domains. Sensitivity analyses were conducted to examine the variations of estimated parameters, including using comparable sample sizes, pooled sample and alternative estimation methods.

Results: Overall, the domains valued most for quality of life differed between people with dementia, carers and older Australians, with memory the least important for all three. For older Australians “physical health” ranked first while “living situation” and “do fun things” ranked first for carers. While poor “living situation” showed the largest utility decrement for people with dementia, it was not statistically significant. The scale parameter test suggested that the three samples should not be pooled.

Conclusion: The study highlighted the variations of health state preferences, thus utility values, across the three populations. However, as memory was valued low by all three populations, interventions targeting memory may appear not as cost-effective as those improving living situations if valued by AD5D sets.

Poster Presentation Abstracts

ID: 460

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Dementia, innovation, crowdsourcing, inclusion, solutions

The wisdom of the crowd – involving the public and people affected by dementia in innovation

Simon Lord, Fiona Carragher

Alzheimer's Society, United Kingdom

Abstract:

Innovation at Alzheimer's Society is based on developing and applying new solutions to meet the needs of people affected by dementia where no effective solutions currently exist.

Our Innovation Team is led by the priorities of people affected by dementia, learning from their experiences, involving them in solution-building and ultimately measuring success by the difference we make to their lives. This person-centred approach to innovation helps us break out from our own limited experiences and develop new ways to take on dementia.

We use three key approaches to innovation: partnering with other organisations who have specialist skills and knowledge to support and run innovation projects; funding innovations and inventions through our Accelerator Programme helping anyone with a strong enough idea work at speed to develop and bring to market their product or service; and innovation sprints.

Our partnership work has seen Alzheimer's Society developing and marketing popular products within a year of the team's formation, including a tool set shown to reduce aggravation for people with moderate to advanced dementia and a self-facilitated course for care homes dealing with questions around sex and intimacy for people with dementia. Additionally, Alzheimer's Society is also developing an Alexa skill to restore independence to people living with early-stage dementia with McCann Worldgroup.

Our Accelerator Programme is currently boosting two exciting products to market, one hydration sweet geared to reduce hospital admissions from dementia-related dehydration and an app allowing users to make and see instructional videos of themselves doing tasks in familiar environments to increase independence.

Through Sprints we rapidly identify opportunities in challenge areas and build solutions to overcome barriers to living well with dementia. These involve wide engagement, connecting with and learning from people affected by dementia and engaging with dementia experts, to learn, co-design, test and deliver impactful solutions.

Underpinning these strands of work is the Alzheimer's Society Innovation Hub. This online community will help steer the direction of sprint projects, unearth partnership opportunities and provide a test bed for our accelerator partners. It will launch externally in October 2019 at which point anyone can share the biggest challenges they face around dementia, feedback on the work we are doing, take part in proposition testing and vote on solutions they believe will make a difference to people affected by dementia.

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The huge number of people affected by dementia includes talented individuals from every sector and every discipline and the decision to make the Alzheimer's Society Innovation Hub a fully open platform is based on an ambition to tap into this wealth of knowledge.

We are challenging the status quo, breaking down barriers to living well with dementia and pushing the limits of what a charity can do to support people affected by dementia.

Poster Presentation Abstracts

ID: 461

Abstract Topic: Epidemiology

Keywords: prevalence, South Africa, Indonesia, LMICs, methodology

Generating quantitative evidence on the prevalence, impact and costs of dementia: the STRiDE model

Nicolas Farina¹, Marguerite Schneider², Yuda Turuna³, Roxanne Jacobs², Tara Puspitarini Sani⁷, Imelda Theresia⁷, Emiliano Albanese⁴, Aliaa Ibnidris⁴, Adelina Comas-Harrera⁵, Sumaiyah Docrat², Cleusa Ferri⁶, Klara Lorenz⁵, Martin Knapp⁵, Sube Banerjee¹

¹Brighton and Sussex Medical School, United Kingdom; ²University of Cape Town, South Africa;

³Universitas Katolik Indonesia Atma Jaya, Indonesia; ⁴Università della Svizzera italiana, Switzerland;

⁵The London School of Economics and Political Science, United Kingdom; ⁶Universidade Federal de São Paulo, Brazil; ⁷Alzheimer's Indonesia, Indonesia

Abstract:

Background: The STRiDE project sets out in part to generate new evidence about the prevalence, costs, and impact of dementia in Lower and Middle-Income Countries (LMICs). Out of the seven STRiDE countries, we identified that there is a particular need for such data to be generated for South Africa and Indonesia. Here we will discuss STRiDE model and the process of its development.

Methods: A multistage, iterative process was used to develop the STRiDE model, which will be used to generate novel data on the prevalence, impact and costs of dementia in LMICs. Steps involved in the creation of this STRiDE model includes a systematic review of existing prevalence literature, and the selection and cross-cultural adaptation of measures.

Results: We will present the STRiDE model for collecting quantitative evidence of prevalence, impact and costs of dementia in South Africa and Indonesia. A focus will be on the measures that make up the STRiDE toolkit (that has a holistic approach to living with dementia) and methods that will be used for data collection.

Discussion: The STRiDE model is an evidence-based approach to collecting data about dementia prevalence in LMICs. The STRiDE model is setup in a way that ensures that the methods are both practical and feasible, whilst also generating useful data for policy makers within the countries. The hope is that this model can be more widely adopted in the future in other countries internationally.

Poster Presentation Abstracts

ID: 462

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Co-production, partnerships, empowerment, co-design, participation

Transforming ambulance services through co-production and effective partnerships

Alison Johnstone

Welsh Ambulance Services NHS Trust, United Kingdom

Abstract:

Background

The Welsh Ambulance Service has a key role to play in supporting patients, carers, families and our own workforce who are affected by dementia, particularly as more people are presenting with emergency and social needs

We have developed a co-production and continuous engagement model and have deployed this in our work to provide better patient outcomes and experiences.

The model has also supported us to co-produce our Dementia Plan which has close alignment with national strategy.

Method

We utilise a variety of methods to engage, with face to face work being our most productive approach. Our work demonstrates that people with dementia expect to receive a timely response in an emergency, regardless of what their clinical need is. People report poor experiences of calling 999 services, and find it difficult to use the telephone to communicate in a stressful situation.

Feedback includes:

- I get flustered using the phone, especially when there is pressure on me. I forget things. Please speak slowly.
- If staff have training and can understand what I'm going through, it takes huge pressure off me.
- You ask me too many questions. It's confusing.

Results

Our familiarisation work allows opportunities for people to visit our control rooms, meet staff, and become familiar with our vehicles, equipment and environments. Feedback influences the redesign of our services.

We have a Learning Framework which allows a blended approach to dementia training, providing staff with different skills and knowledge. People affected by dementia are supporting the delivery of these sessions.

Through a partnership approach with other Blue light organisations in Wales and beyond, we focus on Emergency Services Commitments on Dementia. This includes training for 999 call takers, delivered in partnership with people living with dementia.

We have a range of dementia friendly resources to improve people's knowledge of our services. We capture 'Dementia Voices' that highlight the expectations and experiences of those affected by dementia. These are available here: www.ambulance.wales.nhs.uk >About Us>Dignity in Care.

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People living with dementia tell us that the impact of our work is positive, and enables meaningful interactions with our workforce, and additional knowledge to access and use our different services:

“The work by the Welsh Ambulance Service is an excellent example of true collaboration and full involvement of the experts. They are leading the way. Our contributions were valued and acted on”.

We were awarded the Organisation of the Year at the UK Alzheimer's Society Dementia Friendly Awards 2018.

Conclusions

Involving people living with dementia in our work has been the key to the success of our work programme. We continue to recruit service users, develop and deliver supportive environments and processes that help them to contribute, all of which is underpinned by our dementia values – which include respect, patience, compassion and understanding.

Poster Presentation Abstracts

ID: 463

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Inclusive, research, BAME, participation, recommendations

Increasing participation of Black, Asian and minority ethnic communities in dementia research

Nicola Hart, Daniela Fernandez Gomora, Richard Oxley

Alzheimer's Society, United Kingdom

Abstract:

There are currently around 25,000 people with dementia from black, Asian and minority ethnic (BAME) communities in England and Wales, however this figure is expected to rise significantly as the BAME population ages. It is estimated that there will be a seven-fold increase to 50,000 by 2026, with the steepest increase in the South Asian communities. This compares to an estimated two-fold increase in the number of people with dementia across the whole population in the same time period.

Current research also suggests that people from BAME communities have lower awareness of dementia and experience higher levels of stigma. They often face delays in receiving a diagnosis and barriers to accessing support services. These challenges are likely to negatively impact the wellbeing of the person with dementia and their families, placing them under additional strain and increasing the risk of avoidable crises.

We are in urgent need of research to understand the full scale of dementia in BAME communities and how best to offer culturally sensitive services and support. However existing research to answer these questions is limited. Most of the research studies tend to be small-scale and focused on areas where these populations are more concentrated. In addition, people with dementia from BAME communities have fewer chances to participate in research as they are less likely to access support services. This is compounded by the fact that there is generally a lack of funding to allow researchers enough time and resource to successfully reach out to and engage with a range of communities.

A roundtable discussion was recently hosted with a small group of researchers with expertise in this area, to collate learning and share best practice for engaging with BAME groups. During this presentation we will discuss some of the commitments we have made to ensure dementia research is inclusive, as well as recommendations for the wider research community in order to increase our understanding of dementia in BAME communities.

Poster Presentation Abstracts

ID: 465

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, post-diagnostic, service, Korea

Post-diagnostic services for people with dementia and caregivers in South Korea

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¹National Institute of Dementia, Seongnam, Korea; ²Department of Neuropsychiatry, Seoul National University Bundang Hospital, Seongnam, Korea; ³Department of Brain & Cognitive Sciences, College of Natural Sciences, Seoul National University, Seoul, Korea; ⁴Department of Psychiatry, Seoul National University College of Medicine, Seoul, Korea

Abstract:

The national dementia plans of Korea included the 'convenient and safe diagnosis, treatment, and care' and 'reduction of care burden for family caregivers' as one of their key objectives and implemented tailored post-diagnostic services for PWD and their caregivers.

The National Health Insurance (NHI) covers 40 – 60% of the cost for medications and follow-up evaluations of PWD, and 90% of the cost for the people with early onset dementia and rare type of dementia. When the income of PWD is below 120% of average household income, they can get their out-of-pocket cost reimbursed from the Government.

The National Long-term Care Insurance (NLTCI) provides PWD with various home-based and institutional care services such as home visit care by a long-term care staff, home visit bathing, home visit nursing by a nurse or assistant nurse, day and night care center, and short term respite care regardless of the severity of dementia. The NLTCI also provides PWD welfare equipment such as the location tracker, walker and electric bed.

Local Dementia Centers (LDC), established in 256 Public Health Centers across the country, provide PWD with the care services such as care counseling, case management, care burden evaluation and family education that NLTCI does not provide. LDC also provide some of key care services that are supposed to be provided by NLTCI where these services are practically unavailable.

The National Dementia Helpline provides PWD and their caregivers with the information on dementia and dementia-related services and care counseling over phone on a 24/7 basis.

The Government provides a tax deduction at the end of the year to the households who are taking care of one or more family members with dementia with

All these post-diagnostic services help Korean people live with dementia without discomfort.

Poster Presentation Abstracts

ID: 467

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Dementia, Education, Higher Education, Innovation, Barriers and Facilitators

Implementing a longitudinal dementia educational programme into higher educational institutes: what are the barriers and facilitators?

Yvonne Anne Feeney¹, Stephanie Daley², Breda Flaherty¹, Sube Banerjee¹

¹Brighton and Sussex Medical School, United Kingdom; ²Sussex Partnership NHS Foundation Trust;

Abstract:

Background

Preparing future generations of healthcare professionals to provide person-centred, compassionate care to people living with dementia is dependent on good quality educational initiatives being delivered at undergraduate level. Longitudinal contact with people living with dementia can enhance healthcare students' attitudes and understanding of the condition, but it is argued that these experiences are lacking in traditional medical education. To address this The Time for Dementia (TfD) programme was designed to allow students longitudinal contact with families living with dementia in the community, thereby learning from the experts by experience. The programme is now a mandatory component of the curricula at five UK Higher Educational Institutes (HEI's). Positive learning outcomes have led other HEI's to express interest in implementing the programme however, this can be a complex task that requires changes to an already established curriculum. Detailed understanding of the common barriers and facilitators already encountered by the five HEI's implementing a dementia education programme such as TfD can inform an evidence base to enable spread of the innovation more widely.

The aims of the study were:

1. Investigate the barriers and facilitators of implementing the TfD model of education into a HEI.
2. Apply the findings to a change management framework to guide HEIs planning to implement the model.

Methods

A multi-site qualitative research study was conducted across five HEIs between October 2018 and December 2018. Semi-structured interviews were completed with key staff (n=12) experienced in the implementation of TfD. Interviews were audio-recorded and data was thematically analysed using inductive approaches.

Results

Five key themes were identified: 1) Leadership, 2) Buy-in, 3) Perceived value, 4) Team coalition, and 5) Time and fit. Participants identified commitment and resilience in their leadership styles but felt lack of time was a challenge. Fitting the new programme into an already established curriculum was challenging for some. Participants recognised the value of the programme; this aligned closely with their own sense of intrinsic value and motivated them to implement the programme despite the challenges. Buy-in and team coalition acted as extrinsic drivers motivating change efforts that fostered participant motivation.

Using this information, a change management framework was developed to support new sites to implement the programme.

Conclusion

Improving attitudes and understanding towards dementia is a priority in healthcare. Longitudinal programmes like the TfD programme demonstrate positive outcomes in student learning and attitudes

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towards dementia, however curricular change is a complex task. Findings from this study shed new light on change management literature, emphasising the importance of not only focusing on alleviating the perceived barriers, but more importantly fostering the extrinsic motivators that facilitate change.

Poster Presentation Abstracts

ID: 468

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Personalisation, Integration, Dementia Support, access, long-term

Dementia Connect

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Alzheimer's Society, United Kingdom

Abstract:

The UK's population are living longer and, people are more likely to live with multiple long-term conditions and complexity and don't always get the support they need. Dementia is the leading cause of death in the UK and there are 850,000 people living with dementia, with numbers set to rise to over 2 million by 2051. The condition costs £26bn from the UK economy each year. Dementia affects those diagnosed, and their family and friends too. There are estimated 670,000 unpaid carers and Dementia is the UK's most urgent, yet hidden, social care crisis. However there is still no clear pathway for anybody affected by a diagnosis. Unpaid carers account for around £11.6 billion of the economic cost of dementia, providing 1.3 billion hours of care a year, yet many are struggling in silence, often dealing with stress, depression and ill health.

For a long time now there has been a need for clear access to information and support for those affected. Dementia Connect provides people affected by dementia, including family, friends and carers, with access to advice, support and self-management services through a simple referral pathway. A referral into Dementia Connect can be made by a person themselves, a Health Care Professional working for the individual or somebody within the community who is aware of a support need of somebody affected by dementia. Once referred our Dementia Connect Advisers will contact the person referred directly and develop a tailored support plan. We will help them access resources, provide information and refer to partner providers who enhance our support. We keep in touch, making regular keeping in touch calls to ensure that if their situation changes or needs increase they have the right support available to them.

Dementia Connect ensures that Health and Social Care professionals and people affected by Dementia have a single point of referral to connect the person with the vital practical support they need, working with Primary Care Networks we can reach and support more people affected by dementia to stay well, better manage their conditions and live independently at home for longer. The NHS in England have named Dementia Connect as a solution within the NHS Long Term Plan and have committed to working together to achieve this, - 'We will continue working closely with the voluntary sector, including supporting the Alzheimer's Society to extend its Dementia Connect programme which offers a range of advice and support for people following a dementia diagnosis.'

Dementia Connect will provide long term support, preventing crisis, reducing isolation, and easing pressure on underfunded services. The new pioneering service will allow us to influence the health and social care system to make it better and fairer in terms of ensuring that people with dementia will receive the necessary care and support at the appropriate time.

Poster Presentation Abstracts

ID: 472

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: digital health, innovation, training, app

Minnity - a digital tool to personalize dementia care

Katarzyna Hess-Wiktor

Minnity, Sweden

Abstract:

Long-term dementia care providers lack effective tools for the implementation of person-centered care, usually relying on lengthy paper documents, which are rarely accessible during caregivers' daily work. Care quality is also diminished because of the large turnover of care workers and high number of persons each of them attend to. In Sweden, an individual receiving home care will meet an average of 15 different caregivers within 2 weeks.

The Minnity app enables professional caregivers to deliver individualized care to every caretaker with cognitive decline with the help of a smartphone. It facilitates faster and better care thanks to an innovative interface and efficient collaboration functionalities for both staff and caretaker's family. Minnity improves care continuity by supplying the same information to all caregivers engaged with a caretaker. By providing essential tips on the individual's life story and needs with short sentences, symbols and photos, the tool facilitates communication and relationships, which are crucial to high-quality effective care. It also allows caregivers to improve their caregiving skills through automated and adaptive microlearning programs available in the app.

The Minnity app is based on best practices in dementia care and has been developed in close collaboration with end users. The team's experience in dementia care and training made it possible to create a tool optimized to the needs of caregivers of people with dementia.

The combination of a working tool with customer profiles and a microlearning solution for dementia care make it a unique offer for a quickly growing elderly care market. Currently no other digital solution provides both information about clients and dementia care training in a mobile, adaptive format. The bite-sized learning units of which the training part consist allow even the educationally disadvantaged groups of home care employees, including those with foreign background and insufficient language skills, to provide person-centered care to their clients with dementia. The intuitive user interface of the Minnity app has already been appreciated by users in pilot tests and much preferred over existing solutions.

The presentation will depict the journey, challenges and insights gathered during the development of a digital tool for formal caregivers of people living with dementia. Difficulties in the implementation of research and innovation will be discussed. The presentation will also aim to inspire further innovation in care management and training.

Poster Presentation Abstracts

ID: 473

Abstract Topic: Well being and quality of life

Keywords: decision-making, memory-related diseases, tools, non-governmental organisations

My choice - tools for people with memory-related diseases to make choices, lead a fuller life and get their voice heard

Outi Karoliina Ronkainen

Alzheimer Society of Finland, Finland

Abstract:

Introduction: Finland's social welfare and health care system is going through a major transformation to make it increasingly efficient and customer-centred and in order to make services available to everyone on an equal basis. The new system will give customers more choice, but it also places more responsibility on them to know their rights and ensure that they get the benefits to which they are entitled. The reform of the social welfare and health care system requires customers and their caregivers to learn how to communicate their needs, ask for the right services and make independent decisions.

People with memory-related diseases are often unable to make decisions independently. This is why the Alzheimer Society of Finland has launched a project called *My Choice* to develop new operating models and techniques for helping people with memory-related diseases with these kinds of decisions. These are currently being developed and will be featured in the poster.

Methodology: *My Choice* is about developing operating models and tools that allow people with memory-related diseases to have a say in their care and make choices that benefit them. The project is designed to give people with memory-related diseases a voice and to empower them and their caregivers.

The project team works in close cooperation with the target group as well as various non-governmental organisations. A number of pilots will be run around the country with the aim of disseminating best practices to all parties who work with people with memory-related diseases.

A number of tools will be developed, such as checklists for services, benefits and customers' rights. The needs of people with memory-related diseases and their caregivers are the number-one priority, and social welfare and health care professionals will be consulted along the way. The goal is to produce information that is as clear and user-friendly as possible.

Positive outcomes: The Finnish social welfare and health care system is complex and often unapproachable. Timely access to the right services and benefits is vital for people with memory-related diseases to be able to stay healthy and lead a full and active life. *My Choice* aims to empower people with memory-related diseases and help them to make choices, lead a fuller life and get their voice heard.

Piloting and testing of different techniques and tools will allow us to develop increasingly efficient and user-friendly operating models for non-governmental organisations and other professionals who work with these customers and put people with memory-related diseases in charge of their own lives.

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Perspective: People with memory-related diseases often feel alienated from the decision-making process and services. The aim of the project is to give them the tools to make both small (diet, daily routine and chores) and big decisions and to disseminate information about the kind of help that is available.

Poster Presentation Abstracts

ID: 479

Abstract Topic: Models of care

Keywords: dementia, hospital, multidisciplinary care

Multidisciplinary treatment of people with dementia at the university psychiatric clinic Ljubljana

Polona Rus Prelog, Anja Kokalj Palandačič
University Psychiatric Clinic Ljubljana, Slovenia

Abstract:

Dementia poses an increasing health, social and economic problem. With ageing of the population, we are facing the increase of people living with dementia, whereas the ways of treatment and social care services are not sufficiently adapted to their needs. The common challenge is thus the optimization of management, including acute hospital care and rehabilitation as well as social care services.

National Institute for Public Health of Slovenia estimates the number of people with dementia in Slovenia as 33.000 in 2018. This represents 1.60% of the total Slovenian population (2.067.284 people in 2018).

At the University Psychiatric Clinic Ljubljana, the specialized ninety-bed unit of Gerontopsychiatry with five inpatient and an outpatient ward, provides baseline screening, dementia assessment and comprehensive diagnostic work up for persons with a cognitive decline. A multi-disciplinary team works together and forms a consensus diagnosis and recommends pharmacological and psychosocial interventions appropriate to each individual. In addition a dementia education programme is offered.

Dementia is the most common syndrome treated, but there are other important psychiatric conditions which present with subjective or objective dysmnnesia. Our unit provides a high quality focus for early intervention, treatment, support and research, which we will present.

Poster Presentation Abstracts

ID: 487

Abstract Topic: Well being and quality of life

Keywords: Wellbeing, outdoors, technology, dementia, scoping-review.

The impact of the outdoor environment on the wellbeing of people living with dementia in the community and how virtual access can help keep people connected with the outdoors: a scoping review

Ruth Louise Mantle¹, Leah Macaden²

¹NHS Highland, United Kingdom; ²University of the Highlands & Islands

Abstract:

The objective of the scoping review is to examine and map the range of evidence on the impact of the outdoor environment on the wellbeing of people with dementia living in the community and the contribution that immersive environment technology can make in helping keep people connected to the outdoors. This submission aims to highlight the key literature explored, discuss the gaps in literature and make recommendations for future research on ways to keep people living with dementia connected with the outdoors through the use of technology. The scoping review has been undertaken as part of a PhD which is being conducted as participatory action research to help give a voice to, empower and validate the knowledge of people living with dementia. People with dementia experience poorer health and wellbeing leading to social exclusion, loneliness and isolation. Supporting people with dementia to remain active is essential for maintaining wellbeing and provides a way for people to connect with their environment, reduce symptoms, improve function and help maintain independence. Being outdoors has a positive impact on people with dementia's wellbeing and studies show that reduced outdoor activity can lead to a decrease in quality of life and accelerate the progression of dementia. More is known about the benefits of physical activity but it is less clear about the impact the outdoors has on wellbeing. Having an understanding of how the outdoors impacts wellbeing for people living with dementia will help identify and develop increased opportunities that are informed by evidence to enhance wellbeing, support people to live well, slow down cognitive decline and stay connected to familiar environments. A comprehensive scoping review has been completed which adheres to guidelines published by the Joanna Briggs Institute and the author will present the data and conclusion drawn from the scoping review. There is a gap in research to demonstrate the impact of the outdoors on the wellbeing of people with dementia in the community and the contribution that technology can make towards enhancing wellbeing. Previous research studies have identified the important role that technology can play in improving health and wellbeing but little is known about how people with dementia might benefit directly and this scoping review and the wider research undertaken by the authors will establish how this might help keep people with dementia to stay connected with the outdoors they are familiar with.

Poster Presentation Abstracts

ID: 489

Abstract Topic: Dementia policies and public policy

Keywords: models of care, case vignettes, cost of care

Exploring current and future models of care through case vignettes

Klara Lorenz¹, Adelina Comas-Herrera¹, Sumaiyah Docrat², Martin Knapp¹

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Abstract:

Scarcity of resources, competing demands and the often complex needs and unique life situations of people with dementia and their families pose a challenge to policy makers aiming to develop timely, effective and financially sustainable models of care. Case vignettes offer the possibility to explore selected variables through the realistic, personable and relatable description of a hypothetical situation. The case vignettes developed as part of the 'Strengthening responses to dementia in developing countries' (STRiDE) project aim to enable an understanding of the care and support available to people with dementia and their families in different countries, to estimate associated costs of care and to explore likely future scenarios. The vignettes will be used to inform projection models for the seven STRiDE countries.

Researchers from a number of low- and middle-income countries identified and discussed key variables that affect the care and support for people with dementia and their families in their respective countries during a workshop as part of the STRiDE project in March 2019. Following the meeting key variables identified were organised into proximal and distal factors. Based on this framework five case vignettes were developed exploring the different variables identified. Draft vignettes were shared with workshop participants for feedback and changes were subsequently made to ensure that vignettes reflect the situation of people with dementia and their families across STRiDE countries.

Each of the seven STRiDE country teams will outline the likely care and support available for the people with dementia and their families described in the vignettes. Based on a very thorough situational analysis conducted as part of the project, country teams will also be able to describe likely future scenarios of care. The case vignettes and the likely models of care will then be discussed and verified with stakeholders in each country, including people with dementia and their carers.

Vignettes can be a powerful tool to discuss key issues, such as stigma, care needs, diagnosis and support available to people with dementia and their families with stakeholders in a relatable yet scientific way. The scenarios enable the identification of bottlenecks and key actors, the development of models reflecting resources and costs as well as a comparison of the support available for people in different countries and thereby encourage knowledge exchange and learning.

The vignettes are an interesting tool that due to their consensual development, retain applicability across different cultural settings. The tool will enable the mapping of current and likely future care scenarios and can be used as a comparable basis for the modelling of care models and costs of care across countries. This is particularly relevant in countries with limited data on costs and service receipt.

Poster Presentation Abstracts

ID: 490

Abstract Topic: Dementia and labour laws – NEW

Keywords: Employment service, young-onset dementia, case management, Taiwan

Case management model for employment service in a dementia center in Taiwan.

Wen-Chuin Hsu^{1,2}, Huang-Ju Chi¹, Chi-Pei Wei¹, Pei-Yin Su¹

¹Dementia Center, Chang Gung Memorial Hospital, Taoyuan, Taiwan; ²Taiwan Alzheimer Disease Association

Abstract:

Emergency of dementia in young people (YOD; < 65 years old) who were still working should be recognized in workplace. Early detection, diagnosis and intervention is the key to prevent impact on the workplace and the people with dementia/their family. Work as rehabilitation is an important principle to maintain or even improve the social and occupational functions of YOD.

In Chang Gung Dementia Center (CGDC), people with YOD upon diagnosis were inquired for their intention, knowledge and ability to work. Materials were provided to them and their caregivers by case managers with an interview. For those on work (or about to quit the job), we assist them to maintain the job by work redesign, or to change to a new workplace with adequate mental requirements. For those who have already quitted or 'retired' we offer the possible works such as at sheltered workshops and small-scale workplace.

The final goal of this project is to set up a case management model for employment for YOD in Integrated Dementia Care Center (IDCC) and dementia centers in Taiwan. Referral materials to governmental Employment Services will be distributed.

Poster Presentation Abstracts

ID: 491

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: Dementia, living alone, neighbourhood, social networks, solitude.

'It's our pleasure, we count cars here': an exploration of the 'neighbourhood—based connections' for people living alone with dementia

Elzana Odzakovic¹, Agneta Kullberg², Ingrid Hellström^{1,3}, Andrew Clark⁴, Sarah Campbell⁵, Kainde Manji⁶, Kirstein Rummery⁶, John Keady⁵, Richard Ward⁶

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Abstract:

Background and objectives:The extent of social isolation experienced by people living with dementia who reside in the community has been well acknowledged, yet but little is known how people living alone with dementia maintain neighbourhood-based connections. The purpose of this study is to examine the experiences of people living alone with dementia who live alone, focussing upon how they people living alone with dementia establish social networks and relationships in a neighbourhood context, and how they are supported to maintain this social context within everyday life.

Methods: Multiple data collection methods were used including, semi-structured interviews, walking interviews, guided home tours and social network mapping, which were conducted with 14 community-dwelling people living alone with dementia (11 women and three men) situated across the three international study sites in England; Scotland; and Sweden. Data were analysed using thematic analysis.

Results: The analysis revealed four main themes: i) making the effort to stay connected; ii) befriending by organisations and facilitated friendships; iii) the quiet neighbourhood atmosphere; and iv) changing social connections. The analysis suggests that people living alone with dementia who live alone were active agents who took control to find and maintain relationships and social networks in the lived neighbourhood.

Conclusions: Our findings indicate the need to raise awareness about this specific group in both policy, practice and to find creative ways to help people connect through everyday activities and by spontaneous encounters in the neighbourhood.

Poster Presentation Abstracts

ID: 492

Abstract Topic: Models of care

Keywords: nursing homes, staffing, quality framework, quality of care

Discovering staffing issues and experimenting with staffing levels in Dutch nursing homes

Marleen Prins¹, Janne van Erp¹, Ceciel Heijkants¹, Erica de Vries², Ramona Backhaus², Sil Aarts², Hilde Verbeek², Astrid van der Schot¹

¹Netherlands Institute of Mental Health and Addiction (Trimbos-institute), Netherlands, The;

²Maastricht University, Faculty of Health Medicine and Life Sciences, CAPHRI, Department of Health Services Research, the Netherlands

Abstract:

Background: In 2017, the Dutch National Health Care Institute developed a quality framework describing what high quality nursing home care entails, aimed to improve nursing home care. The current study focuses on evaluating whether or not Dutch nursing homes comply to the framework, specifically regarding norms about staffing and formation of care teams (skill mix and educational level). Care teams that were experimenting with new staffing levels were monitored to evaluate what changes in staffing occurred and which obstructing or promoting factors they experienced.

Methods: Quantitative data about staffing and team characteristics were gathered. In addition, qualitative data about motives for wanting to change, the change approach, obstructing and promoting factors and evaluation of changes was collected. Interviews by telephone were held at baseline, after 3 months and after 6 months. Thirty-two teams participated in the study.

Results: Challenges for making changes in staffing consisted of attracting new care staff, dealing with sickness leave, communication within and between teams, communication with informal carers and combining care for and having attention for well-being of residents in the daily work routine. In addition, teams wanted to better adjust the skill mix of staff to the needs of residents.

Conclusion: For the formation of care teams, there seems to be no 'one-size fits all' approach. A quantitative norm that applies to all nursing homes in the Netherlands as described in the quality framework (e.g. a minimum of two care professionals for eight residents during intensive moments of care) is therefore not always the route to high quality care.

Poster Presentation Abstracts

ID: 495

Abstract Topic: Models of care

Keywords: Diagnosis, neurocognitive disorders, pathways

Pathway for the diagnosis and management of dementias

TOLULOLA TAIWO, OLUMIDE TAIWO

Red Deer Regional Health Centre/Alberta Health Services, Canada

Abstract:

BACKGROUND: Healthcare in the Central Zone in Alberta is provided by multiple disciplines. Dementia patients who are referred to our Geriatric Services come from diverse communities, some of which have a paucity of community services. Adopting a pathway is important in ensuring the appropriate diagnosis and timely disclosure of Alzheimer's dementia to patients and their care partners.

DISCUSSION:

Our interdisciplinary team comprises physicians, nurses, social workers and administrative clerks. Our central focus is on ensuring that patients play an integral role in their health care decisions. We ensure that the patient's primary care/family physician is involved in every aspect of the treatment. A copy of the assessment report including the cognitive evaluation, laboratory and other diagnostic results are conveyed to the patient's family physician promptly. We strive on ensuring that this is available prior to the patient's next primary care visit. Patients are asked to schedule a visit with their family physician 2 weeks after the geriatric assessment. Patients and their care partners also receive a typed synopsis of their clinic appointment which highlights the diagnosis and the recommendations.

Our pathway places the patient and care partner in the center of their Dementia care and journey.

Diagnosis is provided at the initial visit or at a follow-up appointment date.

Verbal (and sometimes written) consent is obtained prior to disclosing the outcome of the patient's performance on the neurocognitive tests and the diagnosis.

Patients and their family members are referred to our local Alzheimer's Society.

Care goals are discussed and patients and their care partners are asked to review their future plans. Specifically, we ask patients about their functional, accommodation/environmental, spiritual and health goals for the next 1, 2 and 5 years.

Follow-up: We contact our patients/care partners on the phone 1 month after their appointment. The timing of the next clinic or home visit is determined based on the issues identified during the phone conversation.

CONCLUSION: Our pathway highlights the benefits of personhood and integrating patient's involvement in (their) dementia trajectory.

Poster Presentation Abstracts

ID: 499

Abstract Topic: Models of care

Keywords: low- and middle-income countries, Imics, developing countries, review

Effectiveness of interventions for dementia in low- and middle-income countries: a systematic review

Maximilian Salcher-Konrad¹, Huseyin Naci², David McDaid¹, Adelina Comas-Herrera¹, - STRiDE Systematic Review Group^{1,3,4,5,6}, - STRiDE Systematic Review Group^{7,8,9,10}, - STRiDE Systematic Review Group^{11,12,13}, - STRiDE Systematic Review Group^{14,15,16}, - STRiDE Systematic Review Group^{17,18}

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Abstract:

Background and objectives of the study: There are more people living with dementia in low- and middle-income countries (LMICs) than in high-income countries. Evidence-based interventions to improve the lives of people living with dementia and their carers in this setting are needed, but best-practice recommendations are often based on studies from high-income countries. We aimed to identify all dementia interventions for which robust evidence on effectiveness in LMICs exists and to synthesise this evidence to answer the question: Which dementia interventions were shown to be effective in LMICs and how do they compare to each other?

Methods: We conducted a systematic literature review (registered on PROSPERO: CRD42018106206) to identify studies that evaluated the effectiveness of a dementia intervention for people living with dementia or mild cognitive impairment or their carers (formal, informal, and family carers); used a robust study design, including randomised and strong non-randomised studies; were conducted in a LMIC; and were published between 2008 and 2018. We searched 12 electronic database searches (MEDLINE, EMBASE, PsycINFO, CINAHL plus, Global Health, WHO Global Index Medicus, Virtual Health Library, Cochrane CENTRAL, Social Care Online, BASE, MODEM toolkit, Cochrane Database of Systematic Reviews), complemented by hand searching of reference lists and local knowledge of existing studies from an international network of dementia researchers from LMICs. Machine learning was used to support abstract screening.

Results: We identified 63,585 records through database searches. Screening was conducted by an international team of 37 reviewers. Over 1,250 full texts were reviewed, resulting in a large collection of evidence on the effectiveness of dementia interventions in LMICs. Included studies came from a variety of countries, including low, lower-middle and upper-middle income countries. Interventions were aimed at people living with dementia in the mild, moderate and severe stages and their carers, as well as people living with mild cognitive impairment. A wide range of interventions was identified, including pharmacological treatments, herbal and microbial remedies, vitamin supplementation, psychosocial

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interventions (e.g., cognitive stimulation, reminiscence, or dance therapy), traditional Chinese medicine, and exercise for people living with the condition, and psychosocial and exercise interventions for their carers.

Conclusions: We conducted the most comprehensive systematic review of dementia interventions in LMICs to date. Robust evidence from studies conducted in relevant settings can inform the development of evidence-based recommendations to improve the lives of people living with dementia and their carers in LMICs.

Poster Presentation Abstracts

ID: 501

Abstract Topic: Young carers – NEW

Keywords: Dementia, imagination, intergenerational, connectedness, grandchildren

Dementia and the game of imagination

Kasper Bormans, Dirk De Wachter, Keith Roe

KULeuven, Belgium

Abstract:

Objective

Every child has on average one grandparent with dementia. The numbers are rising fast and the disease affects us all. The phenomenon of 'excess disability' means that the overdone attention of the environment to the patient's inability causes an 'extra disadvantage' in addition to the actual limitations of the condition. This negative way of looking at things increases the burden for everyone. It is therefore valuable to respond to capacities that remain intact for a longer time in the course of the disease.

Method

The Game of Imagination invites participants to a new form of communication, focused on emotion, the sensory and the unconscious. With cards with clear images, people with dementia and their environment learn to use their imagination and tell new stories together. The capacity for imagination is always present, everything fades, except the wonder. The Game of Imagination is the end result of careful research on patients and their environment and it can restore intergenerational bridges between children and their grandparents.

Results

People with dementia are often still playful, humorous and able to think and associate out-of-the-box. We can open and enlarge that imagination. The Game of Imagination is a start to that. It restores a dialogue that seems to evaporate between people with dementia and their environment. It increases the quality of life of people with dementia and their environment.

Conclusion

The Game of Imagination starts from the world of dementia and immediately confronts us with a playful way of communicating that we as a society have lost. The approach can bring children closer to their grandparents.

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ID: 502

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Future-loss, marketing techniques, compliance-without-pressure

Dementia is future-loss

Kasper Bormans, Dirk De Wachter, Keith Roe

KULeuven, Belgium

Abstract:

Objective

In our interaction with people with dementia, we primarily focus on memories and the past tense. We mainly ask questions about the old days to reactivate sleeping feelings in the here and now (reminiscence). We therefore regard them as hourglasses that have run through. Because of this one-sided emphasis on the past, we threaten to bereave them of their perspective on the future (future-loss). And there lies a great gain in quality of life for us to pick up.

Method

Advanced conversational techniques from marketing can be used to lower resistance and to stimulate people with dementia to share their dreams. Communicative strategies (such as the foot-in-the-door technique and the evoking-freedom technique) make the near future visible and negotiable.

Results

We disentangle the underlying mechanisms of compliance-without-pressure techniques. These instruments re-install a goal in life and a reason to get up in the morning. People with fewer memories also have fewer prospects. Having something to look forward to is a crucial aspect of quality of life.

Conclusion

Advertising techniques are valuable tools to entice people with dementia to share their dreams and shift their focus to the future. These techniques enable the caregivers, family and friends to enter the world of patients.

Poster Presentation Abstracts

ID: 503

Abstract Topic: Registries

Keywords: registry, participation, accessibility, dementia, database

Making research more accessible in Ireland: developing a registry of people with dementia and caregivers who want to participate in research with limited resources

Laura O'Philbin

The Alzheimer Society of Ireland

Abstract:

Introduction

Participant recruitment is one of the largest challenges facing dementia researchers in Ireland and many people with dementia and caregivers are not even aware of opportunities to participate in research. Over the past number of years, the same small numbers of voices are represented again and again in research studies all over Ireland. In the UK, the [National Institute for Health and Care Excellence (NICE)] guidelines recommend that people diagnosed with dementia (at any stage) should be informed about opportunities to take part in research. Currently, there is no national facility to do this in the Republic of Ireland. The [Alzheimer Society of Ireland (ASI)] is taking the lead on this challenge, and developing a national Dementia Research Database (DRD), a place where people with dementia and caregivers can register their interest in participating in research.

Methods

Before starting the project, a full Data Protection Impact Assessment was completed to identify and minimise any potential privacy risks. Following approval from the [Data Protection Commission] in August 2019, work has begun on developing the database and recruiting people with dementia and carers to it. The Dementia Research Database will be hosted on an internal [ASI] database operated through Salesforce. Research studies with ethical approval will apply to use this database to find potential participants to invite to take part in their research studies. Using the study's inclusion/exclusion criteria, [ASI] will 'match' individuals with research studies and connect the person with the researcher who can give them more information and invite them to take part. [ASI] will employ continuous monitoring and evaluation of participant experiences with different research teams and institutions. A lengthy recruitment period of people with dementia and carers to the database will take place, beginning within [ASI] services (e.g. daycare centres, Alzheimer cafes etc.) and then extend nationally. The database will continue to be developed long-term, with ongoing efforts to recruit new volunteers.

Positive Impact

The DRD will enable people with dementia and caregivers to be informed about opportunities to take part in research studies they may not otherwise have been aware of. Research studies will have a larger and more diverse pool of potential participants to recruit to their studies, which in turn, enhances the quality of the research. This will contribute to improving the evidence used to develop policy, services, medical research, and supports.

Perspectives

This presentation will detail the process and progress of developing the database, recruiting volunteers, data protection and consent considerations, in addition to the opportunities, and challenges that we have faced. This will be presented in the context of an extremely limited budget and resource allocation.

Poster Presentation Abstracts

ID: 504

Abstract Topic: Dementia and human rights – NEW

Keywords: Public Guardianship, Adult Guardianship, National Institute of Dementia, Local Dementia Center

The public guardianship system for people with dementia in South Korea

Ki Jung Kim¹, Tae Jin Kim¹, Je Taek Oh¹, Jong Bin Bae^{1,2}, Ki Woong Kim^{1,2,3,4}

¹National Institute of Dementia, Korea, Republic of (South Korea); ²Department of Neuropsychiatry, Seoul National University Bundang Hospital, Korea, Republic of (South Korea); ³Department of Brain & Cognitive Sciences, College of Natural Sciences, Seoul National University, Korea, Republic of (South Korea); ⁴Department of Psychiatry, Seoul National University College of Medicine, Korea, Republic of (South Korea)

Abstract:

Adult Guardianship is a legal process where the court determines that an individual does not have the capacity or ability to make decisions for themselves. An adult guardian is responsible for ensuring that the protected person is receiving proper care and services and managing income and assets of the protected person.

Public Guardianship is the government support system for Adult Guardianship. Since 2014 starting with the public guardianship for people with developmental disabilities, South Korea has adopted Public Guardianship for the people who don't have any family members to take care of them or cannot afford to hire professional guardians because of low income.

Since Dementia Management Act amended in September 2017, adult guardianship support system for people with dementia has been included. Pilot program was launched in September 2018 and the public guardianship system for people with dementia has been implemented nationwide since February 2019. The budget of this public guardian system is allocated by Ministry of Health & Welfare and local governments.

The process of the public guardianship for people with dementia is in order of case finding, training, matching, filing for guardianship, adjudication, supervision. In this procedure, National Institute of dementia cooperates with many institutions. Especially, 256 Local dementia centers operated by local governments take a large role in the process of case finding, recruitment, matching, and supervision.

Since this whole system has been carried out less than a year, each step of the process is still improving. There are efforts to expand the public guardianship for anyone with dementia who have no family regardless of their income or assets. The public guardianship system would be the social safety net for the people with dementia.

Poster Presentation Abstracts

ID: 505

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: Memory palaces, Quality of Life, Improved communication, social cohesion

Memory palaces to improve quality of life in Alzheimer's disease

Kasper Bormans, Dirk De Wachter

KULeuven, Belgium;

Abstract:

Objective

Dementia is the problem of the future in health care. Dementia is hard for the person living with it, but even more burdensome for his/her environment. The conversational dialogue seems to decline. Dementia is more than memory-loss, there is also communication-loss.

The primary objective is to examine whether the addition of (augmented) reality to communication strategies can reconnect subjects in the early phase of Alzheimer's Disease (AD) with their caregivers and family members.

The secondary objective includes a follow-up on quality of life (QOL-AD), feelings of depression (GDR 15) and connectedness (QCPR) of subjects in the early phase of AD and their significant others.

Method

We have developed a mobile health-application (MemoryHome) which allows caregivers to construct virtual scale models of the residential settings / at home situation. These models function as *memory palaces* in which photos of significant others are connected to the architectural, spatial environment. It is a visual-audio-guide through a well-known environment and subjects in the early phase of AD can make this walk together with a caregiver or a family member.

Results

Our intervention is non-pharmacological, rather inexpensive, patient-friendly, unconventional and easy to combine with regular treatment of Alzheimer's disease. Data were collected in two different environments: in homecare and residential settings. Results showed a modest but positive effect on quality of life, connectedness between caregivers and their family members and the absence of feelings of geriatric depression.

Conclusion

The mobile application MemoryHome is a convenient instrument to reinforce the dialogue that seemed to diminish between patients and their environment.

The application allows participants to independently improve the recall and recognition of familiar faces.

Poster Presentation Abstracts

ID: 506

Abstract Topic: New and future treatments

Keywords: Advertising techniques, social death, compliance, emotion

Advertising techniques and dementia

Kasper Bormans, Dirk De Wachter

KULeuven, Belgium

Abstract:

Objective

People with dementia are incorrectly reduced to the irreversible decline of the disease. As a result, patients appear incurable and unreachable at the same time. We risk letting them suffer from a "social death" that precedes their physical end of life. That is why we must continue to communicate meaningfully.

Method

Considering dementia as a communication problem, provides room to maneuver. You can't '*not communicate*'. There are multiple access routes to continue the interaction with patients. We discovered the impact of successful advertising techniques. By reflecting words, mirroring body language, the illusion of choice, the power of the yes-room and other communication tools, you continue to engage in a challenging dialogue.

Results

We unravel the underlying mechanisms of successful advertising techniques. People get a better understanding of how these persuasive messages affect our thoughts, feelings, and behavior. We then use these techniques to optimize our own way of daily communicating.

Conclusion

Advertising techniques are valuable tools to entice people with dementia to come into action and share their feelings in a conversation. These techniques enable the 'shadow victims of the disease' to enter the world of patients.

Poster Presentation Abstracts

ID: 508

Abstract Topic: Attitudes, awareness and stigma

Keywords: Triangle of Hope, Pathway-thinking, Sense of agency, Hopeful future

Dementia and the triangle of hope

Kasper Bormans, Dirk De Wachter, Keith Roe

KULeuven, Belgium

Abstract:

Objective

Every three seconds someone is told that he has dementia. The bad news not only affects the patient but also the people in the immediate environment. They are completely upside down. Dementia as 'memory loss' brings them to a dead end street where the past, the disease and the lack of a cure are the main focus. We are paralyzed. How can we turn this situation around and bring in hope?

Method

Dementia is not only a biological concept, but also a social construct. Dementia as 'memory loss' captures people in a negative triangle whose corners are: a dead end street (no cure), the emphasis on the disease (stigma) and the one-sided focus on the past (reminiscence). You can reverse this paralyzing triangle by shifting the focus from "memory loss" to "communication loss." Let us not only focus on the reduced connection between brain cells, but also on the lost connection between people. The application MemoryHome that we have developed in our research shows inspiring opportunities.

Results

The triangle can be turned around. Introducing the Triangle of Hope which encompasses the exact opposite at the corner points: multiple access roads (pathway thinking), responding to the remaining capabilities (agency) and bringing in the future (goals).

Conclusion

Dementia is a communication problem. By shifting the focus from 'memory loss' to 'communication loss', the paralyzing effect makes way for freedom to move. Turn the triangle and bring in the hope.

Poster Presentation Abstracts

ID: 510

Abstract Topic: Designing and evaluating the impact of funding programmes – NEW

Keywords: cognitive intervention program, dementia

Support center for people with dementia and their families in wen-shan community

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²Department of Long-Term Care, National Taipei University of Nursing and Health Sciences, Taiwan;

³Department of Psychology, Taipei City Hospital, Taipei City Psychiatric Center, Taiwan; ⁴School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan

Abstract:

– Background

Since 2017, the new long-term care plan proposed by the Ministry of Health and Welfare in Taiwan expanded to include people with dementia aged 50 and over. We used a client-centered care model (EMC²), which provides people with dementia with the appropriate environment, medical care, coordinator, and care giver. The new plan is set to extend services provided by the Wen-Shan Support center for People with Dementia and their Families (Wen-Shan SPDF) to the neighborhood. This center is located in the Wen-Shan district of Taipei city, which has a population of 273,762. There are 103,693 people aged 50 and over. Here, it is estimated that there are 3,451 people with dementia aged 50 and over, with a prevalence of 8%. We therefore aimed to assess the significance of services provided by our center to dementia patients in the community.

– Methods

Wen-Shan SPDF provides non-pharmacological management of dementia, including cognitive intervention programs, music therapy, exercise, and art therapy. Between Monday to Friday, two activities per day are conducted for people with dementia. Furthermore, we have established family support groups for caregivers to socialize. We conducted a survey in the neighborhood to understand their health literacy on dementia. In the neighborhood, 290 questionnaires were issued, of which 97 were valid.

– Results

We recruited 34 people with dementia at Wen-Shan SPDF in 2018. The mean age was 78.0 years (SD 9.7), and 67.6% of the participants were female. Approximately 80% caregivers were female and over 50% caregivers were the patient's daughter. Nineteen people (55.9%) with dementia attended cognitive intervention programs. A majority of people with dementia preferred music activities, followed by sports activities, cognitive intervention programs, and art activities such as painting. The results of the survey showed that 92.7% of residents were aware that they could refer to memory clinics for help if they suspected dementia. Approximately 40% of residents believed that the patient's impression of living in the past is indicative of severe disease.

– Conclusions

People with dementia enjoy the activities conducted at Wen-Shan SPDF. Through non-pharmacological treatments, people with dementia and their families can be part of the community. Furthermore, caregiver burden can be improved through a better understanding of dementia.

Poster Presentation Abstracts

ID: 512

Abstract Topic: Well being and quality of life

Keywords: Dementia, Sleep disturbances, Care homes, Formal carers

How do sleep disturbances impact upon care home residents living with dementia: a qualitative study

Lucy Anne Webster, Kingsley Powell, Sergi Costafreda Gonzalez, Gill Livingston

UCL, United Kingdom

Abstract:

Background and objectives: Around 38% of care home residents who are living with dementia will also have some symptoms of disturbed sleep. This includes struggling to fall asleep, awakening throughout the night, and daytime sleepiness. We would expect that sleep disturbances have an impact on care home residents who are living with dementia, however little is known about this. Previous qualitative studies have focussed on what happens during the nighttime in care homes and what might causes sleep disturbances in people with dementia, however, no previous study has focussed on the impact of these disturbances. Therefore, we aimed to qualitatively explore this by asking care home staff about their experiences and opinions using semi-structured interviews.

Methods: We interviewed 18 nurses and healthcare workers who worked both day and night shifts in four care homes in Greater London (UK). They worked in a mix of both charity and privately funded care homes, providing a mix of both residential and nursing care. We used a topic guide as a prompt during the interview, which was reviewed by a family carer who had cared for a relative with dementia and sleep problems before the interviews were conducted. The interviews were analysed by two researchers, using thematic analysis.

Results: All staff members described how sleep disturbances had an impact on the individuals they care for with dementia. Having disturbed sleep not only affected how a resident living with dementia felt the next day, but also how they behaved as a result, with staff describing how residents seemed more irritable or agitated if they'd had a bad night. Residents often felt sleepy during the day, using the daytime to catch up on sleep after a bad night, which then also increased their chances of being awake the following night. For some being sleepy in the day led to missing medication and meals, which then had other impacts such as weight loss or on health conditions such as diabetes. Being sleepy in the day also increased the risk of falls and for some residents staff felt they were unable to communicate as they normally would. Staff had also observed that sleep disturbances not only effected the individual residents, but also other residents who were awoken by those with disturbed sleep from noise or people coming into their rooms. Medication was often considered as a way to treat these disturbances from clinicians, but staff were aware of the side effects and risks of these medications, and often discussed how they did not lead residents to necessarily sleep better, instead making them drowsy.

Conclusions: Sleep disturbances in care home residents living with dementia can impact the physical and psychological wellbeing of the individuals themselves, and interrupt the sleep of other residents. The results from this qualitative study are being used to formulate hypotheses for analysis of the largest longitudinal cohort study of care home residents with dementia in England.

Poster Presentation Abstracts

ID: 513

Abstract Topic: Non-pharmacological interventions

Keywords: person with dementia, cognitive interventions program, qualitative interview and quantitative assessment

“Happy brain exercise program” at the day care centre in the middle of Taiwan

Hui-Wen Chien¹, Ying-Ju Chi², Ya-Chen Lee³, Hui-Chih Chiu⁴, Shang-Yu Yang⁵

¹Asia University, Taiwan.; ²Deputy of Director, Integrated Dementia Care Center (IDCC), Chu Shang Show Chwan Hospital, Nantou County, Taiwan; ³Assistant Professor, Department of Occupational Therapy, College of Medical and Health Science, Asia University, Taiwan.; ⁴Director of Pal Yu Foundation, Show Lau Lan Day Care Centre, Yuanlin City, Changhua County, Taiwan; Assistant Professor, College of Medical and Health Science, Department of Healthcare Administration, Asia University, Taiwan.; ⁵Assistant Professor, Department of Healthcare Administration, Department of Occupational Therapy, College of Medical and Health Science, Asia University, Taiwan

Abstract:

Background and objectives of the study / Introduction:

Dementia not only affects a person's memory but also impairs his/her cognitive ability. Once a person starts loss their calculation ability, unable to recognize the objects, poor judgement on the daily basis ability, it all becoming frustrated and decreasing their quality of life. Therefore, it is important to prevent and delay the deterioration of cognitive ability for person with dementia and maintain their functional daily activities. The purpose of this study was to examine the effectiveness of pilot cognitive interventions program (the Happy Brain Exercise Program) which was designed based on the daily activities to encourage the persons with dementia maintaining their active lifestyle and to improve their cognitive ability.

Methods:

A convenience sample of 12 persons with mild- cognitive impairment (aged ranged from 65 to 93 years) participated in this study. Participants attended a two-hour Happy Brain Exercise Program once a week for 12 consecutive weeks. Each week a different key topic was planned: (1) Word puzzle (2) Symbol balls game (3) Environmental cleaning team work (4) Classification of the objects (5) Animal puzzle (6) Scorpion gymnastics (7) Digging the gold from books (8) Little balls game (9) Big puzzle time (10) Pick and choose (11) My fashion style (12) Old time movie. In order to have a richer understanding of participants' experience, both methods qualitative interview and quantitative assessment were used. The conversations of 12 participants were audio recorded to gather information while completing a Faces Happiness Scale to collect the participants their own expression on happiness before and after attending each program (0 unhappy-10 extremely happy). Data were interrogated using thematic and descriptive analysis.

Results / Positive impact:

Analysis generated five themes from participants: proud of myself (self-confidence); happiness (satisfaction); looking forward each week's class (hope/plan); love to see teacher and classmates (social network and engagement); and teacher encourages me to speak out and share to others (autonomy/decision making). In addition, the results of the Faces Happiness Scale showed that the mean score of the Faces Happiness Scale was 4 before attending the program, but that of the Faces Happiness Scale was increased to the score of 9 after attending the program.

Conclusion

Our findings reveal important aspects of living with dementia which may bring useful information for program providers to consider when designing the intervention program. The Happy Brain Exercise

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Program seems promising to persons with mild-cognitive impairment; however, further research is required to evaluate the effectiveness of program.

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ID: 515

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: peer support, post-diagnostic support, people with dementia, employment for people with dementia

We can do the work “because” we have dementia, not “in spite of” dementia

Tomofumi Tanno

Orange Door, Japan

Abstract:

It has been widely thought, that people cannot work once they develop dementia. Recently in Japan, however, we see a dementia care service facility that provides its service users a work opportunity, such as washing cars at a used car dealer, or distributing commercial flyers. It proves that people can work, in spite of having dementia. Still, I wish to see more people with dementia engaging themselves at work, by making good use of their individual talents and capabilities.

I started a new activity as I wanted to create something that we can do “*because*” we have dementia. In the last four years, I led a program in which the people with dementia listen to other people with dementia who need to talk about their concerns. Then I felt that there would be many more people with dementia who are withdrawn at home and just cannot go out. I thought to myself, “How can I meet with these people and bring a smile to their faces?”

A year ago, I came to realize that a hospital could be a one-good-place, because I can meet them more easily and even have a peer counselling there. I shared this idea with my dear friend Dr. Yamazaki immediately, and together with him created a chance, for the people just diagnosed with dementia coming out of the examination room, to go right into another nearby room, to meet the lively cohorts. This can be the darkest time in their lives and we can help.

It can be looked on as counselling, however done in a casual manner. I talk mainly about my experience, and listen to what the other person with dementia has to say about his/her concerns and problems. People at diagnosis maybe be shocked and very worried about their future. Doctors do provide medical explanations, but the ones who are diagnosed, can hardly imagine what will happen to their daily lives.

People diagnosed with dementia including Alzheimer’s disease are able to connect themselves to those around them, gain appropriate treatment and support, and live well with dementia.

I believe the best way to deliver this message is to show that I was diagnosed six years ago and am still living well with dementia, smiling. When I meet people with dementia and their families at a clinic, they look glum and grim at first. As we engage in our conversation, I see their expressions begin to be softened and soon they start to smile. I am convinced that the people with dementia, have the power to make such a change.

I work for Toyota, while giving lectures and providing peer support to help raise awareness on dementia. This year, my company allowed me to do the advocacy work as my job, treating me equal to the sport players belonging to the company and who do their sports. Currently, I belong to Netz Toyota Sendai, who encourage me to move on with my dementia advocacy work. I believe this is the job that I can do “*because*” I developed dementia.

Poster Presentation Abstracts

ID: 516

Abstract Topic: Informal carers support – pre, during and post

Keywords: Dementia, Family counseling session, Integrated care, Case manager

The effect of family counseling meeting on dementia families: a pilot study

Ching Jung Tseng¹, Maio Yu Liao²

¹Taichung Hospital, Ministry of Health Welfare, Taiwan/ Case Manager of Geriatrics and Dementia;

²Taichung Hospital, Ministry of Health Welfare, Taiwan/Director of Geriatrics and Gerontology Departments

Abstract:

Objectives

As the population ages rapidly and changes in family structure. The care function of family can provide is gradually weakened. However, dementia is a disease with progressive and persistent cognitive deterioration. That makes caregiver feel helpless and the care problem will also affect the family's various levels. Therefore, planning family counseling session services for demented family caregivers and expect through case management services provide professional integration consulting services to alleviate the dilemma of demented family care.

Methods

1. Establish a comprehensive care team for interdisciplinary integration of dementia that include physicians, psychologists, social workers, dietitians, occupational Therapist, physiotherapists, pharmacists, case managers, and nurses.
2. Formulate and build up the notification mechanism and process for high-risk family of outpatient clinic and hospitalized dementia.
3. Develop and establish the service connotation and process of the high-risk family consultation conference for hospitalized dementia and use the caregiver stress self-test form.
4. Provide multi-supportive services for dementia high-risk family caregivers, including diagnosis and condition description of dementia, resource transfer, family support group, psychological consultation, instant connection care guidance, consultation with hospice palliative care team and safety guidance with medication.
- 5.

Result

A total of 24 high-risk family participate the family counseling session service plan since January to December 2018. The average age of the participant was 83.64 (± 8.11) years old, and the cognitive function was mostly in mild and moderate dementia (57.1%). The main caregiver sequence are own child (50%), daughter-in-law (28.6%), spouse (21.4%). Preliminary investigations found the dementia families feel inability and loss that most difficult to face is when new symptoms appear in the course of the disease (57.1%). This situation has caused caregivers to feel pressure likes the "pay attention to patients at all times", "mentally and physically exhausted" and "testing endlessly". The average score of the Caregiver Stress Self-Testing Scale was 23.5 (± 6.95), indicating that pressure signs have emerged and the integrated care must be involved in it. That find the top three consultative needs is "Care issues", "Medication" and "Nutrition", respectively.

Conclusion

Dementia is one of the diseases with high complexity and difficulty. Through the family counseling session service involve to initially understand the needs and dilemma of dementia family. In addition, through the professional counseling service to accompany with the demented family together to face the uneasiness and confusion of the changes in the course of the disease. Preliminary discovery

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through this program find the cross-disciplinary team consultation session is necessary and will strengthen and focus on services for care, medication and nutrition portion in the future.

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ID: 517

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: development social support assessment system dementia family caregivers carers home Japan

Development of social support assessment system for people with dementia and family caregivers at home in Japan

Aya Yasutake¹, Toshihiro Kita², Chie Kawasaki³

¹Kumamoto University, Japan; ²Kumamoto University, Japan; ³Nagano University of Health and Medicine

Abstract:

【Purpose】 Social Support is important for a family care giver of people with dementia at home. The aim of this study was to identifying social supports of the community.

This was a study using an interactive process to visualize the social supports of the community.

【Design】 This was a descriptive study using an interactive process to visualize the social supports of the community.

【Method】 The subjects who cooperated in the study were targeted at 6 regional comprehensive support centers. The social support that the center knows was introduced.

Social supports of the community in this study was developed and named by A.Yasutake [Emotional support], [Practical care and domestic support], [Proper provision of information support], [Support of meaning to care], [Coordination of respite care support] .

The social support of the community are classified and registered in google map.

【Results】 351 social support of the community were registered in google map. When social support was classified, these were [Emotional support(152),30%], [Coordination of respite care support(130),25%], [Practical care and domestic support(115),22%], [Proper provision of information support(67),13%], [Support of meaning to care(50),10%] .

【Conclusions】 It is very important to develop and visualize informal and formal social support for the development of the community where people can live peacefully with dementia. It is possible to the outcome study of the social support of the community for family caregivers and people with dementia.

Poster Presentation Abstracts

ID: 524

Abstract Topic: Epidemiology

Keywords: Antimicrobial Resistance, aged care, Dementia, Urinary Tract Infections

UTI's, antimicrobial resistance and the ageing population. A study of the last two years of life for patients diagnosed with dementia in Queensland

Megan McStea, Kim-Huong Nguyen, Lisa Hall, Tracy Comans

University of Queensland, Australia

Abstract:

Background and objectives of the study

Australia has implemented Antimicrobial resistance (AMR) strategies to mitigate the effects of antibiotic resistance. yet little is known about the impact that resistant organisms have on the health of the Australian population, AMR patients' journeys through our healthcare system and specifically the prevalence of AMR among the aged population.

Ageing is often characterised by the onset of infections. Antimicrobial use is extensive in the ageing population. Urinary tract infections (UTIs) are common diagnosis in older adults requiring antibiotics. Obtaining an accurate history of patients with cognitive impairment and communication difficulties can be challenging, with many clinicians misattributing factors such as functional decline, increased confusion, and nonspecific signs and symptoms to UTIs. People with dementia have been found to have a higher rate of UTI diagnosis compared to other patients. There is an increasing prevalence of AMR urinary pathogens. Evidence suggests UTIs are over diagnosed and a common cause of overuse of antibiotics in this population.

This initial scoping study looks at the relationship between UTI's, AMR and those patients living with dementia.

Methods

Using probabilistically linked hospital administrative databases and state registries, UTI and AMR related ICD-AM-10 codes were extracted from a matched cohort (dementia vs non dementia) of 22000 patients. Patients were identified as having dementia based on the existence of any ICD code relating to dementia in the 5 years prior to the date of death occurring in 2014-2015.

Results

Nearly nine per cent (n=1,799) of the 20,435 included patients had at least one identified resistance code. Of all dementia patients, 10% had an AMR code as compared to 8% of non-dementia patients. A total of 1240 patients (69%) also had a UTI ICD code; 58% were patients with dementia.

We identified 4,525 patients admitted from, or being discharged to, a residential aged care facility (RACF). Of these nearly 13% had an AMR code, compared to 7.6% of those not identified as a RACF resident. Of the RACF residents, 69% were from the cohort of patients living with dementia.

After adjusting for age, gender and comorbidities, RACF residents had almost twice the odds of having AMR. After further adjusting for residence, patients identified as having dementia were 1.2 times more likely to have AMR.

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Conclusion

UTI and AMR presentations are more prevalent for dementia patients. Future research will examine the prevalence of UTIs and the relationship with AMR in community and residential care residents using longitudinal data and transfers between RACFs and hospitals. We aim to provide recommendations for the management of older people living with dementia, particularly those residing in residential care who are at high risk of AMR.

Poster Presentation Abstracts

ID: 527

Abstract Topic: Dementia and labour laws – NEW

Keywords: young-onset dementia, dementia-friendly workplace, right to work, human right

The experience of setting-up a coffee shop by people with young-onset dementia in Taiwan

Li-Yu Tang¹, Huey-Jane Lee¹, Dai-Wei Yu¹, Yu-Chen Chang¹, Ruo-Wei Zhang¹, Te-Jen Lai^{1,2}, Elaine Ee Ning Chan¹

¹Taiwan Alzheimer's Disease Association, Taiwan; ²Chung Shan Medical University, Taichung, Taiwan

Abstract:

When people with young-onset dementia (YOD) are diagnosed, some of them have already withdrawn from the workplace. The early symptoms of dementia, such as poor judgment, facing difficulties with tasks, language problems, affect the performance of people with dementia. Their poor performance causes them to leave the workplace involuntarily. Most of them hope to regain their role in work, so there is an idea of setting a workplace for people with dementia. The "Young Coffee" was set up in April 2018.

To start up "Young Coffee," TADA's professional team (including nurses, occupational therapists, and social workers) make lots of discussion with people with YOD and their families. A proposal was formed after thoughtful consideration, including the condition of people with dementia, business hours, sales of goods, etc. Meanwhile, occupational therapists assessed all workers with dementia and applied many strategies for job accommodation. We simplified the working procedures, rearranged the work environment, making memos for each action to be taken in the work procedures. During the preparatory period, we observed a rapid deterioration of function on the recruited workers that might jeopardize their ability to work. So, the preparation was speeded up to allow the coffee shop to open three months earlier.

Even though Young Coffee has been operated for almost one and a half year, we still need to make rearrangement weekly. We made adjustments according to the condition of the workers and the customer flow. Furthermore, the status of the worker is assessed regularly. Since the opening, seven workers have quit their job, and three new workers joined in. The selection criteria included cognitive function, working ability, and the willingness to work of people with YOD and their families. We found that the underline causes of dementia may affect workers' ability in maintaining their work. Those with brain damage and vascular dementia, although they have been diagnosed for 6 to 10 years, they are still performing well and remain mild stage. Workers with degenerative dementia are more challenging to maintain. However, with the support of family members and medication adjustment, some of them still able to continue their work.

With no doubt, working in a dementia-friendly workplace optimized their functional performance and health of people with dementia. By working in Young Coffee, people with dementia have more opportunities to interact with other people, and regain their competence and have more smiles on their face. Workers in Young Coffee are very excited to be re-employed in the workplace, and so they work hard as a reward. Salary is not the main incentive to work, as people with YOD only wish to be accepted and recognized. Being employed represents the ability to maintain an active role in society.

Poster Presentation Abstracts

ID: 528

Abstract Topic: Models of care

Keywords: Person-Centred Care, Nursing, Persons with Dementia

PCC nursing: a game changer in dementia care

Debbie May Arriola Amata

Apex Harmony Lodge, Singapore

Abstract:

Person-Centred Care (PCC) is a theory proposed by Professor Tom Kitwood that challenges the current disease-focused medical model of care for dementia that often neglects the person behind the disease. Person-centred dementia care emphasizes the humanness of people living with dementia with the primary objective of promoting and improving their well-being.

Apex Harmony Lodge (AHL) is the first purpose-built lodge for Persons with Dementia (PwD) in Singapore. At AHL, we believe that PwD is a gift to all of us and that they should enjoy the same quality of life as any individual.

Our philosophy of care is derived from two main concepts; Person-Centred Care and Fundamentals of Nursing. Daily nursing care goes beyond physical well-being. It is about respecting each resident as a person; recognising their individual abilities and unleashing their potentials. This is achieved through normalising their routines while giving them back as much independence as possible.

The presentation will discuss the impact of PCC Nursing to the residents, caregivers, families and the culture of care. It will showcase how the residents' well-being, quality and safety are enhanced as proven by diligently tracked clinical indicators. This philosophy of care has also inspired the growth of nursing staffs in becoming dementia specialists equipped with deeper knowledge, unique skills and right attitude towards PwD. The benefits on residents' families will also be presented, through the testimonies and examples of how it has helped them to move forward to jointly discover potentials that lie within their beloved elderly with PwD. Lastly, the presentation will also highlight the shift of the culture of care from a typical nursing care to a more humanized and normalized care. The benefits of this are reflected through how residents' responsive behaviours spark creativity and innovation in using different non-pharmacological approach to better empower the residents.

PCC Nursing is a game changer in dementia care. It has breathed new life and possibilities to the world of dementia. Although Dementia is a progressive disease and may not be curable, PCC Nursing has provided many opportunities and learnings that enable and empower residents, their family members and nursing staffs to experience a better quality of life while journeying with PwD.

Poster Presentation Abstracts

ID: 530

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: family caregiver, person with dementia, smart care, mobile application (APP)

A mobile application (app) for family caregivers of persons with dementia in receiving a smart technology assisted home nursing program

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Abstract:

Background: A smart technology assisted home nursing program using smart clothing with a remote monitoring system was used to assist home nursing to facilitate family care for persons with dementia by detecting of get up at nighttime for greater than or equal to 3 times, staying in bathroom for more than 15 minutes, not moving during day time for more than two hours, getting out of the house, daily activities, low battery or disconnection. Responsible home care research nurses downloaded an app to their mobile phones to receive signals and activity level information and then provide consultation to family accordingly. During a feasibility study, family caregivers requested to have a mobile application (APP) specifically for family caregivers to receive and respond to prompt informations regarding the person with dementia. Based on the demand, this APP was therefore developed with three key features, 1. Real-time feedback: when an abnormal condition is detected, the system will send an alarm signal to the family caregiver for taking action for emergency treatment. 2. Monitoring daily life: nursing staff can regularly feedback the trends of collected activity data to family caregivers as references of a care plan. 3. Predictive behavioral problems: comparing smart clothing monitoring with family observations to predict possible behavioral problems.

Method: A family caregiver APP was developed for family caregivers. Recorded Information collected from the daily smart clothing sensors, qualitative data from interviews with family caregivers, and home visit record of the home nurses were used for the design of the APP.

Results: A family caregiver APP for receiving feedback information of the smart cloth and nursing health information has been developed. This APP includes weekly summary of the situation of the person with dementia, including average activity level, daily number of getting up at night, daily number of getting out of house, not moving during day time for more than two hours, staying in bathroom for more than 15 minutes. The interpretation of the weekly summary and recommendations accordingly were also provided in the APP. In addition to monitoring items for people with dementia, it also provides information on family caregivers such as dementia care, network resources, and caring for family caregivers. The detailed information of the APP and feedback from the family caregivers will be presented.

Conclusion: A family caregiver APP was developed for family caregivers who receive a smart technology assisted home nursing program. The usefulness of this APP will be discussed.

Poster Presentation Abstracts

ID: 532

Abstract Topic: Diagnostic tools

Keywords: early identification, risk of dementia, cognitive communication deficit, Khoo Teck Puat hospital

A cognitive communication screener for early identification of patients at risk of dementia (Singapore): Khoo Teck Puat hospital-cognitive communication screener (KTPH-CCS)

Cora Yi Neng Tan, Ai jia Loo, Angeline Lay Ting Tan

Khoo teck puat hospital, Singapore

Abstract:

Background

The Khoo Teck Puat Hospital (KTPH) Geriatric team runs Dyad Engagement and Enrichment Program on alternate Mondays every month. A speech therapist is involved in this program to assist doctors in identifying patients at risk of dementia by administering a cognitive communication assessment. Cognitive communication deficits could result from an impaired cognition secondary to degenerative diseases such as Parkinson's disease, Alzheimer's disease, or other forms of dementia. It is important to identify these individuals for early treatment. However, most cognitive communication assessments available do not have reference scores to identify patients at risk of dementia. To the authors' knowledge, there is currently no known cognitive communication screeners with local normative data, and this could lead to subjective interpretation of results.

Objectives

The KTPH Speech Therapy team aimed to create a cognitive communication screener that is more sensitive, comprehensive and culturally appropriate for the identification of patients at risk of dementia.

Methods

The KTPH-CCS includes subtests adapted from international and local assessment tools to cover all neurocognitive domains stated in DSM-5: learning & memory, language, perceptual-motor function, executive function and social cognition. The KTPH-CCS was administered on seven healthy participants working as therapy assistants, who had normal cognition determined by Mini Mental State Examination (MMSE). The same instructions and prompts were given to all participants by the same speech therapist. The 20th percentile values and average scores were calculated to provide an objective guide in identifying patients who fall below the average range.

Results

Four participants out of the seven assessed had one or more subtest scores at or below the 20th percentile. Out of these four participants, three were above 60 years of age, suggesting that age appears to be a factor in the competency of this screener. KTPH-CCS is culturally appropriate as all participants who are from three different races were familiar with all test items. It is a comprehensive screener as it takes forty-five minutes to assess all neurocognitive domains, making it suitable for clinical settings.

Conclusion

With average scores and 20th percentile values made available, future therapist who administers the KTPH-CCS will be able to objectively interpret results. KTPH-CCS takes forty-five minutes to administer and is suitable for use in a clinical setting with individuals aged 60 years and above, regardless of race. This is a pilot project with aims of extending it into a prospective research study where patients who have completed the KTPH-CCS can be tracked over two-five years to see if dementia develops.

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Although more research with a bigger sample size is required to validate the KTPH-CCS, this pilot project demonstrates the potential of KTPH-CCS as a quick and useful screener to identify patients at risk of dementia.

Poster Presentation Abstracts

ID: 537

Abstract Topic: Risk factors

Keywords: dementia, cognitive impairment, social networks, dementia risk reduction, observational studies

Social network size, cognition, and incident dementia in the Sydney memory and ageing study

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Background and objectives: Research evidence indicate that having a restricted social network is a risk factor for dementia and having a robust network can be protective against cognitive decline (Penninkilampi et al., 2018). This study's objective was to investigate whether the number of friends and family that people contact monthly (social network size) influences cognitive ability and diagnosis over time, controlling for demographic and health-related variables (covariates).

Methods: Participant data were collected at four timepoints (baseline, year 2, year 4, year 6) in the Sydney Memory and Ageing Study. Descriptive statistics were used to analyse association between 1) social network size and global cognition (based on comprehensive neuropsychological assessment) and 2) social network size and diagnosis (no impairment, mild cognitive impairment, dementia). Statistical modelling including structural equation modelling (SEM), logistic regression, and linear regression were used to explore association between network size and cognition, and network size and diagnosis, over time controlling for covariates.

Results: Of the 1037 Sydney residents aged 70-90 years without dementia who completed baseline assessments 55.2% were female and 476 provided social network data at all four timepoints. On average, cognitive ability and social network size declined over time. SEM modelling indicated that after controlling for covariates including age, education and depression, higher cognitive ability at year 2 predicted larger network size at year 4. Logistic regression indicated that people who received a diagnosis of dementia after baseline were less likely to have answered the social network question at baseline (OR 0.27, 95% CI 0.10-0.68). Nearly half of people who completed the social network question at all timepoints ($n=224$, 47.1%) had maintained or grown their social network at follow-up (year 6), and just over half had smaller networks. People who received a dementia diagnosis over the six years had smaller networks at baseline than did 1) people diagnosed with MCI who did not progress to dementia and 2) people with no cognitive impairment. However, linear regression indicated that baseline network size was not significantly associated with dementia diagnosis, controlling for covariates.

Conclusions: Although study outcomes were mixed, results overall did not indicate a predictive relationship between the size of a person's social network and their cognitive ability across six years. Some people with dementia did not report their social network size. It is important to understand why people do not respond to social network items. Future research should investigate reasons for non-response and potential association with early changes in cognition around social relationships. Identifying causal associations may require longer study timeframes and more detailed information about social relationships since relationship quality matters as well as quantity.

Poster Presentation Abstracts

ID: 539

Abstract Topic: Well being and quality of life

Keywords: Quality of life, communication

Text to pictures - a better way to measure how people feel about their quality of life

Tracy Comans, Kim-Huong Nguyen

The University of Queensland, Australia

Abstract:

Background

The QOL-AD is a dementia specific quality of life instrument. A five domain version the AD-5D is now available for use in economic evaluation. The domains cover physical health, memory, mood, living situation and doing things for fun. However written questionnaires become increasingly difficult for people with dementia to self complete as the disease progresses. Using visual communication (images) to represent the levels of health may help people to identify how they are feeling if written communication is a challenge. This preliminary work aimed to understand whether people would be able to select pictures that represented how they felt about quality of life.

Methods

We conducted two focus groups with people with dementia, carers, and aged care providers to test whether people could sort and select pictures to represent the levels of the domains. A range of printed images (>100) of people and activities were presented and the participants were asked to choose pictures that represented excellent, good, fair and poor health to them in the domains of mood and physical health. A consensus exercise in groups then asked people to choose one of the images that all would agree represented that level.

Results

A total of 24 people participated in the groups including 5 people living with dementia and their carers. Most people were able to select images and found the task interesting, with three participants unable to complete the task. A variety of images were chosen for each level of physical health and mood however patterns could be found. For example, for excellent physical health, nine different images were chosen which showed people doing strenuous activities such as trail running, running on the beach and boxercise classes. The good level was more likely to contain images of people walking whereas all fair images showed people using some type of walking aid. For excellent mood, most images chosen showed groups of people laughing and enjoying themselves and for poor, images showed people on their own, with white backgrounds. Consensus was able to be reached on one image that best represented each level of the physical health and mood domains of quality of life

Conclusions

This pilot work has established that groups of people can reach consensus on images that represent to them what excellent, good, fair and poor health states look like. This provides the basis for conversion of the AD-5D tool to a pictorial tool in future. This will require repeating this task with all domains and with people with different socio-economic and ethnic differences in order to ascertain if they view quality of life differently.

Poster Presentation Abstracts

ID: 546

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: Mild cognitive impairment, visual attention, visual perception, visual cognition, daily function questionnaire

Developing a questionnaire of visual perception related daily function for mild cognitive impairments: preliminary study

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Abstract:

Introduction: Literature have shown that people with mild cognitive impairment (MCI) have problems in visual perception and difficulties in activities of daily living (ADL). However, there is limited knowledge of the extent of ADL difficulties persons with MCI experienced as a result of visual deficits, as well as ways to detect these problems. This research aims to develop a questionnaire of visual perception related daily function difficulties for people with MCI.

Methods: 20 healthy adults and 26 people with confirmed MCI diagnosis were recruited. All participants completed the assessment of visual attention (VA), visual perception (VP), and visual cognition (VC). Daily function questionnaire were conducted by participants' family with Disability Assessment for Dementia (DAD) and Visual Perceptual Activity Questionnaire (VPAQ). We developed VPAQ after literature review (Visual Activity Questionnaires, 14-item Visual Functioning Index, and relevant literature) and reviews from 5 experts from the fields of dementia, visual perception, and questionnaire design. The final version of VPAQ comprised of 27 questions of daily function in 3 domains of visual related activities, including VA, space perception (SP), and visual memory (VM) and also 2 questions about the information of visual related disease. Daily function questions are answered based on 5-point Likert Scale. Mann-Whitney test and linear regression model were used to compare intergroup differences. The Spearman correlation was used to determine the correlation between the results of VPAQ and VA, VP, VC, or DAD.

Results: MCI group had lower education and tend to be older than healthy group. After controlling education and age, there were no intergroup significant differences on most results of VA, VP, VC, DAD and VPAQ. However, MCI group tended to perform worse than the healthy group on the total score ($p=0.079$) and the VM ($p=0.066$) subscale score of VPAQ. There were moderate to high correlation within the subscale score of VPAQ each other and total score ($r=0.452\sim 0.848$). The score of VPAQ was lowly to moderately correlated with the scores of different subscales and total score of DAD ($r=0.291\sim 0.638$), and the results of VA ($r= - 0.320 \sim - 0.498$), VP ($r= 0.299\sim 0.466$), VC ($r=0.353\sim 0.428$) evaluation.

Conclusions: The findings showed that VPAQ correlated with the results of daily function and visual related function. In addition, VPAQ could have the potential to detect the level of visual related functional difficulties in people with MCI. However, small sample size and the sensitivity of the VPAQ may contribute to fail detecting the difference in this study. To clearly understand the visual related daily function in MCI population, future study can recruit more participants to examine the feasibility and the psychometric properties of VPAQ.

Poster Presentation Abstracts

ID: 549

Abstract Topic: Psychosocial interventions

Keywords: CST International, Implementation, Tanzania

Cognitive stimulation therapy (CST) for people with dementia in Tanzania: results of an implementation research programme

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¹Mt Meru Hospital, Arusha, Tanzania; ²Newcastle University, United Kingdom; ³Newcastle University Hospitals NHS Foundation Trust, United Kingdom; ⁴Kilimanjaro Christian Medical College, Moshi, Tanzania; ⁵UCL, London, United Kingdom; ⁶Northumbria Healthcare NHS Foundation Trust, United Kingdom

Abstract:

Background: This work forms part of the CST-International research programme. Cognitive Stimulation Therapy (CST) is a low-cost, evidence-based, group psychosocial therapy with the potential to improve outcomes for people living with dementia in low- and middle-income countries. CST has previously been adapted and successfully piloted in Tanzania. The current challenge is to successfully implement this low-cost and evidence-based intervention across Tanzania. Barriers and facilitators to CST were identified and an implementation plan for Tanzania was developed.

Objectives: To evaluate the CST implementation strategy in Arusha, Tanzania. Parameters included:

1. Feasibility (adherence, acceptability and attrition)
2. Success (number of trained facilitators, numbers of groups run)
3. Outcomes (cognition, quality of life)
4. Costs/affordability

Methods: Mount Meru is a government owned hospital that provides a referral service for hospitals in the Arusha Region and serves a population of approximately 1.69 million. Potential CST facilitators were identified during stakeholder meetings with healthcare personnel working at the hospital and were trained to deliver CST using an internationally standardized approach. Participants were recruited from a dementia screening programme of all people aged 60 and over presenting to the outpatient department. Participants were included if they met the DSM-IV criteria for dementia, impairments were mild to moderate as rated on the Clinical Dementia Rating scale and if they had sufficient eyesight and hearing to take part in a group. The full programme of 14 CST sessions was delivered over 7 weeks. The sessions were delivered in designated rooms in Mount Meru Hospital. Assessments were conducted the week prior to CST and immediately after the 7-week CST programme. Assessments were conducted by trained healthcare professionals who were not involved in the delivery of CST. The following information was collected: Demographic and clinical information, CST feasibility outcomes, cognition, quality of life, activities of daily living, caregiver burden and experience and cost effectiveness.

Results: Eight nurses were recruited and trained to deliver CST. Fifty-three participants were found to be suitable for CST from the screening programme. A total of 8 groups containing 4-6 participants were formed. The 7-week CST programme has now been completed and post-CST assessments are currently ongoing. Results from the formal analysis will be presented at the conference.

Conclusion: Preliminary results suggest that it is possible to recruit facilitators and participants for CST and deliver a full CST programme. Once post-assessments have been completed results on

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feasibility, success, outcomes and costs of CST implementation will permit further conclusions to be drawn.

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ID: 555

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: social innovation, entrepreneurship, co-design, learning & teaching

Entrepreneurship and intergenerational engagement to tackle ageing in place: a case study of an undergraduate coursework.

Kishan Kariippanon

University of Wollongong, Australia

Abstract:

Background

The University of Wollongong's School of Health and Society runs a subject called Social Innovation and People-Centred Design for undergraduates in their final year over 13 weeks. The subject is also open to all final year students across the faculties of business, humanities and engineering. The format of the subject is designed for students to use interdisciplinary theory (Fogg Behaviour Model, Anthropology, Dementia Friendly Design, Business Model & Value Proposition Canvas) and tools to tackle ageing in place while considering the needs of people living with dementia.

Method

Students were given four assessments: two individual reflective/critical thinking tasks, one peer feedback task and one group work. The group work is a simulation of a healthy ageing social entrepreneurship accelerator. After each individual has generated proposals for one idea in their first assessment, the teams pick the top five ideas and get to work with elderly members of their family/network who are willing to help. Every week, they present a five min update on their project, the insights gained from their interviews with elderly people and how they tweaked their ideas to create value for their early adopters. At the end of the semester, the teams pitch their ideas to a panel of engineers, public health practitioners, and dementia researchers. The teams are provided five minutes of question time much like the TV show 'Shark Tank'. This exercise reflects how well they were able to engage in an intergenerational mode with their elderly co-designers to generate learning, skills and potentially a solid solution for the identified problem.

Analysis

As a final assessment, students write a reflective piece on their work and engagement with their stakeholders during the term. A general analysis of their work found elements of intergenerational engagement (with elderly people) an effective platform to learn about ageing in place and the dementia friendly design needs of an ageing population. Students come to a collective conclusion that creative problem solving is necessary to improve and enable ageing in place and can be achieved systematically through qualitative interviewing, ethnography, co-design and lean startup methodology. Elderly stakeholders must be involved from the start and each team developed their own methods of engagement and testing with their stakeholders.

Conclusion

This is an example of innovation in interdisciplinary undergraduate coursework in the context of ageing in place and dementia friendly design. Both the students and their elderly stakeholders engage in a co-design space with entrepreneurial thinking to tackle day to day challenges of ageing. The students come out of this subject confident that they can make a significant contribution to dementia friendly design and their elderly stakeholders feel empowered by their ability to contribute intellectually and experientially to a university assessment.

Poster Presentation Abstracts

ID: 557

Abstract Topic: Risk factors

Keywords: Sarcopenia; Sarcopenic Obesity; Cognitive Functioning

Impact of sarcopenia and sarcopenic obesity on cognitive functioning in healthy community dwelling older adults (GERILABS2 study)

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Abstract:

Background

Current literature has shown that obesity is associated with cognitive impairment. However, research on relationship of body composition phenotypes, especially on sarcopenia and sarcopenic obesity with cognitive functioning in older adults remains inconsistent. We aim to examine the associations of body composition phenotypes with cognitive functioning. We also examine dual tasking performance, which has recently gained increased interest as an early marker of cognitive impairment, amongst the 4 groups.

Methods

We recruited 191 well community dwelling older adults from the GERILABS2 study. They were grouped into 4 body composition phenotypes: i) normal (non-sarcopenic/non-obese), ii) obese/non-sarcopenic (O), iii) sarcopenic/non-obese (S) and iv) sarcopenic obese (SO). Obesity was defined using waist circumference (Asia Pacific Consensus cut-offs) and sarcopenia using Asia Working Group for Sarcopenia criteria. Cognitive functioning was assessed with Chinese Mini-mental State Examination and Chinese Frontal Assessment Battery (CFAB). Their baseline characteristics, functional and physical activity/performance (including dual tasking gait speed with cognitive tasks of counting backwards (DT-CB) and animal naming(DT-Ani) were also examined across the 4 phenotypes. We calculated dual task cognitive cost by dividing the difference of dual task gait speed and single task gait speed by single task gait speed, and expressing this as a percentage. Univariate analysis was conducted to compare means and proportions amongst the 4 groups. Multiple regression was performed to examine the association of body composition phenotype with dual task cognitive cost.

Results

S and SO subjects were older (mean age 69-73yrs). S subjects have lowest Mini-Nutrition Assessment (MNA) score, poorest functional parameters of activities of daily living (ADL), instrumental ADL, and physical performances of grip strength and leg extension. There were statistically significant differences amongst the 4 groups for CFAB, DT-Ani and DT-CB, with S groups performing the worst, followed by SO. There was statistically significant difference in dual task cognitive cost for DT-Ani amongst the 4 groups, but no difference for dual task cognitive cost for DT-CB. Multiple regression analysis showed that sarcopenic group was significantly associated with increased dual task cognitive cost for DT-Ani, even after correcting for nutrition, education level, and cognitive scores.

Discussions & Conclusions

Our study shows that the sarcopenic group has worst cognitive performance, including dual task performance, amongst the 4 body composition phenotypes, independent of age, prior education level and nutrition level. This is similar to other studies done before demonstrating that sarcopenia predicts

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physical and cognitive decline. However, contrary to other studies, no associations of SO with poorer cognitive performance was found in our study.

Poster Presentation Abstracts

ID: 560

Abstract Topic: Well being and quality of life

Keywords: Countering negativity, informal carer support, communicating with those with dementia, changing attitudes, living well with dementia

Reframing dementia: creating positive attitudes to assist dementia carers

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Abstract:

When a person is diagnosed with dementia both that person and their family members are frequently delivered a message of doom and gloom, as in 'this is a tragic (currently) incurable disease, for which there is little that can be done'. This is devastating news for those with dementia as well as those who share their lives. For those who take on the care of someone with dementia, he or she is also cast into this gloomy space, one without hope or support. It is inevitable that the so-called 'carer burden' will become a self-fulfilling prophecy. This negative medical message works against good care, both for people with dementia and the care needed for their carers.

However, good care, support and engagement for those with dementia and their carers is possible, both at home and in residential facilities. Indeed, good care is the best treatment available at present for those with dementia. This presentation showcases a new website, designed by experienced and knowledgeable dementia carers for other carers. We acknowledge the challenges of living with dementia (for all those affected) and approach these challenges in positive, creative, constructive and enabling ways. We focus on carer stories as an important, enlightening way that new carers learn, and we follow the world of the dementia carer, from the early days through to the grief associated with the death of an intimate partner or family member for whom they have been caring.

Dementia care is distinctive, and unlike other forms of care. We need to know how and why it is distinctive in the demands it makes of carers if we are to care well, and to develop enabling supports for a whole range of carer situations; and we need to recognise that those who have been through this experience are the real experts: they are the best people to teach us about what is needed to support dementia care and dementia carers themselves.

Hopeful, positive and practical messages about communicating in the context of dementia challenge and change the dismal culture of dementia and dementia care. This resource shows how this can be accomplished. It is designed to ensure that those diagnosed with dementia and all those who support them can live as well as possible and most importantly, we demonstrate that it is possible to reframe the negativity implicit in the messages currently being conveyed about dementia and its impacts, recognise and draw on the knowledge and experiences of carers and create positive attitudes.

Poster Presentation Abstracts

ID: 561

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: social innovation, entrepreneurship, co-design, dementia-friendly

Desert rose house: an integrated approach to designing a dementia friendly sustainable house for ageing in place.

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¹Faculty of Social Science, University of Wollongong; ²Sustainable Buildings Research Center, University of Wollongong; ³Faculty of Engineering and Information Sciences, University of Wollongong

Abstract:

Background

The Desert Rose House is an innovative residential construction with maximum comfort, elegance, privacy and a design that combines sustainable living with ageing in place. The design is based on the Dementia Enabling Environmental Principles[1][2]. This framework was complemented with a co-design process, which included a partnership with people living with dementia, their carers, retirees and the building industry as well as researchers and doctoral students.

Methods

The co-design process allowed counter-narratives to influence its design and construction. The use of ethnography and auto-ethnographic-methods from the social sciences gave importance to the experiences of people living with dementia and disrupted norms of design, research practice and representation. The data in the form of talks, narratives, video-narratives and photo-voice including observations were analysed with the help of a multidisciplinary team represented by faculty and students from engineering, the humanities and vocational institutions (TAFE).

Analysis

The process of analysis required collective reflexivity to layer the different requirements and needs of the various stakeholders in order to create solutions and decisions that are comprehensible, meaningful and manageable[1]. Regular meetings with members of the community and people living with dementia were organised to provide consistent critique and feedback to the team. The co-design process acknowledged that there were assumptions that required validation and a paucity of design decisions that were meaningful to elderly people. The collected narratives transformed professional practice by providing insights into the lived experience of people who want to age in place. As a result of this reflexive co-design process, a shift from a clinical design to one that reduces the stigma of ageing and dementia was achieved. The house is relevant to all age groups but capable of allowing its residents to age in place.

At the Solar Decathlon Middle East Competition, the house was empirically evaluated for comfort, an essential factor for dementia-friendly design, and was awarded the first prize in this category. Overall, the Desert Rose House won 2nd prize.

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Poster Presentation Abstracts

ID: 567

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Patient and public involvement, dementia, lower and middle income countries (LMIC), South Asia

Patient and public involvement (PPI) for dementia research in LMIC: developing capacity and capability in south Asia

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Abstract:

Background: Patient and public involvement (PPI) is 'an active partnership between the public and researchers in the research process. Active involvement may take the form of consultation, collaboration or user control to direct and guide research. PPI for dementia research is essential to ensure that a person with 'lived experience' of dementia offers a perspective based on direct personal experiences, but the concept and practice of PPI is not well known in most lower and middle income countries (LMIC). Here, we describe initial PPI activities in seven

Objective: To undertake and describe different types of dementia-related PPI activities related to a dementia research project in South Asia.

Methods: At seven clinical research sites in Indian, Pakistan and Bangladesh, the research teams each set up a new PPI group (2-4 individuals) and undertook a PPI activity representing one of the 'rings' 'The Public Engagement Onion' model (The Wellcome Trust: 2011) ranging from basic engagement activities with larger audiences to more intense activities with small groups and having greater impact. Each site reported on various outcomes regarding their PPI activity, including changing attitudes and behaviour, informing the study, sharing knowledge and outcomes, and co-producing research.

Results: The capacity and capability to include PPI in dementia research was significantly enhanced across the sites. Members of the research team reported that engaging in PPI activities enhanced their understanding of dementia research and increased the meaningfulness of the work.

Conclusions: Introducing PPI for dementia research in LMIC settings, using a variety of types of activities is important for meaningful and impactful dementia research.

Poster Presentation Abstracts

ID: 568

Abstract Topic: Informal carers training

Keywords: iSupport, caregivers of people with dementia, Internet-based psychosocial program, RCT

iSupport, caregivers of people with dementia, Internet-based psychosocial program, RCT

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Abstract:

【Background】

Japan is deemed as one of the most aged country in the world and it is estimated that the number of people with dementia in Japan will increase to about 20% (about 7 million) of those aged 65 and over in 2025. As caregivers are often aged, their burden and cost is an issue of whole society. Psychosocial interventions such as cognitive behavioral therapy have been reported to reduce caregivers' mental distress and improve health, and randomized control trials (RCTs) suggested that caregivers' knowledge may be improved through the Internet-based psychosocial program, which also may reduce burnout, anxiety, and depression. The World Health Organization (WHO) developed iSupport with the aim of improving caregiver knowledge and skills, reducing mental stress, and improving the quality of lives for both dementia and caregivers. iSupport is an online self-learning support program that uses cognitive behavioral therapy technology, and can be easily accessed from a personal computers, tablets, or smartphones. We have accomplished Japanese adaptation of iSupport with the cooperation of "Dementia People and Family Association" in accordance with Japanese local culture and custom. A similar project using iSupport is performed at the whole world.

【Methods and design】

Our study consists of two parts. On Part 1, we predict the effect size and modify the contents of the program by an open-label, uncontrolled study on an expert panel. On Part 2, We conducts a RCT for caregivers and verifies the effectiveness of the iSupport Japanese version. Participants considered necessary by Part 1 are expected to be recruited. Inclusion criteria for participation in the trial are (1) 18 years old or more, (2) caregiver of a person with dementia as per self-report, (3) internet literacy, (4) his/her family member has a diagnosis of dementia (AD8 \geq 2) as per self-report, (5) Zarit Burden Interview (ZBI) score of 20 or more (6) Beck Depression Inventory (BDI-II) score between 5 and 29, (7) Generalized Anxiety Disorder Scale 7-item (GAD-7) score between 4 and 14. The intervention group will be offered iSupport. The comparison group will receive an education book containing similar content. The primary endpoints of this trial are : ZBI, BDI-II, GAD-7, Neuropsychiatric Inventory and secondary endpoints are scales of quality of life, person-centered attitude, degree of utilization of social resources. It is estimated to take 20-40 hours for participants to finish iSupport. To reduce the dropouts, we will watch the activity of participants and periodically contact them electronically.

【Discussion】

The results will show how iSupport can be helpful to reduce the burden on caregivers in Japan and promote the health of cared people. Since trials similar to this study are being conducted around the world, it may become clear that the knowledge and support required for caregivers differ from region to region.

Poster Presentation Abstracts

ID: 569

Abstract Topic: Attitudes, awareness and stigma

Keywords: Hope Ek ASHA, Dementia friendly, Stigma, Rural

ROLE OF HOPE EK ASHA IN CREATING AWARENESS AND A DEMENTIA FRIENDLY SOCIETY

Sushma Chawla

Hope Ek A.S.H.A., India

Abstract:

How many of us really know about Alzheimer's in India? Sadly, India has not matured enough to understand Alzheimer's and the socio-economic burden that it brings to the society and the Nation. It is considered more as an old age condition rather than a disease like Dementia where a person needs specialised medication, care and brain stimulation exercises to slow down its progression. Even in more advanced society, stigma attached to the disease is a primary concern of people living with Alzheimer's and even for their caregivers who are more often than not, are the family members.

So, how do we tackle the spectre of a disease like this? Awareness is the key factor and HEA is working on it from the last 18 years. It is of utmost importance to dispel myths and misconception surrounding this disease. Every person affected with this ailment, he/she has all the right to lead a quality life with dignity. So, it falls on the society to compassionately accept people with dementia and empower their care partners. But it is quite a challenge in a country like India where rural population is bigger, compounded by low literacy.

Lack of basic medical facilities in rural areas is another reason for cases of Alzheimer's going unreported, thus making this disease an enigma. It is a humungous task for a country that has around 4 million people suffering from some form of dementia. A collective and concerted effort equipped with knowledge about the disease will help in changing our mindset about Alzheimer's to build a conducive ecosystem and a DEMENTIA FRIENDLY SOCIETY. Hope Ek ASHA is committed to create awareness among masses and had its 103rd Camp on 22nd July 2019. Pleased to announce the opening of an "AFFECTIONATE, SECURE HOEM FOR ALZHEIMERS" (A.S.H.A) in New Delhi a month ago. Caring and Respite to the Caregivers is extremely important and that's what we are doing at A.S.H.A.. It is first of its kind in Northern India having structured schedule in a COST EFFECTIVE way..

Poster Presentation Abstracts

ID: 576

Abstract Topic: Models of care

Keywords: PCC, Individual, Enhanced, Dementia, improved outcomes

Developing a person centered care plan for improved outcomes of persons with dementia in the community

Namrata Sadarangani, Charu Wadhwa

St. Andrew's Community Hospital, Singapore

Abstract:

Introduction:

Person-centered care (PCC) (Tom Kitwood, 1997) is a model of dementia care with the aim to promote well-being, emphasizes on informed care based on social, functional and clinical history.

Current practices in most dementia care facilities use a "one size fits all" approach with poor outcomes due to varied cognitive and functional capacity, lack of knowledge of residual abilities, life story, needs and preferences of Persons with Dementia (PWD).

Objective:

The objective of this project was to empower the care staff and the family caregivers to practice PCC based on the knowledge of the person's life story, needs, preferences and responses to meaningful engagement as observed during PCC sessions.

Aim: To study the effectiveness of an Individualized care plan for moderate to severe Dementia clients for improved wellbeing.

Methods

A retrospective study of sixteen moderate to severe dementia patients who participated in one to one PCC sessions conducted by an Occupational therapist at a frequency of once/month.

The sessions were based on the individuals' residual functional abilities, needs and knowledge of the client's social and occupational role in the past.

The outcome measures used were the Mini Mental State Examination (MMSE), the Functional Assessment Staging Tool (FAST), the Challenging Behavior Scale (CBS) and the Zarit Caregiver Burden Index (ZBI-4). Each client was assessed on admission and at six months intervals.

Results:

65% of PWD showed a positive change on MMSE and reduced CBS scores, 88% of them maintained their FAST scores.

69% clients and caregivers showed positive changes on Wellbeing scores and ZBI-4 scores respectively.

Conclusion:

The PCC sessions help develop an individualized and informed care plan for dementia clients, thus enabling delivery of PCC by the care team and family caregivers with positive outcomes.

Limitation: Lack of a feedback survey from family caregivers.

Poster Presentation Abstracts

ID: 578

Abstract Topic: Attitudes, awareness and stigma

Keywords: Stigma, Millennials, Exposure, Education, Dementia

Indonesian millennials' stigma towards dementia and the importance of exposure to dementia in formal education

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¹School of Medicine and Health Sciences, Atma Jaya Catholic University of Indonesia; ²Department of Statistics, Hamzanwadi University

Abstract:

Background: A higher level of contact with people with dementia results in better understanding and lower level of stigma in the adolescent. Addressing education about ageing in formal education is important as it is also included as one of the action plans in Indonesia's National Dementia Plan. This study will assess the arising population's stigma towards dementia and their previous dementia's exposure in formal education.

Methods: Qualitative data were collected from focus group discussions (FGDs) among 6 people with no personal experience with dementia and 4 caregivers of people with dementia to inform the questionnaire development for quantitative step. A quantitative study was then conducted using a structured questionnaire, involving 244 millennials (born between 1980-2000) living in Special Region of Jakarta, Indonesia. Collected data from the quantitative step were analyzed with data mining and decision tree method using RStudio software.

Results: Population's mean age is 22 ± 2.51 years old, female (63%), all of them are high school graduates, and most of them are currently studying for or had graduated with a bachelor's degree (91.83%). Not being previously exposed with dementia in formal education (58.4% of total population) had higher probability to express agreement with all these statements: "dementia is a normal part of ageing", "people with dementia's opinion is not reliable", and "people should keep dementia as a secret" (75%).

Conclusion: Stigma is more commonly found in respondents who have not had any exposure to dementia issues in their formal education. Previous exposure or experience related to dementia in formal education might increase attitude and prevent stigma. Dementia awareness raising can be implemented in an education setting in the form of forum or study visit to a long term care facility to increase the level of contact. The implementation of the National Dementia Plan needs more participation from the central and regional government as well as educational institutions.

Poster Presentation Abstracts

ID: 579

Abstract Topic: Models of care

Keywords: Behavioral problems, dementia care, models of care

The RECAGE project (respectful caring for agitated elderly) : a new model for management and care of BPSD

Annalisa Baglieri¹, Rocco Amendolara¹, Barbara Manni¹, Lucia Bergamini¹, Luigi De Salvatore¹, Linda Morselli², Simona Moscardini¹, Francesca Neviani¹, Luisanna Palmisano¹, Andrea Toschi¹, Marina Turci¹, Andrea Fabbo¹, Mario Possenti³

¹Health Authority and Services of Modena (AUSL), Italy; ²Villa Igea Special Care Unit for BPSD, Modena, Italy; ³Federazione Alzheimer Italia, Milano, Italy

Abstract:

Background and objectives:

The management of Behavioural and Psychological Symptoms of Dementia (BPSD) represents a major burden both to persons with dementia (PwD) and to the formal (staff) and informal (family) caregivers. The aim of this study (founded by the European Commission in the framework of the H2020 calls, number: 779237) is to assess the short- and long-term efficacy of a new intervention, the Special Care Unit for patients with BPSD (SCU-B) as well as its cost-effectiveness. We define the SCU-B as "a residential medical structure lying outside a nursing home, where PwD are temporarily admitted when their BPSD are not controlled at home". The mission of the SCU-B is to improve behaviour and to permit, when possible, their coming back home. Some SCU-Bs have been already implemented in some European Countries, as France and Germany, but are not widespread and not yet validated as to its efficacy. The aims of the study are: a) to evaluate the efficacy, both short- and long-term, of the SCU-B as component of the care pathways for PwD; b) to assess the quality of life of PwD and caregivers, and to estimate the cost-effectiveness of the SCU-B; c) to evaluate the capacity of the SCU-B to delay institutionalization.

Methods:

RECAGE is a prospective observational study comparing two cohorts of community-dwelling PwD of any etiology with significant BPSD. The duration of the follow-up will be 36 months. The total number of patients will be 500, divided in two cohorts of 250 each. The follow-up visits are scheduled every 6 months. The first cohort will be followed up by 6 centres endowed with a SCU-B and the second one by 6 centres without a SCU-B. Each patient must have a primary caregiver committed to stand by the patient during the three years of the study. The primary endpoint will be measured through the NPI and CMAI scales. The secondary endpoint will be estimated through QoL-AD (patient) and ACQoL, EQ-5D-5L, CBI (carer); the comparison of the drug consumption between cohorts will be measured through the number of psychotropic drugs used. In a second phase the analysis of the data collected will be performed and in the third phase the results will be widely disseminated.

Results: In the health service of Modena, the SCU-B is represented by Nodaia, a dementia hospital unit with high intensity care. The health service of Modena has enrolled 93 PwD with related caregivers. The drop-outs are 7. All subjects have been submitted to screening and baseline visits and 64 subjects to the first visit of follow-up after 6 months. Clinical scales of the study have been administered to all subjects.

Conclusions: The possibility to access facilities dedicated to the treatment of behavioural disorders as the SCU-B can represent a valid opportunity to manage the phases of behavioural decompensation and allow people with dementia to live at home for as long as possible. We hope that the results of the RECAGE project will be in line with our suggestions.

Poster Presentation Abstracts

ID: 580

Abstract Topic: Psychosocial interventions

Keywords: Cognitive stimulation therapy, mild dementia, occupational therapy

The cogs club in Italy : a multi-modal intervention for people with dementia

Petra Bevilacqua¹, Lucia Bergamini¹, Vincenzo Galgano², Claudia Lograno², Barbara Manni¹, Katia Pinto², Pietro Schino², Angela Vocale², Andrea Fabbo¹

¹Health Authority and Services of Modena (AUSL), Italy; ²Bari Alzheimer Association , Federazione Alzheimer Italia, Italy

Abstract:

Background: The "Cogs Club" is a multi-modal intervention based on the Cognitive Stimulation Therapy (CST, Spector A.). CST is cost-effective for people with mild-to-moderate dementia and is recommended in the UK by NICE. CST, in our adaptative model, is related to other psycho-social activities (OT, music, physical activity). Cogs Club changes a traditional session of about an hour into 4 hours of activities. Objectives: the aim of this study is to verify the efficacy of this multidimensional psychosocial intervention.

Methods: the project is promoted by the local Alzheimer's associations situated in Modena and Bari conducted by 3 professionals (a psychologist, an occupational therapy and a fisioterapist) who provide scheduled interventions ad : cognitive stimulation therapy (CST), occupational therapy and physical activities with music. Participants who took part in the second pilot observational study (n° 26 people with mild- moderate Alzheimer's dementia , M9: F 17, mean age 78.23 ±5.11 years, mean education: 7.2 ± 3.86 years) were submitted at T0 (basal evaluation) and T1 (after 3 months) to a multidimensional assessment composed by ACE-R, GDS-15, DAD, QoL-AD and ZBI, at the beginning and at the end of the study. People with sensorial deficit, motor or behaviour disorder was excluded . The sample at T0 had the following features: a mild cognitive impairment (MMSE 22.6±2.35, ACER 63.54±12.52) , mild depression (GDS 5.35±3.22), impairment, difficulty in instrumental activities of daily living (DAD 68% ±20%) , a satisfying perception of quality of life (QuolAD 31.34 ±7.23) while the perception of family caregivers is much lower (QuolAD CG 29.33±6.02) with associated stress (Zarit 34.25 ±14.76).

Results: data derived from the statistical analysis (T test for paired samples), at T1 all indicators of multidimensional assessment (cognitive: MMSE 22,6 vs 23,4 , p 0,096; ACE – R 63,54 vs 65,96 p 0,066; functional: DAD 0,68 vs 0,69, p 0,103; emotional-affective : GDS 5,35 vs 4,12 p 0,039 and quality of life : QoL AD pz 31,5 vs 33,38, p 0.129; QoL AD cg: 29,04 vs 30,96, p 0,459) of the patient have improved even if only the depression is of clinical relevance. Regarding the caregiver we found an improvement in the quality of life of their family living with dementia even with an increase in perceived care stress (Zarit 34,09 vs 36,65, p 0,098).

Conclusions: the purpose of the project is also to offer the opportunity of a psycho-social intervention, creating a context for the socialisation and a net of formal and informal connection to people with mild-moderate neurocognitive disorders who traditionally don't ask to access health services. The main goal is to delay as much as possible the development of the disability but further studies are necessary to encourage this preliminary results and remains the problem to define the real benefit of this intervention for family caregivers.

Poster Presentation Abstracts

ID: 581

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, Stigma, Millennial Generation, Screening

Impact of stigma on dementia towards the urge of screening from Indonesian millennial generation's perspective

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Abstract:

Background: Stigma towards dementia has been identified as a major barrier to seek diagnostic evaluation; it is predicted that less than 50% of people with dementia are formally diagnosed due this problem. Sadly, even in this easily accessible information era, young generation is still bound to misconceptions and stigma believed by their older generation. It is highly beneficial to assess which stigma that influences millennial generation's most in terms of the urge to seek screening or recommend screening. This study aims to assess millennial generation's stigma towards dementia especially its importance of early screening behavior.

Methods: Quantitative study was conducted by previous focus group discussion (FGD) between 6 people with no personal experience on dementia and 4 caregivers of people with dementia. Survey using validated questionnaire consisting of 12 questions was disseminated towards 244 millennial (born between 1980 - 2000) living in Special Region of Jakarta, Indonesia. Collected data were then analyzed with data mining classification using R statistical software.

Results: Population's mean age is 22 ± 2.51 years old, female (63%), all of them are high school graduates, and most of them are currently studying for or had graduated with a bachelor's degree (91.83%). Based on the analysis, the stigma about memory impairment as a normal part of ageing process appeared to be preventing the respondents to seek screening the most. Moreover, stigmas such as dementia is normal, curable and not preventable also helped to shape society's mindset about the unimportance of screening. The same most influential stigma also explained the lack of screening recommendation. It is also supported by the view that dementia should remain as a secret for themselves.

Conclusion: Millennial generation's urge to screen is majorly influenced by stigmas about dementia, especially with the thought that memory impairment in older generation is a normal process. Therefore, this suggests the importance of creating an effective awareness-raising module which are targeted to millennials since they can act as caregiver and patient in the future.

Poster Presentation Abstracts

ID: 584

Abstract Topic: Psychosocial interventions

Keywords: lifelong learning, psychosocial interventions, pilot study, feasibility, cognitive training

The effect of a lifelong learning intervention on people with dementia: a pilot control study

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Abstract:

Introduction: An education service in Denmark is providing lifelong learning for people diagnosed with early stage dementia. Lessons are specially developed to support cognitive function, quality of life, problem solving, self-esteem and social engagement. These are provided through classes in cognitive training, music, art and woodwork. Qualitative studies report positive outcomes for the students, who feel the lifelong learning is supporting them to stay independent for longer and to develop their friendships. This pilot study estimates the variability of the measures used to explore the potential effect of lifelong learning on people with dementia (intervention), compared with receiving treatment as usual (controls) and assesses the feasibility of using them in this population.

Methods: This study compared people with dementia attending lifelong learning classes (n=36) and people with dementia receiving treatment as usual (n=34). The utilised tests were cognition (MMSE), quality of life (QOL-AD), self-efficacy (General Self-Efficacy Scale), self-esteem (Rosenburg Self-Esteem Scale), and socialisation (Hawthorne Friendship Scale). Data was analysed using descriptive statistics and repeated measures analysis of variance. The study is part of a mixed-methods study where qualitative research investigates how people with dementia experience these measures, and how best to support their dignity.

Results: The estimates of variability of the tests can be used in designing a future, definitive study. Recruitment of participants relies heavily on the motivation and understanding of the concept with the staff at the education service. Mean changes in scores in the control (C) and intervention (I) groups (baseline to follow-up) for three of the measures appear to warrant further investigation. The mean and standard deviations (SD) for the scores were: MMSE (C) 0.030 (2.963), (I) 0.588 (3.350); General Self-Efficacy Scale (C) -1.060 (5.127), (I) 0.219 (4.353); Hawthorne Friendship Scale: (C) -0.500 (3.670), (I) 0.224 (2.407). Repeated measures analysis of variance showed no significant differences from baseline to follow-up within the same group or between the intervention and control groups.

Conclusions: This pilot-study had low power in detecting significant changes in the groups, but does, however, provide information for estimating sample sizes in future, larger studies. Differences between the intervention and control group were indicated by a slightly greater increase in MMSE scores per person in the intervention group, a slight decrease in QOL-AD score for both groups, a small increase in the General-Self Efficacy score for the intervention group, and a small average increase in Hawthorne Friendship Scale scores for the intervention group.

Poster Presentation Abstracts

ID: 585

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, film, stigma, health-awareness, young-generation

Breaking dementia stigma in younger generation through film in industry 4.0

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¹School of Medicine and Health Science, Atma Jaya Catholic University of Indonesia, Indonesia;

²School of Statistic, Hamzanwadi University

Abstract:

Background

Exposing young generation with positive attitudes and adequate knowledge towards dementia is important to break stigmas, create dementia-friendly communities as well as preparing themselves as future caregivers. Leveraging on high advance mobile technology and high internet millennial users in Indonesia during this industrial 4.0 era, film is believed to act as a promising tool to correct stigma regarding the topic. Due to those reasons, this study aims to assess effectiveness of film as an intervention tool to educate millennials about the topic.

Methods

A triangular study using both qualitative and quantitative methods were performed. Target respondents are millennials, defined as people born between 1980 – 2000. Qualitative data were collected from Focus Group Discussion (FGD) with 7 millennial medical students in clinical clerkship program that had participated in Remember Me Film Festival (RMFF), as part of Alzheimer Indonesia organisation awareness-raising program in 2017. From that, a validated self-administered questionnaire was made and distributed among 244 non-medically trained millennial in order to know more about their stigmas and preferences in health media promotion tools. All of the collected data were then analyzed using qualitative interpretative thematic approach and data mining classification using R statistical software.

Results

FGD participants were 4 and 5th year medical students in clinical clerkship program, as for survey respondents were dominated by female high school graduates 63% with mean age of $22 \pm 2,51$. From FGD, all participants agreed RMFF successfully raised dementia awareness through film among young people, and brought large benefits to both society and participants. It was also found that majority of young people actually had enough comprehension regarding early dementia prevention, especially before 40 years old. However this was not followed by substantial lifestyle changes. Moreover, it was also not supported from our education perspective. Young people might view early screening as less important due to the lack of exposure to dementia issue in education. From the performed analysis, film was found to have high probability as a tool to shape and/or correct as well as a breaking dementia stigmas in society.

Conclusion

Educating younger generation through film in this industrial 4.0 era is likely to be effective and have high probability as a tool to shape and/or correct as well as a breaking dementia stigma in society.

Keywords: Dementia, film, stigma, health-awareness, young-generation

Poster Presentation Abstracts

ID: 586

Abstract Topic: Psychosocial interventions

Keywords: Dementia, Cognitive Stimulation Therapy, cross-cultural implementation, touch-screen application, adaptation

Crossing cultural barriers: introducing a new cognitive stimulation touch-screen application from the United Kingdom to people with dementia and carers in Jakarta, Indonesia.

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¹University of Nottingham, United Kingdom; ²Alzheimer Indonesia, Indonesia;

Abstract:

Introduction

Globally, there are not enough resources for the mental stimulation and engagement of people with dementia. Cognitive Stimulation Therapy (CST) is a psycho-social intervention which provides people with dementia with mentally stimulating activities and has shown to improve the cognition and quality of life. CST has been translated to Bahasa Indonesia and is offered at day centres in Jakarta.

Researchers in the UK have now developed a touch-screen individualised CST (iCST) app to improve on accessibility and level of interactivity. Indonesia's internet population is expected to boom in the next five years reaching a penetration rate of 53%, meaning that technology will play an increasingly important part in the daily lives of the residents. However, not much is known about the application of technology in the health care industry particularly in the care for people with dementia compared to more developed countries.

Considering the existing use of CST in Indonesia and the expected technology boom, researchers from the University of Nottingham and Alzheimer Indonesia collaboratively aimed to explore the attitudes of people with dementia, carers and health professionals in Jakarta, Indonesia towards the iCST app and related technology.

Methods

Four focus groups discussions were organised: one with carers (n = 3), two mixed with people with dementia and carers (n = 12), and one with community carers (n = 3). Participants discussed topics such as current and potential uses of technology, tried-out the iCST app and completed a short usability questionnaire. Furthermore, 21 health professionals attended a stakeholder meeting to discuss the potential of implementing the iCST app in the community.

Results

Attitudes towards technology were positive and the iCST app was well-received. Mental stimulation was an important aspect and the iCST app was seen as a meaningful way to spend time. Carers were more willing to use the app due to their preference for technology over paper materials and rated its usability higher than people with dementia. Feedback also included that the iCST app would be most helpful in the early stages of dementia. Connectivity and access to appropriate technology would need to be improved for implementation. Stakeholders valued the iCST app as well but highlighted the need for strengthening the diagnostic process before implementing post-diagnostic technological resources.

Discussion

By uncovering the willingness of people with dementia and carers to adopt technology and the iCST app in particular, steps towards offering such technology can be made in order to combat the lack of resources for the care of people with dementia in Indonesia and perhaps other countries. There is a

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need to empower end-users, strengthen access and connectivity to technology, and improve diagnostic support. These aspects will help prepare for the rise in technology usage in order to facilitate the uptake of technological resources such as the iCST app.

Poster Presentation Abstracts

ID: 588

Abstract Topic: Non-pharmacological interventions

Keywords: neurocognitive disorder, physical activity, multimodal intervention, functionality, alzheimer's disease

Contributions of a multicomponent exercise program for people with dementia: cognitive preliminary data

Flávia Borges-Machado¹, Óscar Ribeiro², Inês Marques-Aleixo¹, José Magalhães¹, Arnaldina Sampaio¹, Joana Carvalho¹

¹Research Centre in Physical Activity, Health and Leisure, Faculty of Sport Science, University of Porto, Porto, Portugal; ²Center for Health Technology and Services Research - Ageing Cluster (CINTESIS), University of Porto, Porto, Portugal

Abstract:

Introduction: Dementia affects around 50 million people worldwide. This irreversible syndrome compromises memory, learning capacities, calculation, judgment, the ability to independently perform activities of daily living, and adversely affects physical conditioning. It represents 11.9% of the years lived with disability in later life due to a noncommunicable diseases, and its impact is extended to informal caregivers and to the community. Physical exercise appears to have potential benefits for People with Dementia (PwD) due to its possible positive influence on cognitive function, diminished neuropsychiatric symptoms, and daily functioning in addition to the intrinsic benefits of exercise on physical fitness, cardiovascular health and individual wellness. The aim of this study was to evaluate the effectiveness of a Multicomponent Training (MT) on cognitive function of PwD.

Methods: A 6-month MT exercise program with 50-minute group-based sessions was conducted twice a week. This community-based intervention included PwD and their caregivers at light-to-moderate intensity exercise activities. Sessions were conducted by a specialized trainer and divided in 3 main parts: warm-up; specific training (aerobic and strength exercises, and coordination or balance training); cool down (respiratory and stretching exercises). The *Alzheimer Disease Assessment Scale – Cognitive* (ADAS-Cog) was used before and after intervention in 25 participants who were referred from hospitals, daycare centers and municipalities from the metropolitan area of Porto (Portugal). Scores range from 0 to 70, with higher scores suggesting greater severity of cognitive impairment.

Results: This intervention was conducted in 6 different settings, with institutionalized and community-dwelling subjects. The sample comprised 18 women with medium age of 77 years [range 62-90]. Results from Wilcoxon Signed Rank test ($Z = -1,201$; $p \text{ value} = 0,230$) revealed a slight increase on ADAS-Cog score from pre ($29,44 \pm 12,52$) to post-intervention ($30,56 \pm 13,74$), which are considered positive results whereas 12 subjects maintained or diminished their scores.

Conclusions: Data suggests that a 6-month MT intervention may be an important non-pharmacological strategy to mitigate the decline or promote the maintenance of cognitive function on PwD. Further examination is necessary to compare the impact of a MT intervention to a social activity program (control group) and analyze the effects on cognitive performance. Furthermore, a full-scale non-randomized controlled trial, designated "Body and Brain" Project, will investigate the impact of a community-based MT intervention on physical fitness, cognitive function and psychosocial aspects for PwD and caregivers' burden.

Funding: Portuguese Foundation for Science and Technology: CIAFEL (UID/DTP/00617/2019), "Body and Brain" Project (POCI-01-0145-FEDER-031808), and PhD Grant (SFRH/BD/136635/2018); & Instituto Português do Desporto e Juventude.

Poster Presentation Abstracts

ID: 589

Abstract Topic: Epidemiology

Keywords: dementia incidence, data linkage, risk factors

Measuring dementia incidence within a cohort of 267,153 older Australians using routinely collected linked administrative data

Heidi Welberry, Henry Brodaty, Benjumin Hsu, Sebastiano Barbieri, Louisa Jorm

University of New South Wales, Australia

Abstract:

Aim

This study examines dementia incidence within different Australian administrative datasets and how characteristics vary across datasets for groups detected as having dementia.

Methods

This was an observational data linkage study based on a prospective cohort of 267,153 people in New South Wales, Australia from the 45 and Up Study. Participants completed a baseline survey in 2006-2009 and dementia was identified using linked pharmaceutical claims (provided by the Department of Human Services), hospitalisations, assessments of aged care eligibility, care needs at entry to residential aged care and death certificates. Data linkage was undertaken by the Centre for Health Record Linkage (CHeReL) and the Australian Institute of Health and Welfare. Age-specific and age-standardised incidence rates, incidence rate ratios and survival from first dementia diagnosis were calculated.

Results

Age-standardised dementia incidence was 16.9 cases per 1000 person years (PY) for people aged 65 years and over. Estimates for those aged 80-89 years were closest to published incidence rates (91% of rates for high-income countries). Relationships with dementia incidence were inconsistent across datasets for certain characteristics including sex, relative socio-economic disadvantage, number of people that can be depended upon, marital status, functional limitations and diabetes. Median survival from first pharmaceutical claim for an anti-dementia medicine was 3.7 years compared to 3.0 years from first aged care eligibility assessment, 2.0 years from a dementia-related hospitalisation and 1.8 years from first residential aged care needs assessment.

Conclusions

People identified with dementia in different administrative datasets have different characteristics, reflecting the factors that drive interaction with specific services. This suggests bias may be introduced if single data sources are used to identify dementia as an outcome in observational studies. Combining multiple sources provides population estimates that have similar age-specific patterns to other cohort studies, but coverage was highest in those aged 80-89 years.

Poster Presentation Abstracts

ID: 592

Abstract Topic: Informal carers support – pre, during and post

Keywords: frontotemporal dementia, spouse, experiences, consultation process

A successful experience by the spouse of a patient with frontotemporal dementia of persuading the patient to see a doctor

Maki Kato¹, Sachiko Hara¹, Mika Mitsusada²

¹Shimane University, Japan; ²Nursing Unit, Shimane University School of Medicine

Abstract:

目的:

この研究は、前頭側頭型認知症（FTD）の患者の配偶者の経験を、配偶者が患者の変化に気づいてから、医師に診てもらうように説得するまでを明らかにします。この研究は、FTD患者の配偶者がケアを提供している状況を垣間見ることができます。

方法:

1) 研究デザイン: ケーススタディ。2) 対象範囲: FTDと診断された配偶者と同居している個人。3) データ収集方法: 半構造化インタビュー。4) 分析方法: データはコンテキストを考慮して詳細に分析されました。物語の時系列順は、データを分類する際に考慮され、ストーリーラインに反映されました。

倫理的配慮:

この研究は、島根大学医学部の看護研究倫理審査委員会によって承認されました。

結果:

1) ケースの概要: A夫人は70代です。彼女の夫（70代）は、約5年前にFTDと診断されました。A夫人は50代半ばまで仕事をしていました。A夫人は60歳まで働いていました。現在は夫とのみ同居しています。

2) 参加者が配偶者の変化に気づいてからFTDと診断されるまでの経験

Mrs. A was having “experiences of feeling changes in [her husband’s] personality and ways of expressing anger” compared to approximately 20 years prior. However, she “interpreted that such changes were caused by stress from relationships and male menopause.” Mrs. A continued on with her everyday life while “dealing with daily conflicts” with her spouse. Mrs. A occasionally “encouraged the spouse to go see a doctor but could not persuade him,” and time went by. Mrs. A noticed the “functions which her husband was losing” in a situation in which the “symptoms...continued to exacerbate.” At that time, she also considered “other causative diseases” and “was trying to find the appropriate time to suggest to her husband that he see a doctor for consultation, so that her suggestion would not be rejected.” Mrs. A continued to “observe everyday concerns” and “waited for the appropriate time.” On the patient’s 60th birthday, Mrs. A managed to “persuade the patient to see a doctor for a consultation.”

視点:

FTD患者の配偶者は、彼らの変化に気付く傾向があります。しかし、そのような変化が認知症に早期に由来することを彼らが認識することはありそうにない。この研究は、配偶者が患者に対処している間に症状が悪化していることに気付いたときに、患者が認知症を発症していることに気付く可能性があることを示唆しています。患者とその家族の経験に基づいて認知症の知識を深めるさらなる機会を一般市民に提供する必要があります。また、早期の診察につながるような方法で、患者とその家族への支援を改善する必要があるかもしれません。

Poster Presentation Abstracts

ID: 593

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, post diagnostic support

Navigating dementia: a pilot project for post diagnostic support

Stephani Shivers¹, Charlotte Swarbrick²

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Abstract:

In the US health system, there is no wide-spread, systematic support for individuals who are newly diagnosed with Alzheimer's or another form of dementia. A quick survey of families will consistently reveal that they are commonly told to get their 'affairs' in order and return for a follow up visit with their physician in six months. Families are largely left on their own to learn about the disease, symptom and behavior management, and plan for current and future needs. In April 2019, LiveWell Alliance, based in Connecticut, USA began piloting a new post-diagnostic support (PDS) program to begin addressing this critical gap.

Since its creation as a not-for profit dementia services provider in 1990, LiveWell Alliance has been a national pioneer and thought leader committed to positively transform the way people living with dementia (PLWD) are viewed, engaged and supported. In September 2018, LiveWell was awarded a 3-year grant (2018-2021) from the United States Administration on Community Living Alzheimer's Disease Program Initiative (ACL-ADPI). The ACL-ADPI program funds projects designed to fill gaps in services and supports at the community level for PLWD and their care partners/families. The program supports quality, person-centered services that help PLWD remain independent and safe in their communities.

Building on the 5, 8 and Advanced Dementia Practice models of project partner Alzheimer's Scotland, and working in collaboration with PLWD and family care partners, LiveWell has developed a framework for PDS with 5 key focus areas grounded in a comprehensive understanding of the PLWD. Through a series of individual meetings and complimentary education sessions, PLWD and their families are guided through each focus area including: Understanding Dementia and Adaptive Strategies, Social and Meaningful Engagement, Emotional Support, Health and Wellness, and Planning. To begin PDS, each PLWD and/or family is paired with a "Navigator" who administers standardized measures to identify current levels of knowledge and preparedness, along with an assessment tool to identify priorities and the order which the 5 focus areas will be addressed. Subsequent sessions focus on knowledge building, goal setting, and resource identification for each area. Over the course of PDS, a personalized plan is created as a resource for current and future needs and goals. Once all focus areas have been explored, PLWD/families are educated on indicators of disease progression and guidelines for when additional PDS may be warranted. PLWD/families then move into a phase of self-management.

This session/poster will explore the framework development (including partnerships with Alzheimer Scotland, PLWD and family care partners), implementation, session tools and preliminary outcomes from pilot project which began in April 2019. Video testimonials of program participants and the PLWD and carepartners involved in the framework development will be included.

Poster Presentation Abstracts

ID: 596

Abstract Topic: Epidemiology

Keywords: atrial fibrillation, dementia, antipsychotic, stroke

Antipsychotic use and risk of ischemic stroke in atrial fibrillation patients with dementia

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Abstract:

Background:

Antipsychotic drugs are commonly prescribed to elderly patients with dementia. Evidence accumulated from several studies in recent years have raised strong concern about the association of antipsychotics use and increased risk of stroke in this population especially those with cardiovascular disease.

Objectives:

Determine the prevalence of individual antipsychotics use in AF patients with dementia in Taiwan. Investigate the effect of haloperidol, risperidone and quetiapine use on the risk of ischemic stroke in patients with AF and dementia. Evaluate the dose-response relationship of antipsychotics use in patients with AF and dementia.

Methods:

The present study conducted a retrospective cohort study with data from National Health Insurance Research Database (NHIRD). The cohort consisted of patients with atrial fibrillation (AF) and dementia who initiated antipsychotic treatment between January 1, 2006, and December 31, 2010. The risk of ischemic stroke associated with the use of individual antipsychotic drugs was evaluated by using an adjusted multivariate Cox proportional hazards model with haloperidol as the reference.

Results:

Of the cohort, quetiapine was the most commonly prescribed antipsychotic drugs followed by haloperidol and risperidone among patients with AF and dementia. Compared with haloperidol, patients receiving quetiapine were significantly associated with lower risk of ischemic stroke (HR=0.776, 95% CI, 0.631-0.955) while risperidone users showed insignificant lower stroke risk (HR=0.832, 95% CI, 0.653-1.060). High dose of risperidone use was found significantly associated with increased risk of ischemic stroke (HR=1.601, 95% CI, 1.070-2.396) compared to the low-dose group.

Conclusion:

The present study indicated that the use of quetiapine was significantly associated with lower risk of ischemic stroke compared with haloperidol in patients with AF and dementia. Although the study cannot prove causality, the findings provide more evidence of the risk, assisting in decision making for clinicians considering antipsychotics for the treatment of behavioral and psychological symptoms in patients with AF and dementia. When the use of antipsychotics is inevitable, the study suggests prescribing quetiapine in lower possible dose in this population who possess the preexisting high risk of stroke.

Poster Presentation Abstracts

ID: 597

Abstract Topic: Non-pharmacological interventions

Keywords: Non-pharmacological management, BPSD, NDB, PWD

Non-pharmacological interventions in the management of behavioural and psychological symptoms of dementia in Malaysia

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Abstract:

Background: Managing behavioural and psychological symptoms of dementia (BPSD) such as agitation, restlessness, sleep disturbances and anxiety can be distressing to people living with dementia (PWD) and their caregivers. Whilst pharmacotherapy is reserved for severe symptoms of BPSD, the associated adverse effects can be detrimental. Non-pharmacological intervention is therefore recommended to be the frontline in the management of BPSD. Need-driven, dementia-compromised behaviour (NDB) is another concept explaining BPSD as the result of combination of inability of the care providers to understand patient's needs and the inability of patients to express them. The aims of this study were to explore the non-pharmacological approaches in the management of BPSD or NDB and the strategies as well as the barriers of implementing them in the secondary care facilities in Malaysia.

Methods: Qualitative study design was employed. Upon getting the ethical approval from the Universiti Teknologi MARA Research Ethics Committee, data were collected through observations and semi-structured interviews of caregivers and PWD at several nursing care centres in Malaysia. Observations were written in the field notes and interviews were audio recorded and then transcribed verbatim. All data were subjected to thematic analysis. This study was funded by the Ministry of Education, Malaysia through the Fundamental Research Grant Scheme (FRGS/1//2017/SKK02/UITM/02/1).

Results: Personalised approach, social interaction and poor understanding of BPSD were among the major themes that emerged from the study. Some personalised management for non-pharmacological interventions such as physical exercise, music therapy, reminiscence therapy, and pet therapy were conducted in several nursing care centres. Collaborative care between care provider and family members were found to be an important facilitating factor to manage NDB. However, lack of social interactions especially family support led to additional workloads which were beyond the job scope of the care providers. Cultural and language differences among care providers and PWD, lack of training, staffs' inadequacies and time constraints were among the barriers identified.

Conclusion: Although non-pharmacological approaches are conducted to some extent in Malaysia, continuous education and training for the healthcare providers as well as the family members are needed to overcome the challenges with regards to the management of BPSD.

Poster Presentation Abstracts

ID: 599

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: co-research, involvement, valued roles, collaboration

Valuing expert experience: involving people with lived experience of dementia and care partners in translational research

Lenore de la Perrelle¹, Billingsley Kaambwa¹, Monica Cations¹, Gaery Barbery², Kate Laver¹

¹Flinders University, Australia; ²Griffith University, Australia

Abstract:

Background

Involvement of people with lived experience in dementia care research is recognised for bringing unique and valuable insights into the design, conduct and translation of evidence into practice. The Agents of Change translational research involved experts by experience of dementia in developing the proposal, identifying priorities and content as well as providing feedback and advice to clinicians on their implementation of Clinical Guidelines for dementia care. The evaluation of this process will be presented to explore the impact of valuing expert experience in developing meaningful roles for co-researchers and identifying costs and benefits of involvement.

Methods:

An in-built process evaluation in the Agents of Change project focuses on valuing the contribution of people with lived experience of dementia and family carers in the research project. A mixed methods approach is used involving:

- Semi structured interviews and focus groups with expert advisors with lived experience and care partners, both pre-intervention and post-intervention to identify themes and explore examples of the contribution made and improvements needed
- Cost Benefit Analysis weighing costs for support and involvement with identified contributions and benefit to the implementation of the guidelines.

Results:

Results from interviews and focus groups with experts by experience will be presented identifying themes at post implementation stage with a discussion on the challenges and opportunities for monitoring and valuing influence in the project.

Preliminary exploration of costs and benefits will be presented with a cost benefit analysis to be undertaken in April 2020.

Conclusion:

The development of meaningful public roles as co-researchers and identification of costs and benefits of involvement are expected to contribute to improved understanding and opportunities for people with dementia and care partners to be involved in research

Poster Presentation Abstracts

ID: 602

Abstract Topic: Models of care

Keywords: dementia, family caregiver, integrated care model, community care center

Integrated care model for family caregivers of persons with dementia in the community care centers

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¹Chang Gung University of Science and Technology, Taiwan; ²Keelung Chang Gung Memorial Hospital

Abstract:

Background and objectives of the study/Introduction

With the aging of the population, the incidence of dementia is growing annually. Currently, most persons with dementia are taken care of by their family caregivers. Although these family caregivers are faced with heavy burdens, they are usually unable to obtain proper support and help. Care teams have reviewed relevant literature, interviewed employees in community care centers as well as family caregivers, and conducted field observations. They found that services provided by some community care centers focus mainly on activities for the elderly, and very few provide support for caregivers. However, in caring for persons with dementia, family caregivers usually need various forms of help. Therefore, to relieve the stress on them, it is necessary to design an integrated care model for family caregivers of persons with dementia.

Methods

The development and application of this service model can be divided into two phases. The first phase is the service development phase in which service planning is carried out around four major types of services, namely consultations for long-term caregiving resources, consultations for caregiving tips, caregiver support groups, and health promotion activities. An assessment form for service demand is designed to investigate the needs of family caregivers. Priority is then given to providing service according to the demands of family caregivers. Regarding long-term care resources, consultations pertinent to caregiving resources and an organized dementia caregiving resources list are offered to family members. Consultations for caregiving tips are provided by professional volunteers equipped to assist family caregivers of persons with dementia. The second phase is the implementation phase. In this phase, a partnership is forged between people in the community care center and professional volunteers from schools to provide professional and desirable services for dementia patients and their family caregivers.

Results/Positive impact

The results of the study revealed that the most needed service items are consultations for long-term care resources, consultations for caregiving tips, and caregiver support group. More specifically, the most needed services for long-term care resources are special hotlines for long-term care resource consultations (48%), respite care (43%), and daycare centers (33%). This innovative service model emphasizes the following: 1) it is centered on family caregiver; 2) it combines singular service models in an integrated multiservice model; 3) it is able to provide accessible services for family caregivers in the community; and 4) Expertise can be combined with local experience of community care centers, forming a partnership.

Conclusions/Perspectives

The integrated care model can provide needed caregiving services according to individual demands of family caregivers, thus reducing the stress on family caregivers and promoting health.

Poster Presentation Abstracts

ID: 603

Abstract Topic: Psychosocial interventions

Keywords: In-community, art-based, open studio, art therapy

De-kopitiam: in-community art-based open studio for persons living with dementia

Jue Ann Ng, Lay Lay Pee, Jiajia Lu

Montfort Care, Singapore

Abstract:

There is a growing demand of initiatives and interventions in addressing the complex needs of various conditions as the world's population continues to age. In Singapore, care services for people living with dementia (PLD) and family are ranged from home personal and nursing care, home based intervention care, senior activity centers, dementia day care and etc (Silver Pages Singapore, 2019). Just as in other countries, Singapore's population is ageing and there is a need to proactively develop services to attend to those living with dementia, especially those living in the community. In our agency, we piloted a public community cafe and De-Kopitiam, an open studio which uses art therapy modality to engage the PLDs whom still residing in the North Singapore. Different care service providers have been driving to develop holistic care by various professional disciplines, and art therapy is just of such discipline that has positive effects such as longer attention span, orientation, positive social behaviors and easing the caregivers' burden (Wang & Li, 2016). The aim of this study is to study the impacts of in-community art therapy program: De-Kopitiam for PLDs, the relative views of the impacts of the sessions on the PLDs from the family and caregivers, and the potential constraints which may have affected the service utilization. The methodology of the study to understand the engagement of PLD adapted observational tool, Bradford Well Being profiling Tool, accompanied by artistic based inquiry on the artworks created during sessions. Phenomenological inquiry using semi-structured interviews for family and caregivers' lived experiences in understanding the impacts on PLDs after attending the De-Kopitiam sessions, and to understand the constraints or barriers for service utilization. Through this study, we explored the effectiveness of introduction of community-based art-based open studio program for PLDs living in community, re-integration of PLDs into the community via Community Cafe, also bridging the gap to increase the service utilization for the community based program, and lastly to support the PLDs to age in community for as long as possible, with dignified care.

References

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Poster Presentation Abstracts

ID: 604

Abstract Topic: Psychosocial interventions

Keywords: cognitive stimulation therapy, mild cognitive impairment, community

Cognitive stimulation therapy: research and capacity building in a religious community in Indonesia

Tara Puspitarini Sani¹, Gerry Wino¹, Lisye Konny¹, Yoan Chou¹, Hady Syarif², Veronica Wiwing³, Magdalena S Halim⁴, Yuda Turana¹, Yvonne S Handajani¹

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Abstract:

Background and objectives

Cognitive Stimulation Therapy (CST) is an effective, low-cost, nonpharmacological intervention for dementia. It has been implemented as a part of the memory clinic service in the UK, but not yet widely spread in Indonesia. Research has been done in several small population, mostly in nursing homes. In this study, we aim to investigate the effectiveness of CST in improving the cognitive function, social participation, and quality of life of older adults with MCI, and to build capacity of volunteers to be CST facilitators.

Methods

This study consists of quantitative and qualitative parts. Participants were recruited through Health and Older People's Division of Kalideres Parish, Santa Maria Imakulata Church. We screened 81 older adults (> 60 y.o) for Mild Cognitive Impairment (MCI) using the CERAD battery test and Lawton's IADL. MCI was defined as an impairment in either MMSE/Clock Drawing Test/Word List Memory Immediate Recall AND a normal IADL. Quality of life was documented using WHOQoL-BREF instrument. Consenting participants were then invited to join group CST session once a week for 28 weeks. Reassessment of cognitive function and quality of life are done in the 14th and 28th week. Social participation are documented qualitatively every session by the facilitator using personal notes for each participants.

During the first 14 weeks, the researcher team takes lead of the facilitator role and build the capacity of the local community volunteers. During the 14th-28th weeks, the local community volunteers facilitate the sessions, with the researcher team providing support through regular meetings and Whatsapp/phone call consultations.

Results

Eleven participants fulfilled the inclusion criteria. The average number of participants per session is 7. Sessions are held once a week for 2 hours. It started with a prayer and a reading from the Bible led by one of the participants, continued by a 12-minutes setting-up exercises and opening. The CST main activities follow the original module with a modification to Indonesian context and the participants' ability. On the 6th session, participants were given a feedback questionnaire. Most participants enjoy discussion on music, politics and current affairs. Discussions were held with volunteers after every session to evaluate things which went well and which can be improved. Local volunteers expressed their concern regarding their availability to conduct sessions once a week independently.

Conclusion

CST can be offered as a regular group activity for older people with MCI in a religious community. It is

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not only a mean of improving cognition and maintaining social participation through mental and physical stimulation, but also spiritual activities. Establishing CST programme in a community needs support from local stakeholders and should also be tailored to build their capacity as facilitators. Challenges that might arise include limited time and human resources.

Poster Presentation Abstracts

ID: 605

Abstract Topic: Economics of dementia

Keywords: Socio, Economics, Benefits, Dementia, Care

Socio-economic benefits of a dementia care centre

Tak Bin Chau

Comfort Aged Care Group PLT, Malaysia

Abstract:

As we age, more dementia cases are being diagnosed. Medical statistics show that one out of 5 persons who ages 80 years and above would suffer from dementia.

Due to medical advancement, better health care awareness, human life span is getting longer, that inadvertently leading to an increase number of elderly being diagnosed with dementia. Alzheimer's disease is an epidemic, it's on the rise, and currently there is no cure, or effective way to delay or prevent it.

Furthermore, Alzheimer's disease is not only affecting the patients, but also their family, friends, caregivers, local community and government. About 60% caregivers reported high level of physical, emotional and mental stress while providing care and around 40% of them may suffer from depression.

Additionally, taking care of a person with dementia or Alzheimer's disease will encounter high financial expenses. The daily care, responsibilities of family members change in family roles and choices on situation in care facility can be very challenging. It is a full-time commitment.

Besides focusing in developing medicines, to cure this disease and training more skilled workers to take care of our elderly with dementia, more Dementia Care Centres is required to meet the demand and become another effective and important approach to moderate the aggravation of the increases of dementia cases.

Direct Socio-Economic Benefits that we can achieve from Dementia Care Centres under a multi-disciplinary care approach:-

1.0 People with Dementia

- 1.1 Sleeping time is normalized by engagement of guided activities
- 1.2 Mobility & Alertness is improved by engaging physio exercise
- 1.3 Alertness is improved through social interaction
- 1.4 Calmer character with less mood swings due to proper attention
- 1.5 More organized thought & improve memory
- 1.6 Better verbal communication
- 1.7 Better appetite
- 1.8 Improved general health

2.0 Early stage Dementia People

- 2.1 Maintain and improve quality of life
- 2.2 Keep them safe from possible dangers at home

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2.3 Restore their dignity and respect

3.0 Family Primary Carers

3.1 Relief both their physical and mental stress

3.2 Gain back valuable personal time to do what they want to pursue

3.3 Regains their quality of life

4.0 Family Members

4.1 Resolve the conflicts and stress among family members of dementia people

4.2 No need to quit job to care for a family member with dementia

4.3 family members can learn dementia care skill faster

5.0 Local Community

5.1 Provide training and employment opportunities to school /university leavers

5.2 Provide employment opportunities to able retirees

5.3 Reduce "missing" person cases

5.4 Create community awareness of Dementia / Alzheimer disease

5.5 Remove social stigma of the disease

6.0 Government

6.1 Extend healthcare service that ease out the crowded hospital

6.2 Develop/ create an effective Training Facility to train staff on Dementia Care Skills

Poster Presentation Abstracts

ID: 606

Abstract Topic: Polypharmacy – NEW

Keywords: polypharmacy, complex medication regimens, randomised controlled trial, residential aged care

The simplification of medications prescribed to long-term care residents (simpler) cluster randomised controlled trial

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¹Monash University, Australia; ²NHMRC Cognitive Decline Partnership Centre; ³University of South Australia; ⁴Helping Hand Aged Care; ⁵Royal North Shore Hospital; ⁶University of Sydney;

Abstract:

Objective.

Complex medication regimens are burdensome for residents of aged care facilities, particularly for residents with dementia who often have swallowing difficulties. The objective of this cluster randomised controlled trial was to assess the application of a structured 5-step process to consolidate the number of medication administration times in residential aged care facilities (RACFs).

Method.

A non-blinded, matched-pair, cluster randomised controlled trial was undertaken in eight South Australian RACFs. A representative sample of permanent residents with and without dementia was recruited by trained research nurses. The intervention involved a clinical pharmacist applying a new validated, implicit five-step tool to reduce medication complexity (e.g. by administering medications at the same time, or through use of longer-acting or combination formulations). The primary outcome was the number of daily medication administration times at the four-month follow-up. Data were analysed using linear mixed models with the RACF included as a random effect.

Results.

There were 99 residents in the intervention arm and 143 in the comparison arm, of whom 179 (74%) were female and the median age was 87 years. In total, 92 opportunities for medication regimen simplification were identified for 62 (65%) residents in the intervention group. At the four-month follow-up, 57 (62%) of pharmacist's suggested changes were implemented. The mean number of resident medication administration times was reduced among residents in the intervention compared to the comparison arm (-0.36, 95% confidence interval (CI) -0.63 to -0.09, $p=0.01$).

Conclusion.

One-off application of a new 5-step process to simplify and consolidate the number of medication administration times can reduce medication regimen complexity in RACFs. It is possible to considerably reduce the burden of medication taking for residents of RACFs [Australian New Zealand Clinical Trials Registry, ACTRN12617001060336].

Poster Presentation Abstracts

ID: 609

Abstract Topic: Formal carers education and training

Keywords: training, community, nursing home, care staff

Confidence, attitude and knowledge of care staff caring for persons with dementia (PWD) in nursing homes: an evaluation of gerind (geriatric integration network for dementia)

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Abstract:

Background

Geriatric Integrated Network for Dementia (GerIND) is a collaboration between cognition specialists in tertiary care and community partners, which aims to increase the overall capacity of the healthcare system to manage persons with dementia (PWD), across the cognitive spectrum from healthy cognitive aging to end of life care, through right-siting and community integration. Community partners involved in this dementia shared care training program funded by Ministry of Health included two nursing homes (NH). We aim to evaluate the impact of dementia training on confidence, attitudes and knowledge of care staff from these NH.

Method

8 designated care staff from two NH in Singapore were trained by dementia shared care team since 2018. Training was conducted via a train-the-trainers approach, with interactive and didactic lectures, attachments to specialised dementia care units in Tan Tock Seng Hospital, bed-side teachings and multi-disciplinary discussions over 6 months. Pre- and post-training questionnaires were administered to care staff to evaluate their confidence, attitudes and knowledge in care for PWD.

Results

Majority of the care staff trained were female (87.5%). Varied professions ranging from nursing aides, staff nurses, to physiotherapist and occupational therapist were trained in this program.

There was improvement of care staff's knowledge in dementia post training (mean score 9.7 vs 8.0 pre-training out of 15). Notably, 100% of these care staff rated themselves highly in dementia knowledge on disease process, complications, behavioural management and caregiver stress upon completion of training.

Confidence in dementia care was lacking among the care staff prior to training program with only 41.2% expressing confidence in caring for PWD. Post-training, all of them rated themselves "confident" in managing PWD, with 37.5% of them rating themselves "very confident". Similar high level of confidence post-training was also noted on their communication with PWD or caregivers, management of behavioural issues and training of fellow colleagues in dementia care.

These care staff displayed dementia positive attitudes with all of them agreeing that concerted efforts are needed to care for PWD and their caregivers. There were also improvements in their perceptions of the role that community care teams can play in delivering good dementia care post training. However some attitudes remained post-training whereby majority opined that communication with PWD should

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be done in euphemistic terms, management of dementia was frequently frustrating and dementia was best diagnosed by specialist.

Conclusion

Overall the training program had improved the care staff's confidence and knowledge in dementia care, with some improvement in their attitudes towards PWD. A further study could be done to evaluate if above improvements would translate into better patient care and if so, the training should be further extended to more community care partners.

Poster Presentation Abstracts

ID: 612

Abstract Topic: Non-pharmacological interventions

Keywords: ylang-ylang, essential oil, BPSD

Alleviation of behavioural and psychological disorders by ylang-ylang essential oil to benefit patients with dementia: a systematic review

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Department of Pharmacy Practice, Faculty of Pharmacy, Universiti Teknologi MARA, Malaysia

Abstract:

Background: Behavioural and psychological symptoms of dementia (BPSD) is the most common symptoms observed in patients with dementia. Ylang-ylang or *Cananga odorata* is a fast-growing tree indigenous to tropical Asia countries. The use of ylang-ylang essential oil as a complementary and alternative medicine (CAM) therapy in management of behavioural and psychological disorders has been documented in various studies. It has been proven to improve health and wellness in various ways such as to reduce stress, induce calmness and relaxation and improve alertness. These properties can be linked to some of the symptoms commonly present in patients with dementia. However, to the best of our knowledge, less is known on the effects of ylang-ylang for alleviating BPSD.

Objective: This systematic review was aimed to look at the use of ylang-ylang essential oil in alleviation of any BPSD and compile the related studies.

Methods: PubMed, Science Direct, Scopus, Springer Link, Web of Science and Google Scholar were searched to identify all relevant papers up to April 2018 by using the combinations of the MeSH terms. Papers which fit the inclusion criteria (i) published in English language; (ii) full-text articles; (iii) any types of human-based studies i.e. pilot study, randomised or non-randomised controlled trials, qualitative studies, quantitative studies, conference papers; (iv) related to the application of aromatherapy or essential oils particularly ylang-ylang on population with BPSD were included. The full text of each paper which was selected after the initial title and abstract screening was then assessed for eligibility against the inclusion criteria. Quality of the studies was assessed using Jadad score and the data were extracted from the studies by using a standardized data extraction form which is the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2009 Checklist.

Results: 15 studies published from 2002 to 2017 that described the use of ylang-ylang essential oil in BPSD were obtained. Methods of administration of the oils in the studies include inhalation, transdermal application by massage or a combination of both inhalation and massage and essential oils blend as mouthwash. These studies have reported significant decrease in fatigue level and increase of relaxation; a reduction of disturbed behavior i.e. anxiety, agitation and delusions; a significant improvement in attentiveness, alertness and sleep quality; and an increase in self-esteem, energy, concentration as well as patience levels in the participants after the intervention with ylang-ylang essential oil was given.

Conclusion: Ylang-ylang essential oil could potentially be a useful treatment option in the management of BPSD. Further studies particularly on dementia population itself is required to support its use as CAM in dementia.

Poster Presentation Abstracts

ID: 614

Abstract Topic: Diagnostic tools

Keywords: Montreal Cognitive Assessment, Cut off scores Indian population, ROC, Cognitive Impairment, Community

Performance of Montreal Cognitive Assessment (MoCA) as a screening tool for cognitive impairment in community setting- Kerala, South India

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Abstract:

Background: Cognitive impairment is only slowly getting recognised as a disease among the elderly population in India. The Montreal Cognitive Assessment (MoCA) tool which measures global cognitive functions is widely proposed as a screening tool for measuring the cognitive status in varied settings. Studies have identified the need for redefining the original cut off scores of MoCA, to reduce the false-positive rates. A revised cut off of MoCA in the Indian community has not been documented.

Aim: This study aims to redefine the cut off scores of MoCA for the screening of the rural elderly Indian population.

Methods: The study participants were elders aged 65 years and above, belonging to a rural area (Kalliyoor) in Thiruvananthapuram district, Kerala, South India. Trained health volunteers administered MoCA-M (validated Malayalam version of MoCA) in 364 elders sampled systematically from the area. A team of neurologists, public health experts and neuropsychologists revisited the participants and diagnosis of neurocognitive disorders were made using DSM V criteria. Keeping the DSM V criteria as the gold standard, a Receiver Operating Characteristic Curve (ROC) was drawn. The area under the Curve (AUC), sensitivity and specificity was computed and the best cut off scores was determined.

Results: The mean (SD) age of the study population was 71.6 (6.5) years and more than half of the population were females (184, 59%). Majority of individuals [296 (95.2%)] had formal school education below ten years. Out of 311 individuals, 59 (19%) had a minor neurocognitive disorder and 21 (6.8%) had a major neurocognitive disorder. The median (IQR) MoCA score for the population was 19 (14-23). We obtained a ROC with AUC of 71 % (p=0.002). For a cut off score of 15, we obtained a sensitivity of 74% and a specificity of 54%.

Conclusion: The suggested cut off of 26 cannot be applied to screen this rural population of elderly Individuals. A far lower cut off of 15 could be more appropriate to screen for cognitive impairment in this group of elder individuals with lower educational status.

Disclaimer: This study is a part of the Dementia Prevention and Enhanced Care (DePEC) project, funded by NIHR, Global Health Research Group. The lead PI of the project is Prof. Louise Robinson.

Poster Presentation Abstracts

ID: 615

Abstract Topic: Dementia policies and public policy

Keywords: residential aged care, policy, long-term care

Does Australia rely too heavily on providing aged care in institutions?

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¹Rehabilitation, Aged and Extended Care, Flinders University, Australia; ²NHMRC Cognitive Decline Partnership Centre; ³THEMA Consulting Pty Ltd, Sydney, Australia

Abstract:

Introduction: As people age and particularly for those living with dementia, the need for long-term care (LTC) increases. A comparison of how different countries provide LTC to their older population as both residential and home-based LTC was undertaken.

Methods: A review of international aged care systems was conducted using grey and mainstream literature and international online data sources. Data available on recipients of formal long-term care (LTC) in institutions in different countries was obtained from OECD.stat (2016 or nearest year). LTC in institutions refers to facilities which provide accommodation and LTC as a package. Home care recipients excludes those receiving LTC for instrumental activities of daily living alone. The proportion of the population aged ≥ 80 and ≥ 65 receiving LTC in institutions or as home/community care was compared for 11 nations including New Zealand, USA, Canada, the Republic of Korea, Japan and several European nations.

Results: Available OECD.stat data indicates that Australia provides residential-based LTC for 19.7% of the population ≥ 80 years and 6.3% of those ≥ 65 . The range for 10 other countries for people ≥ 80 years was 6.1% (USA) to 16.7% (Switzerland); for those ≥ 65 years 2.4% (USA) to 5.8% (Switzerland). Of people ≥ 80 years receiving formal LTC, Australia provided care in institutions for 58.6% compared to 23.1% in Japan, 35.6% in New Zealand and 41.8% in Canada.

Conclusion: Whilst these data do not take account of any differences in dependency levels of older populations (including the proportion of people living with dementia), and there may be differences in reporting methodology between nations, they indicate that Australia may be a comparatively high user of residential LTC. These data provide further support for increased provision of home care packages for Australians with higher levels of dependency. Comparisons of the relative levels of dependency of people in residential LTC between Australia and similar nations are needed.

Poster Presentation Abstracts

ID: 617

Abstract Topic: Models of care

Keywords: dementia, residential aged care, built environment, health economics, resource allocation

What are the financial implications of providing residential aged care in a clustered domestic, home-like model of care?

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¹Rehabilitation, Aged and Extended Care, Flinders University, Australia; ²NHMRC Cognitive Decline Partnership Centre; ³THEMA Consulting Pty Ltd, Sydney, Australia

Abstract:

Introduction: Recently, better consumer-rated quality of care has been reported for a home-like, clustered domestic model of residential aged care (RAC) in comparison to Australian standard RAC homes in a cross-sectional study (INSPIRED, 17 facilities, n = 541). Running costs were similar between the models, but after adjusting for potential confounders the clustered model had AU\$12, 962 lower facility costs annually per resident. However, the additional capital costs for establishment are uncertain. We report data on the estimated capital cost of the clustered domestic, in comparison to standard RAC homes.

Methods: Data on gross floor area (GFA) per resident were obtained from one provider of clustered models of RAC for eight facilities (1995–2017) in New South Wales (NSW) and from a quantity surveyor for 11 Australian RAC homes built by six providers (2013–2017; eight NSW, two Australian Capital Territory, one Victoria).

Results: The average GFA per bed was 17% higher for a clustered model compared to standard care facilities (weighted mean 59 m²/bed standard versus 69 m²/bed clustered). The build cost per unit GFA was reported to be similar between models. In 2008 the cost to construct a standard RAC place was estimated as AU\$219,611.14 Applying a 4.5% inflation factor estimates the cost per standard place as AU\$312,309 in 2016 dollars. Assuming additional capital costs of 17%, the cost per clustered care place is AU\$365,402.

Conclusions: It is estimated that providing RAC in a clustered domestic model can be achieved without an increase in running costs and a 17% increase in capital establishment costs. Despite the higher capital establishment costs, consideration should be made to additional investment in clustered models of care given the reported benefits including better consumer-rated care quality, reduced hospitalisations, reduced chance of being prescribed potentially inappropriate medications and improved quality of life.

Poster Presentation Abstracts

ID: 619

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: dementia-friendly community, community resource assessment

Establishing Zhongzheng dementia-friendly community with care, humanity, respect and technology

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Zhongzheng District Health Center, Taiwan

Abstract:

Introduction

The increasing number of people with dementia has made a considerable impact on whole society in Taiwan. To diminish the influence, the Ministry of Health and Welfare announced the "Taiwan Dementia Policy" and set a goal of "555" - education of dementia in at least 5% of the population, 50% of dementia patients getting diagnosis, training and support for at least 50% of caregivers. In this project, we try to build a dementia-friendly community to reach the goal of 555.

Methods

To develop a "community-based" model for dementia-friendly community and achieve the goal of "Dementia-friendly 555" in 2020, community resource assessment was used. This approach classifies resources into three categories: fundamental asset, secondary asset, and developable asset.

1. Fundamental asset: setting up a self-reliant team for dementia patients and recruiting memory guards. These two actions were taken to help the resident understand what dementia is.
2. Secondary asset: six dimensions involved including food, medical, housing, transportation, education and recreation. "Food" means creation of work opportunities for dementia patients in friendly cafes. "Medical" refers to one-stop referral service by which the time from symptom onset to confirmation of diagnosis is shortened. "Housing" means an integration of the police and the fire fighter, which is helpful to upgrade the community safety network. "Transportation" means updating the literacy with regard to dementia in transporters to lower the barrier of getting outside for patients. "Education" means an increase in museum visitation rate and development of prescription for dementia. "Recreation" denotes an integration of green garden and first-aid items with healthy life for creating a memory-guard park.
3. Developable asset: three parts - public information, public investment, and social welfare - included. "Public information" means development of Q&A robot for dementia, which may benefit an efficient propaganda. "Public investment" denotes an introduction of fingerprint sensing scheme to reduce the risk of getting lost. "Social welfare" involves the SOP development for dementia care and improving the rate of resource utilization for the family with dementia patient.

Results

The following outcomes including knowledge promotion of dementia in the public, improving the referral and management process of dementia patient, and relieving the burden of caregivers, were achieved. These achievements are rewarded by the Health Promotion Administration and become the first model community in Taipei city.

Conclusions

We supported localized resources, including assisting the upgrade of church services to make sustainable development. It used the PDCA model, we should promote the health program, build a structure of the promotion dementia friendly, and create a friendly community of dementia with the caregivers.

Poster Presentation Abstracts

ID: 622

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: Cognitive impairment, Four Square Step Test, Valid detection

Four square step test is a valid test to detect cognitive impairment

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Abstract:

Background:

Current research have shown that cognitive impairment was related to motor ability and balance function. Four Square Step Test (FSST), which is a clinical test for dynamic standing balance, measured ability of multidirectional rapid stepping, obstacle avoidance and sequence memory. FSST may be useful to detect cognitive impairment.

Objectives:

The aims of this study were (1) to find the optimal cutoff value of FSST for cognitive impairment in the community-dwelling adults, and (2) to verify whether the cutoff value of FSST useful to differentiate people with or without cognitive impairment.

Methods:

This was a two-phases, cross-sectional descriptive design study. Inclusion criteria of subjects in two-phases were age > 50 years old and can walk independently. In Phase-I, we included people with cognitive impairment (Mini-Mental Status Examination, MMSE < 24) and normal control. In Phase-II, we included voluntary subject from community-dwelling regardless of cognitive function. All participants received MMSE, which indicate general cognitive function, and FSST. The optimal cutoff value was determined based on the Receiver Operating Characteristic (ROC) analysis results.

Results:

In Phase-I, 34 subjects (age: 77.3 ± 8.7 , 4 male and 30 female) participated in this study. The mean of educational years was 7.4 ± 4.7 years and MMSE score was 18.2 ± 7.6 . High negative correlation was found between FSST and MMSE ($r = -0.82$, $p < 0.05$). The optimal cutoff value of FSST for cognitive impairment was 13.5 sec. The sensitivity was 0.88 and specificity was 0.80. The area under the curve (AUC) was 0.91.

In Phase-II, 120 subjects (age: 70.4 ± 8.1 , 42 male and 78 female) participated in this study. The mean of educational years was 9.4 ± 4.2 years and FSST score was 9.96 ± 5.3 sec. There is moderate negative correlation between MMSE and FSST ($r = -0.68$, $p < 0.05$). Subjects were divided into two groups with the cutoff value 13.5 sec of FSST. The ROC analysis results showed that the great AUC was 0.94 and the high sensitivity (0.88) and specificity (0.88) were found at 24 of MMSE.

Conclusion:

FSST is not only a balance assessment tool, but also a screening test for cognitive dysfunction. There is great sensitivity and specificity of FSST to detect cognitive impairment. According to our results, the time more than 13.5 sec to complete FSST means that people have high probability with cognitive impairment. Medical staff and caregiver can use FSST to detect whether people with or without cognitive impairment quickly and accurately.

Poster Presentation Abstracts

ID: 623

Abstract Topic: Epidemiology

Keywords: Psychotropic, prevalence, outcomes, anti

Quantitative analysis of psychotropic prescribing in dementia - prevalence and functional outcomes in a neurocognitive unit in Queensland, Australia

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Abstract:

Objectives/Background: Dementia is a highly prevalent syndrome in the geriatric population. Psychotropic medications have demonstrated moderate efficacy in the reduction of the behavioural and psychological symptoms of dementia. However, their use is associated with a variety of adverse effects, including extra-pyramidal symptoms, falls, weight gain, and cerebrovascular accidents. This study aims to quantify the prevalence and outcomes associated with psychotropic medication use in an in-patient setting.

Methods: A retrospective medication audit was conducted on 147 in-patients with dementia admitted to a neuro-cognitive unit over two-year period (Jan 2015 to Dec 2016). Primary outcomes included fall rate and the Drug Burden Index (DBI), a measure of anticholinergic and sedative exposure.

Results: All patients were administered at least one psychotropic medication, with a mean of 3.83 (SD: 1.80) unique psychotropic prescriptions. 94.6% of patients were placed on one or more anti-psychotic medications, most commonly risperidone (63.3%) & olanzapine (28.0%). Additionally, 89.3% of patients were prescribed at least one benzodiazepine, notably oxazepam (87.3%).

DBI was positively associated with increasing age ($p=0.002$), male gender ($p=0.028$), and greater length of stay ($p<0.001$). Fall rate was significantly correlated with DBI ($p<0.001$), as well as 90+ consecutive days of anti-psychotic (RR: 1.91; 95% CI: 1.36-2.70) and benzodiazepine use (RR: 1.92; 95% CI: 1.35-2.73).

Conclusion: Psychotropic medications are a widely used management option in people with dementia. Antipsychotics and benzodiazepines are most commonly represented. However, co-prescribing of multiple psychotropic medications, as well as long-term use, are associated with a significantly increased incidence of adverse effects, especially falls. It is important to consider these risks, conduct regular medication reviews, and continually assess adverse effects when prescribing psychotropic drugs in a geriatric setting.

Poster Presentation Abstracts

ID: 625

Abstract Topic: Psychosocial interventions

Keywords: Cognitive Stimulation Therapy, Localisation, Dementia, Feasibility, Singapore

Feasibility of localised cognitive stimulation therapy programme in the Singapore context

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Abstract:

Background

Cognitive Stimulation Therapy (CST) is an evidence-based, structured group programme for persons with mild to moderate dementia (Spector et al., 2006). It has been found to be effective in maintaining cognitive and language functions as well as improving quality of life.

Currently, there is no formal structured group therapy programme for persons with dementia and localisation done to the CST programme in Singapore. Thus, there is a need to adapt the CST programme to make it culturally relevant to the Singapore population.

Methods

Community Psychogeriatric Programme (CPGP) collaborated with St Luke ElderCare (SLEC) in the localisation of CST. The CST was localised according to the five phases of the formative method for adapting psychotherapy (Hwang, 2009).

Two focus groups were conducted by the CPGP psychologist, with the Occupational Therapists (OTs) and care staff from SLEC respectively. Feasibility of the programme structure, alternate themes and contents needing adaptation were identified and discussed. Adaptations were made to the contents and themes based on the focus groups' findings. After adaptation, OTs from SLEC conducted further training to familiarise their care staff with the adapted CST. Two pilot runs of the localised version were conducted. Another focus group was done to gather feedback for evaluation. Contents of localised CST were further refined and finalised based on the focus group results.

Results

No changes are made to the structure of the CST programme and all fourteen themes are kept. Taking into consideration literacy rates and interest of the local population, activities, and contents are modified under the themes: current affairs, faces and scenes, word games and word association to be relevant locally. Materials and stimulus used for various themes were localised, in catering to the needs of the Singapore context.

Feedback from end users was positive. The OTs and care staff from SLEC reported that the use of CST allowed them and the person with dementia to be better prepared for the group sessions.

Conclusions

This study shows that it is feasible for localised CST to be implemented in the Singapore.

Resources such as time and manpower are perceived limitations in the process of localisation of CST in the community. The collaboration helps pool together resources and expertise to create a mutual learning opportunity. Future research can be conducted to evaluate the efficacy of localised CST on persons with dementia in Singapore.

Poster Presentation Abstracts

ID: 626

Abstract Topic: Diagnostic tools

Keywords: cognition, emotion, language, dementia, interdisciplinary

Relationships between cognition, emotion and language in dementia syndrome, from interdisciplinary to transdisciplinary research: a case study

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Abstract:

Most studies investigating emotional processes from the language point of view focused mainly on both visual and auditory perception, while as far as production is concerned, the greatest attention was paid to the prosodic aspect. Previous studies show that subjects suffering from dementia, when faced with a semantic impairment, produce a number of sentences emotionally connoted equal to those of the cases of control. As far as emotional language is concerned, it is important to distinguish between emotion's expression and emotion's thematization. Mimicry, gestures, prosodic intonation and vocabulary accompany the emotion's expression. Emotion also becomes the subject of conversation, whether through the conceptual denomination of emotion or through the description of emotional states related to an emotion or even through the narration or mention of an event with emotional value.

In this pilot study, we propose a Corpus-based study of emotional language in Neurodegenerative Diseases with cognitive impairment, particularly in Alzheimer's disease. Our work is based on the construction of a Corpus of spontaneous speech in which all the speech phenomena are recorded according to the tradition of the Corpus Linguistics. This study analyzes quantitatively and qualitatively the emotional lexicon, assessing the capacity of emotional expression with respect to emotion's narrative. The analysis was carried out starting from two transcriptions recorded in an 80-year-old woman, diagnosed with mild Alzheimer's dementia, at the 2nd Division of Neurology, Alzheimer's Evaluation Unit, University of Campania, Naples (Italy). The two outpatient meetings with the patient took place 5 months apart. In this interval of time the patient had a cognitive decline (Mini-Mental-State-Examination 26/30, in the first meeting; 23/30 in the second). The elicitation test consisted of asking the patient to describe a cartoon and, since the end of the test, she has been asked some questions about her daily life habits. The transcriptions were made using the Italian tools of Corpus Linguistics, CLIPS and CIPPS (www.clips.unina.it) The patient's total speaking times were counted for each of the two transcriptions. For each assessment, the emotional vocabulary was recorded into two macro-categories: elements falling within the category of emotion's expression and elements falling within the category of emotion's thematization.

According to the literature, in the case presented here we have observed, despite the cognitive decline, a preservation of the emotional vocabulary, especially with regard to emotion's thematization, suggesting new research perspectives into the relationship between cognition and emotional language. Therefore, according to the evidence of behavioural, linguistic and neuroscientific research, we believe that a new conceptual framework is necessary to study the relationship between cognition, emotion and language, in cognitive decline.

Poster Presentation Abstracts

ID: 637

Abstract Topic: Dementia policies and public policy

Keywords: Advocacy, education, cooperation, policy, Macau

Advocacy, education and cooperation: a nursing college's efforts and impact on the development of dementia policy in Macau

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Abstract:

Introduction: The prevalence of dementia worldwide is increasing rapidly and dementia was proposed to be a public health priority by Alzheimer's Disease International (ADI) and World Health Organization (WHO). Macau is also facing the challenges of ageing population and dementia. In response to the challenges, the government of Macau Special Administrative Region adopted Dementia Policy in 2016. Kiang Wu Nursing College of Macau (KWNC), the oldest nursing education institute in Macau, has been making efforts and contributions to tackle ageing society in the past decades. This article summarized KWNC's efforts and impact on the development of dementia policy in Macau.

Methods:

1. Advocacy targets government to make dementia a public health priority. Early in this century, professors from KWNC began to unite with other health professionals to pay attention to dementia issues and established Macao Alzheimer's Disease Association (MADA) in 2010, which became the full member of ADI in 2013. MADA together with other NGOs made great efforts to advocate government to make dementia a public health priority.
2. A systematic educational programme designed to tackle the ageing population. KWNC initiated a systematic educational programme issued public education on dementia in the first stage to tackle ageing population in 2011. Six categories of people, including the elderly, young students, family caregivers, public service practitioners, healthcare professionals and general public were listed as key targets for raising awareness of dementia.
3. Efforts on cooperation. KWNC and MADA try best to develop mutually beneficial working partnerships and relationships with community associations and international society.

Positive impact:

1. The government of Macau SAR became the 27th to adopt an official dementia policy in 2016, which includes a 10-year strategic framework to establish a dementia friendly community.
2. Public education has a significant effect. The above educational programme has engaged nearly 100 seminars and training workshops, benefiting more than 10,000 people. And nearly 300 health professionals and 1,000 frontline police officers were trained, and about 100 young students were educated to be young ambassadors. A study in 2019 showed that Macao residents have reasonably good knowledge of dementia.
3. Mutually beneficial working partnerships in the community and overseas were developed well. In total of 104 NGOs actually pledged to become dementia friendly organizations initiated by MADA and the government in the dementia friendly community project in 2017 and 2018.

Perspectives: KWNC and MADA with other NGOs will continue advocating for the development of Macau Dementia Policy, especially in the top-down design, budget allocation and cooperation between government and local NGOs. Meanwhile, KWNC will continue to focus on public education and cultivation of health professionals by facilitating and encouraging combination of education, research and social practice.

Poster Presentation Abstracts

ID: 641

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: dementia, Alzheimer, stigma

Establishing the National Federation of Alzheimer's associations in Iran

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Iran Alzheimer's association, Iran, Islamic Republic of

Abstract:

Introduction: In the past decades, urbanization, increase in the marriage age, single child families, migration within Iran and immigration have all created changes in the Iranian social structure resulting in more people living alone. It is evident that loneliness, isolation and depression are significant risk factors of dementia. Unhealthy lifestyles, rising prevalence of non-communicable diseases, economic hardships, stress and mental pressure have all impacted the sharp increase of dementia statistics in Iran. In 2018, the population of over 65 was 5 million which will rise to 26 million by 2050. Today, in Iran, every 7 minutes one person develops dementia. It is estimated that over 700,000 are living with the condition. Lack of awareness and stigma in the communities prevent individuals seek help and early diagnosis.

Objectives: In 2015, Iran Alzheimer's Association delivered training workshops for 100 volunteers of Pension Organizations who later became dementia ambassadors in different provinces reaching out to people with dementia and their families. The aim was to enhance motivation for establishing Alzheimer's associations throughout the country and ultimately form a federation of Alzheimer's associations. This would improve the quality life of people with dementia and their carers receiving support, information and appropriate services locally.

Method: An exchange of Memorandum of Understanding between Iran Alzheimer's Association and Pension Organization initiated a two day workshop in Tehran. The cost of the event was undertaken by the Pension Organization. Human resources and content were IAA's responsibility. A second workshop was followed in the city of Mashhad addressing dementia topics. The successful candidates received an introductory letter to the provincial Medical Sciences universities for their academic help and support. A MoU between IAA and Health Ministry facilitated this process.

Results: 20 provinces have dementia ambassadors and 12 have now established Alzheimer's associations. A few more are in the process. In December, 2018, IAA invited the new associations to participate in a one day workshop. At the end of the session by signing MoU, they became a member of Iran Dementia and Alzheimer's federation, serving better people with dementia and their carers, enhancing research in provincial universities and creating friendly dementia communities.

Conclusion: The project of establishing a federation of AD association has been very cost effective as a result of IAA's 2 collaborations. Future annual conferences and workshops have already been planned.

Poster Presentation Abstracts

ID: 642

Abstract Topic: Formal carers education and training

Keywords: Dementia, Nurse Education, Scotland, Promoting Excellence, Future Workforce.

Building cognitive bridges on dementia for undergraduate nurse education: empowering future agents of change for dementia care excellence

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Abstract:

Background: The number of older people living with dementia has been significantly rising due to global population ageing with a projection of 75 million people living with dementia by 2030. This is projected to further escalate to 131.5 million by 2050¹. The support and care of people living with dementia and their families requires knowledge, expertise, positive attitudes and a competent skill base. Investing in education and training of all frontline staff needs to be at the core of national dementia policies and standards of dementia care in the future². Gaps in dementia specific knowledge and skills amongst staff working in hospital settings have been reported in previous research³.

Method: The aim of this initiative was to close this gap for the future through dementia focussed undergraduate nurse education and build dementia capability to shift the paradigm of dementia care. Being Dementia Smart (BDS) a precursor to Dementia Enhanced Education to Promote Excellence DEEPE was developed and implemented in 2014 as a compulsory undergraduate component. DEEPE is mapped along the stages of the dementia journey using Barbara's story (Pre diagnosis – End of Life Care including carer support, improving community connections and dementia inclusive indoor and outdoor environments) and the Scottish Promoting Excellence Framework⁴ developed in consultation with our local NHS partners and Alzheimer Scotland. DEEPE is delivered across six semesters with input from people living with dementia, informal carers and interdisciplinary dementia care experts. Students use a blended approach to learning with face to face sessions and semester specific digital interactive workbooks.

Results: This is the first and only programme of its kind. Since 2017, nearly 1000 students have completed the programme and have been certified at the Enhanced Level of the Scottish Promoting Excellence Framework. Students have embraced the programme with passion and share anecdotes of being empowered as agents of change in practice environments.

Conclusion: This curriculum innovation could be relevant as a model to build future health and social care capability with dementia expertise given the magnitude of dementia prevalence globally.

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Poster Presentation Abstracts

ID: 645

Abstract Topic: Polypharmacy – NEW

Keywords: Polypharmacy, potentially inappropriate medication use, dementia, psychotropic, India

Use of potentially inappropriate psychotropic medications and polypharmacy in persons with dementia in Chennai, India

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Schizophrenia Research Foundation (SCARF), India

Abstract:

Background: Considering the physical comorbidities associated with ageing, persons with dementia are at risk for polypharmacy and use of potentially inappropriate medication (PIM) which is also a growing concern. However, polypharmacy and the use of PIM in persons with dementia is not very well described in India. At present, this study aims to extend the existing literature by assessing polypharmacy and the use of potentially inappropriate psychotropic medication use in persons with dementia presenting to the Dementia Care in SCARF (DEMCARES), Chennai, India.

Methods: In the present study, we reviewed the case records of persons with dementia who presented to our outpatient clinic in Chennai. The number of medications being taken by the persons with dementia during their first visit was reviewed to using Beers' criteria to assess polypharmacy and use of potentially inappropriate psychotropic medication.

Results: All persons diagnosed with dementia between June 2018 and June 2019 in our outpatient clinic were included in the study. Polypharmacy and the distribution of potentially inappropriate psychotropic medication use were analyzed and compared with their presenting complaints.

Conclusions: Inappropriate psychotropic medication use in persons with dementia can potentially lead to several poor health outcomes such as confusion, cognitive impairment, falls and even mortality. Our study identified and described the magnitude of polypharmacy and the use of potentially inappropriate psychotropic medications in persons with dementia in Chennai, India. This highlights the need for the development of a standardized treatment protocol for elderly persons with dementia in India.

Poster Presentation Abstracts

ID: 646

Abstract Topic: Diagnostic tools

Keywords: Dementia, Diagnosis, Modeling, Predicting

Predicting dementia diagnosis with a comprehensive web app assessment

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Abstract:

Background The Northern Health and Social Care Trust (NHSCT), Northern Ireland, established a Memory Service in 2013 to offer timely differential diagnosis and improve quality of care in dementia. Timely diagnosis offers advantages for the person which include; better adjustment, slowing of progression and planning ahead. There are also significant savings to the health economy. There is currently no diagnostic test for dementia and diagnosis is based on exclusion and clinical impression. A comprehensive assessment is completed to inform diagnosis. Diagnosis requires complex decision making, taking into consideration the large volume of information collected at assessment.

Method An anonymised database was set up to record information about the profile of people referred to the Memory Service and the data has been coded. Data includes background information; demographics, details about social, medical and psychiatric history, performance on the Addenbrooks Cognitive Examination-III (ACE-III), Bristol Activities of Daily Living Scale (BADLS), Zarit Caregiver Burden Scale (ZCBS) and the outcome of the assessment.

Machine learning techniques have been applied to the data to build a predictive model that will support clinicians to make a diagnosis. To date, using only the ACE-III scores, two models have been built. The first classifies referrals as "Cognitively impaired" or "Non-cognitively impaired". Cognitively impaired includes MCI and Dementia. The second model classifies referrals as "Dementia" or "Non-dementia". Work to combine these models into a multi-tier diagnostic support tool is ongoing.

A web-app of the complete assessment has also been developed, consisting of digitised versions of both the background information questions and the formal assessments. This enables capture, validation and storage of a robust data set of the entire assessment for each person.

Results The accuracy, sensitivity, and specificity of each model are taken as the average of 100 simulations of the dementia assessment data. The first model determines whether a person has a cognitive impairment with 75.2 % accuracy, sensitivity 0.72 and specificity 0.78. The second model predicts whether the person has dementia with 76% accuracy, sensitivity 0.77 and specificity 0.74.

Conclusions The easy to use web-app comprises a comprehensive assessment which includes the information that is important to inform a decision about whether a person has a dementia. The data is collected and stored in a format designed to facilitate further analysis and provide the clinician with information about whether the person is likely to have a dementia and which type of dementia. To date, two models to predict diagnostic outcome achieve an accuracy of around 75% using only the ACE-III scores. As the remaining data from the BADLS and ZCBS together with the background information is incorporated into the model, improvements in predictive abilities are expected.

Poster Presentation Abstracts

ID: 648

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: dementia, informal carers, relationship centered care, technology, interface

Relationship centered dementia care: an academic – industry partnership and innovation

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Abstract:

Introduction

Most dementia care at home is provided informally by family members who often manage a range of behaviours and symptoms associated with dementia with limited training or support. Lack of awareness, training and support for informal carers tend to impact both physical and mental health and their overall wellbeing.

Initial consultations with informal carers highlighted the gaps in training and support for informal carers. This was followed up with an academic – industry Interface project to enhance the development of an additional symptom monitoring and tracking feature within (CogniCare). Relationship-centered care (RCC) is a popular concept within health care systems that emphasises the importance of the nature and quality of relationships within the dementia care triad being critical for effective health care provision. Health / Social care consultations can often be daunting for people living with dementia and their carers. The aim of this project was to strengthen support for informal carers by seeking expert input from dementia care professionals with a focus to enhance informal carers' competence and confidence in early identification of relevant symptoms to provide a seamless interface with relevant information via the App that would facilitate a meaningful consultation for everyone within the dementia care triad.

Methods

The academic partner developed an A²BC²D²EF² framework with key symptoms, including cognitive, functional and behavioural changes associated with dementia. A 45-item online questionnaire was developed based on this framework with Likert scale responses indicating the importance or relevance of each item. Red alerts requiring immediate escalation, informal carer wellbeing, and benefits for health professionals were included as additional constructs. Two focus group discussions were held with dementia nurse consultants and social care professionals.

Results

Twenty-six dementia care experts from health and social care completed the survey or participated in focus groups. Most participants (n=25) identified acute confusion and frequent falls as the most important symptoms requiring rapid escalation. Monitoring informal carers' experience was considered facilitative of their wellbeing with a relationship centered approach to dementia care. Routine monitoring of cognition, function and behaviour by informal carers at home could complement existing care by health professionals including early risk identification, crises aversion, proactive care and predictive intervention. Most experts (n=19) considered it probable that the App could reduce hospital admissions, and most (n=23) agreed it could capture cognitive decline over time.

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Poster Presentation Abstracts

Conclusion

(CogniCare) has the potential to improve informal carers' wellbeing and relationship-centered dementia care. Dementia care experts have endorsed the utility of the app and proposed practical suggestions for future development.

Poster Presentation Abstracts

ID: 649

Abstract Topic: Formal carers education and training

Keywords: Dementia, Training, Distress, Carers, CLEAR

CLEAR Dementia Care © helps carers to understand behaviour and reduce distress

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Abstract:

Background People with dementia can present with behaviours that carers find challenging and difficult to understand. These behaviours are often caused by the stress the person experiences as they try to meet their needs and cope with the challenges of living with dementia. Failure to understand behaviour and address unmet need can result in unnecessary breakdown in care arrangements, unnecessary hospital admission and increased distress.

CLEAR Dementia Care © was developed by a specialist team working with care homes in the Northern Health and Social Care Trust (NHSCT), Northern Ireland. Simple assessment tools help carers to assess what factors may be contributing to behaviour. Behaviour Record Charts help staff to understand behaviour in the context of the person and their environment; to identify appropriate supports. Following success of the model in care homes, a whole system approach is being developed facilitated by a comprehensive training programme.

Method: (1) CLEAR Dementia Care was delivered to 68 care homes in the NHSCT area. Clinical and cost saving outcomes were measured. (2) A range of training programmes were developed. Training was commissioned and delivered to staff in care homes in the NHSCT, GPs through Project ECHO© and NHS trust staff. A handbook was produced to support implementation. Post training feedback questionnaires were completed. (3) A nursing outreach post was piloted in an acute psychiatric ward to support hospital discharge.

Results: (1) Following implementation of CLEAR Dementia Care in care homes, the Challenging Behaviour Scale (Moniz-Cook, 2001) pre and post intervention highlighted a reduction in the incidence and frequency of distress behaviours. There was over 50% reduction in both the number of face to face contacts and the duration of the clinical episode needed from the specialist team. Cost savings were achieved in both the community and through reduced hospital admissions. (2) Training has been delivered to over 1500 care staff in the NHSCT. Following training staff report greater understanding of dementia, behaviour in dementia and effective communication. Training was commissioned and delivered to over 300 staff in all trusts in Northern Ireland, NHS trust in the UK and other health organisations. Following training staff reported that the training would benefit their practice and they felt more able to engage with care staff to help them to offer support to people with dementia (3) When a hospital admission is necessary, the outreach service to acute hospital supports timely discharge.

Conclusion: CLEAR Dementia Care helps carers to see the whole person with dementia. When carers understand the perspective of the person, they can find ways to reduce distress. The outcome is better care and enhanced quality of life for the person with dementia. A whole system approach facilitates early identification and timely support. The model can be successfully implemented in other organisations.

Poster Presentation Abstracts

ID: 653

Abstract Topic: Other syndromes and dementia – NEW

Keywords: HAND, cART, vascular, Tanzania

Vascular risk factors for HIV-associated neurocognitive disorders (hand) in older adults in northern Tanzania

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Abstract:

Background/Aims

HIV-associated neurocognitive disorders (HAND) are highly prevalent in older HIV-positive adults, despite treatment with combination antiretroviral therapy (cART). In sub-Saharan Africa (SSA), there is a rapidly growing older population of people with HIV due to increased cART coverage who are likely to be at similarly high risk. There is limited understanding of the pathophysiology of HAND, but accelerated atherosclerosis and increased vascular burden are hypothesised to be contributory, particularly in older adults. We aimed to 1. investigate the prevalence of vascular risk factors (VRFs) in an older HIV-positive population and 2. compare vascular risk factors and evidence of vascular end-organ damage in those with and without HAND.

Methods

145 HIV-positive individuals aged ≥ 50 years were systematically sampled from a Government free-of-charge HIV clinic in northern Tanzania. Diagnosis of HAND involved in-depth neuropsychiatric testing based on local norms and a collateral history for cognitive impairment and was based on Frascati criteria. HIV disease control was assessed by CD4, HIV viral load and cART treatment. Vascular risk factors (VRFs) were assessed using the following methods: self-report of stroke, smoking and alcohol history and hypertension and objective measurements including three resting blood pressure readings, urine protein (for renal damage), ankle-brachial pressure index, electrocardiogram (for left ventricular hypertrophy) and serum total cholesterol.

Results

HAND prevalence was 70.3% in our cohort (n=145) who were well-managed with a median CD4 of 468 cells/ μ and 84.3% having a suppressed viral load. The overall presence of ≥ 2 VRFs was 24.1% and prevalence of any vascular end-organ damage was 29.0%. No significant associations were found between VRFs and HAND. The only significant association found between HAND and vascular damage was that left ventricular hypertrophy (LVH) appeared to be protective against HAND.

Conclusions

In this older cohort, prevalence of HAND was very high, despite good HIV-disease control. The prevalence of VRFs appeared lower than other Tanzanian community cohorts reported locally and this low vascular burden may be due to participants attending regular medical review at the clinic. The high prevalence of HAND in this cohort may not be related to excess vascular disease burden.

Poster Presentation Abstracts

ID: 655

Abstract Topic: Epidemiology

Keywords: HIV-associated neurocognitive disorder, Tanzania

Prevalence of HIV-associated neurocognitive disorders (hand) in older adults in northern Tanzania

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Abstract:

Background/Aims

A growing ageing HIV positive global population presents new challenges in management of subsequent comorbidities, including HIV-associated neurocognitive disorder (HAND). Previous literature indicates changes in 2017 to Tanzanian national HIV management guidelines, including universal access to combined antiretroviral therapy (cART), viral load monitoring to detect treatment failure and switching to second-line cART regimens in individuals with treatment failure, could improve HIV control and possibly reduce HAND prevalence.

We aimed to calculate HAND prevalence in a cohort aged 50 and over attending an HIV clinic in Moshi, Tanzania, and to compare prevalence with a cohort from 2016 sampled from the same clinic to assess the impact of changes in HIV management made in 2017.

Methods

In 2019, 145 adults aged 50 and over were systematically sampled and assessed using American Academy of Neurology (AAN) criteria for HAND, including local normed neuropsychological assessment, neurological examination, functional assessment and collateral history from a close informant. HAND diagnosis included the three subcategories of asymptomatic neurocognitive impairment (ANI), mild neurocognitive disorder (MND) and HIV-associated dementia (HAD). Comparison with data from the 2016 cohort of 253 adults aged 50 and over was conducted.

Results

Provisional results indicate that HAND prevalence in the 2019 cohort was 70.3%, compared to 47.0% in 2016. There was a significant increase in the prevalence of overall HAND and the MND category, but a significant difference in distribution of subtypes with reduced numbers of HAD. Since the change in guidelines, cART coverage and the proportion of people on second line regimens (due to introduction of HIV viral load testing) increased substantially and the proportion with a detectable viral load (indicating inadequate control) reduced.

Conclusions

Whilst implementation of the new guidelines has been successful (as measured by changes in medication regimen and measures of disease control), this has not led to a reduction in HAND prevalence. These results support the idea that cART does not prevent HAND but does potentially reduce severity

Poster Presentation Abstracts

ID: 656

Abstract Topic: Dementia policies and public policy

Keywords: dementia care in Brazil, mapping, strategies.

Mapping the provision of dementia care in Brazil

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Abstract:

Background and objectives: There are more than two million people living with dementia in Brazil. Even though universal health and social care systems are available, little is known about which and how services are provided and/or could be tailored to attend the needs of people with dementia in Brazil. This study aims to explore what is currently available for supporting people living with dementia and their family carers in Brazil in terms of policies, health and social care.

Methods: This study was undertaken as part of STRiDE, an international collaborative research programme aimed at strengthening responses to dementia in low- and middle-income countries. A situational analysis that included details about the provision of dementia care in Brazil was conducted in 2019. Current research, policies, service providers, care pathways, training schema were consulted in order to gather relevant information. A SWOT (Strength, Weakness, Opportunity and Threat) analysis was developed and used as a guide for mapping the current provision of dementia care in Brazil.

Results/Positive Impacts: The results of this study provided organized and schematic information on the services and care pathways offered for people with dementia in Brazil. In addition, potential gaps in the provision of dementia care were identified. In general, dementia care is offered as part of the general health system for older people. No specific system or pathway for dementia health and social care were found, although some research and policies were identified. The mapping of the provision of care will be presented at the conference.

Conclusions/Perspectives: These results may help clarify the strategies that need to be taken to meet the needs of people with dementia and their family carers in Brazil.

Poster Presentation Abstracts

ID: 659

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: lgbt, dementia care, provider, practices, attitudes, knowledge

Dementia care providers' practices, attitudes, and knowledge in treating LGBT communities

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Abstract:

Introduction

Lesbian, gay, bisexual, and transgender (LGBT) older adults face risk factors known to increase cognitive impairment and dementias such as social isolation, discrimination, poor health accessibility, limited social support and caregivers, and higher rates of chronic medical conditions. Although data is sparse, there is some research to suggest that LGBT older adults who are more depressed and/or with functional impairments have high subjective cognitive decline (SCD). Thus it is imperative that dementia care providers understand the unique associations between demographic factors, dementia risk factors, other health and psychosocial factors, and SCD among the LGBT community.

Methods

Utilizing the 7-point Likert LGBT Development of Clinical Skills Scale (LGBT-DOCSS), this study is assessing the fund of LGBT clinical preparedness, attitudinal awareness, and basic knowledge that dementia care providers possess.

Results

Preliminary data (N=20) suggest that while dementia care providers have moderate clinical readiness (M=4.95) and knowledge (M=4.98), they have very high affirming attitudes (M=6.62) about the LGBT population.

Conclusions

In this study, dementia care providers demonstrate only moderate clinical preparedness and knowledge about LGBT healthcare. Yet they do endorse strong positive attitudes about the LGBT population, which may invite an avenue to translate this appreciation into improvement (e.g., through patient panels and cultural competency training). This study will continue to collect data from many more dementia care providers across the country over the next year in order to evaluate LGBT-DOCSS scores as well as assess how these scales differ across various demographics. This knowledge will not only further the scope of knowledge and appreciation for dementia diversity research but also reveal potential gaps in cultural competency and the need for growth among dementia care professionals.

Poster Presentation Abstracts

ID: 660

Abstract Topic: Young onset dementia

Keywords: driving, young onset dementia, intervention, support

Living with young onset dementia and staying engaged without driving

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Abstract:

Background and objectives: Driving disruptions have significant impact on individuals living with dementia and their care partners and family members. For many people with dementia, stopping driving is one of the hardest things that they cope with. This study aimed to understand the expressed needs and experiences of people living with young onset dementia who are adjusting to life without driving (phase 1), to translate an existing driving cessation intervention ('CarFreeMe') to be appropriate for their needs (phase 2).

Methods: We conducted in-depth interviews with 5 people living with dementia and 4 care partners to elicit their lived experiences in relation to driving disruptions and driving cessation. Interviews were recorded and transcribed verbatim. Thematic analysis was applied to interview transcriptions to identify and analyse themes within these data.

Results: The themes discovered went beyond mobility loss to include loss of identity, role, social cohesion and self-worth; financial and relationship strain; and highlighted the impact of lack of appropriate available services and transport alternatives, in particular in regional areas; and perceived unfair and taxing driver safety assessments.

Conclusions: For people living with young onset dementia, driving disruptions often come at a time when they are likely to have significant financial and family commitments, or they/their partners may be employed or raising a family. This has significant negative effects on people's roles and self-identities. Intervention to support emotional and practical adjustment and reduce social isolation is necessary. Future research (phase 2) will involve an expert reference group to translate these findings to practice, and pilot test the translated driving cessation intervention.

Poster Presentation Abstracts

ID: 664

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, idiom, stigma, STRIDE, Kenya

Local idioms of dementia and stigma: a Kenyan perspective

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Abstract:

Background and objective: Understanding local interpretations of dementia might help us to understand negative stereotypes and stigma which negatively impact on interpersonal relationships and dementia care for persons with dementia and their caregivers. We examined the local use of the term dementia and its relationship with stigma and access to care.

Methods: Two Focus Group Discussions (FGDs) consisting of 6-8 participants per group were conducted in a rural setting in Kenya among stakeholder groups: health care workers and the general public. In addition, one FGD and seven key informant interviews were performed with caregivers. All interviews and FGDs were audio-recorded. Audio recordings were transcribed and emerging themes on the impact of local use of the term dementia identified.

Results: Our findings suggest that the use of the local idiom of dementia included: (i) Considered part of the normal aging process; (ii) used for only late stages of dementia; (iii) Considered derogatory if used for early-stage dementia; (iv) associated with a curse or failure to perform an obligation; and (v) Less treatable than physical conditions with poor prognosis and is commonly associated with terms such as *"losing it [network]"*, *"mad"* etc. These perceptions were considered stigmatizing and reduced access to care as persons with dementia only accessed a health facility if there was evidence of a physical condition.

Conclusions: Due to the stigma associated with the use of local idioms of dementia, there needs to be a paradigm shift from socio-cultural explanations of dementia to more acceptable terms that can contribute to increase in awareness of the condition, access to care and promotion of government funding for services. These findings form part of the multifaceted STRiDE (Strengthening Responses to Dementia in Developing Countries) project conducted in seven countries including Kenya. STRiDE incorporates an anti-stigma element as a critical component to improving the capacity to access and deliver dementia care and quality of life for people living with dementia and their family carers.

Poster Presentation Abstracts

ID: 667

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: loneliness, social isolation, well-being, dignity, dementia inclusiveness

Understanding and addressing dementia and loneliness in Ireland

Bernadette Rock

The Alzheimer Society of Ireland, Ireland

Abstract:

Background and objectives

In 2019 The Alzheimer Society of Ireland (ASI) commissioned research to understand how individuals with dementia living at home experience loneliness, and explore key factors that contribute to maintaining social networks that foster connections. This research sought to understand whether individuals living with dementia felt lonely as their conditions worsened. Do persons living with dementia in Ireland have opportunities to engage in social activities? Are they able to maintain meaningful relationships with others? Do they have the adequate public supports to help them and their families through their journey? Or, do they feel that they are isolated and alone? This research informed ASI's policy position on dementia and loneliness, and how loneliness in dementia can be addressed and alleviated.

Methods

To explore the concept of loneliness in an Irish context, a qualitative methodology was undertaken and in-depth interviews were conducted with individuals with a dementia diagnosis age >55. The interviews explored the key elements associated with the reported presence or absence of feelings of loneliness by participants. Broadly, four factors listed below were identified:

1. Relationships and family,
2. Public supports and social connection,
3. Independence and confidence,
4. The multiple stigmas of dementia and loneliness.

Results

The qualitative interviews demonstrate the unique nature of loneliness for people with dementia living at home. The study found that access to home care support and public nurses enabled families to manage living life with dementia and by the same token, however, the difficulties of securing these supports were a source of anxiety, frustration, and loneliness. It is important to note that people with dementia emphasised the importance of "alone time", which helped them cope with their increased vulnerability to stressors that occurs as a result of their condition. Participants also reported feelings of stigma which contributed to social isolation and lack of engagement in activities. Human contact and a meaningful relationship were described as key factors to maintaining social networks that foster connections and prevent loneliness. Overall, not all participants explicitly stated they were lonely but they described various nuances that imply that they are consciously engaging in activities in order to prevent loneliness.

Conclusions

Based on the above research, ASI endorses seven recommendations. These recommendations are in line with WHO's proposed actions relating to Area 4, 'Dementia diagnosis, treatment, care and support', specifically in relation to needs and preferences of people with dementia culturally appropriate, person-centred, community-based health, psychosocial, long-term care and support.

Poster Presentation Abstracts

ID: 668

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia-Friendly, Virtual Reality, dementia-positive, care staff, medical students

A walk through dementia: a virtual reality tool to promote dementia awareness

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Abstract:

Background and objective: Current policy directives emphasise the need for 'Dementia-friendly' communities where people are knowledgeable about dementia and demonstrate positive attitudes towards those living with the condition. This is particularly important for care home staff and trainee medical professionals who will be responsible for driving forward this agenda and ensuring appropriate care is provided to the growing numbers of people with dementia. With funding from Alzheimer's Research UK, a portable, immersive virtual reality (VR) tool was developed in collaboration with people with dementia and designed to provide the user with a first-hand perspective of living with dementia whilst participating in three scenarios: walking in the community; making a cup of tea; and shopping in a supermarket. With further funding from Health Education England and Higher Education Innovation Funding, research was undertaken to examine the experiences of care home staff and undergraduate nursing students in the UK of engaging with the VR tool and their perspectives on whether it could be used as a device to enhance dementia-awareness.

Method: A mixed method approach was adopted. This consisted of 414 questionnaires delivered to undergraduate healthcare students from Bournemouth University and focus groups undertaken with 30 care staff across the south of England.

Results: The findings suggested the VR tool was positively received by the participants and provided them with an immersive and realistic experience of walking in the shoes of someone with dementia. This complimented as well as enhanced previous dementia-awareness training they had attended by providing them a more holistic understanding of the emotional and social impacts of dementia. Although participants advised that certain modifications could be made to the tool to enhance its realism and ensure it was more user-friendly, such as better defined graphics and more comfortable headsets, they were keen for a wider range of VR scenarios to be developed in collaboration with people with dementia and adopted onto the device.

Conclusions: This study demonstrates the potential for VR to be used as a creative and engaging training tool for supporting dementia-awareness in populations that are experienced with dementia care as well as novices. Further research is being undertaken to explore its impact on dementia attitudes and future care practices, and to incorporate the tool into a wider 'Dementia-Friendly' training package and online resource.

Poster Presentation Abstracts

ID: 669

Abstract Topic: Attitudes, awareness and stigma

Keywords: Memory Screening Attitude Millennials Dementia

The impact of exposure to dementia in formal education towards Indonesian millennials' attitude on screening

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Abstract:

Background: A low level of dementia and memory loss screening remains a challenge in Indonesia for decades. The challenge rises as stigma dementia and memory loss as a normal part of ageing are still believed. Addressing education about healthy ageing in formal education is important as it is also included as one of the action plans in Indonesia's National Dementia Plan. This study will assess the impact of exposure to dementia in formal education towards screening attitude, both urge to screen and recommend screening.

Methods: Qualitative data were collected from focus group discussions (FGDs) among 6 people with no personal experience with dementia and 4 caregivers of people with dementia to inform the questionnaire development for quantitative step. A quantitative study was then conducted using a structured questionnaire, involving 244 millennials (born between 1980-2000) living in Special Region of Jakarta, Indonesia. Collected data from the quantitative step were analysed with data mining and decision tree method using RStudio software.

Results: Mean age is 22 ± 2.51 years old, mostly female (63%) and currently studying for or had graduated with a bachelor's degree (91.83%). All of them are high school graduates. Not being previously exposed with dementia in formal education (58.4% of the total population) had a higher probability of not screening if having memory loss symptoms, the same probability also seen in not giving screening recommendation to family members with memory loss symptoms.

Conclusion: Low screening urge and screening recommendation more commonly found in respondents who have not had any exposure to dementia issues in their formal education. Previous exposure or experience related to dementia in formal education might increase screening attitude towards memory loss problems. Dementia, healthy ageing, and memory loss awareness raising can be implemented in an education setting as Indonesia is expected to have higher numbers of formal education (primary, secondary and high school) graduates. The implementation of Indonesia's National Dementia Plan needs more participation from the central and regional government as well as educational institutions.

Poster Presentation Abstracts

ID: 670

Abstract Topic: Models of care

Keywords: Integrated care, models of care

Integrated hospital model for geriatric care - Alexandra hospital

Li Feng Tan, Liyue Hong, Santhosh Seetharaman

Division of Healthy Ageing, Alexandra Hospital, Singapore

Abstract:

Alexandra Hospital is a 326-bedder hospital that seeks to provide one-stop comprehensive care to the Southwest region of Singapore.

It is the first Integrated General Hospital in Singapore providing seamless, holistic care from acute to sub-acute to rehabilitative settings, reducing the need for a patient to transfer from one institution to another to receive step-down care.

Geriatric Care is one of the core programmes of the hospital and the geriatric services were planned to cater to the needs of the elderly population in our catchment area.

For hospitalized patients, the geriatric ward was designed to evoke a sense of nostalgia and familiarity for the elderly. Wall murals reflect olden day Singapore and give the ward a more homely feel. There are spaces created for communal dining and activities. Entrances and doors are camouflaged in case patients should wander and a bus stop was built should patients with dementia request to go home.

Group based activities ("Happy Hour") are held weekly where caregivers are engaged to promote interaction amongst the patients. We have also partnered with the childcare centre located on the hospital's premises to provide inter-generational therapy. The lush greenery of the hospital also provides an ideal setting for horticultural therapy for suitable patients.

There is a specialized delirium unit within the geriatric ward to provide timely intervention for patients with delirium. We practise a restraint-free policy in this unit. Nurses trained in geriatric care deliver care and multi-disciplinary team meetings are held twice a week led by Geriatricians to review patients' progress.

There is a growing recognition of the needs and importance of Geriatric Care in Hospitals. New hospitals allow for innovative designs and care models that cater to the needs of Geriatric patients and their caregivers.

Poster Presentation Abstracts

ID: 674

Abstract Topic: Attitudes, awareness and stigma

Keywords: dementia, informal caregivers, awareness about dementia

Awareness of dementia from the perspective of informal caregivers

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Abstract:

The present study is part of the participatory action research which aims to organize support groups which empower the informal caregivers of people with dementia. From February to March in 2017 narratives were carried out with 16 caregivers from different Estonian counties. The research is based on a phenomenological approach and narrative inquiry. One of the study subthemes was to explore the experiences of the informal caregivers about the awareness of dementia in the caring process and find out their expectations of supporting them. The results are divided into four thematic headings and one of them is awareness of dementia. The current study revealed that the caregivers noticed the deteriorating of cognitive functioning already years ago, but they did not seek help, because they taught that these are normal signs of aging. The caregivers pointed out the lack of knowledge among professionals in the process of diagnosing, or their uncompassionate attitude and they experienced a lack of collaboration with health and social care services. Also, the caregivers felt the lack of advice and suggestions on how to get support and how to care for their relatives. They emphasized that they had to search the internet for additional information. To empower informal caregivers, it is necessary to raise awareness among health and social care professionals. It is also important to raise public awareness about dementia and encourage citizens to support person with dementia and their family members.

Poster Presentation Abstracts

ID: 675

Abstract Topic: Consumer empowerment

Keywords: Consumers, Care Partners, Alzheimer's, Advertising, Media

Exploring care partners' media usage

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University of Louisiana at Lafayette, United States of America

Abstract:

Dementia Awareness and Friendliness/Consumer Empowerment

Background

People with Alzheimer's and their family care partners are *consumers* of products, services and media content. They have consumption needs like anyone else, but must meet those needs in the context of life with Alzheimer's. This abstract calls for increased international, interdisciplinary quantitative research to serve care partners with useful, ethical and dementia-friendly research methods, directions, and ultimately, improved media content. Such research is crucial, as Marketwatch.com estimated the global market for Alzheimer's drugs alone at 2870 million US\$ in 2017. In the U.S., untrained care partners provide about 18.2 billion hours of unpaid care valued at \$230 billion annually (FCA, 2019) for people with Alzheimer's. According to ADI (2015), "if global dementia care were a country, it would be the 18th largest economy in the world," larger than the economies of global companies like Apple and Google.

Methods

This research agenda faces two primary challenges: identification and development of appropriate quantitative methods and tools, and reaching large numbers of Alzheimer's care partners to participate as respondents, thus providing data for quantitative analysis. Consistent use of three carefully defined variables offers a stable platform for research development.

Media Usage can be explored via tools like Ferguson's (2013) Media Usage Scale measuring participants' preferred media content and access devices. Care Partner Needs and Challenges may be examined with modernized versions of the "Caregiver Burden Inventory (CBI)" developed by Novak and Guest (1989); Zarit (1990); and Lund et al. (2010). Care Partner Characteristics can be measured via an 8-item scale asking age in years, number of years as a care partner, gender, education level, employment status, relationship to the care recipient, geographic location, and living arrangements. These scales are easily combined as survey and content analysis tools.

Impact

Positive impacts far outweigh the challenges of attracting large numbers of care partners as survey participants; and finding time needed to train coders, code units of analysis, and enter data for content analysis. A large data set from either method can fuel multiple analyses addressing any number of research questions, resulting rich knowledge development. Combining data from both methods would be invaluable for determining whether media content successfully addresses needs and interests identified by care partners as consumers.

Conclusions

The foregoing call for increased research activity reflects the vast power of media industries paired with the vast numbers of care partners as audience members and consumers. International, interdisciplinary efforts reflecting WHO's Action Plan on Dementia (ADI, 2019) will be best equipped to enhance knowledge in service to people with Alzheimer's and their care partners worldwide.

Poster Presentation Abstracts

ID: 678

Abstract Topic: Well being and quality of life

Keywords: Quality of life, empowerment, training, formal carers, community care

Journey in improving quality of life for elders with dementia in community care at SLEC senior care centres (SCC)

May Low, Sundar Subramaniam, Lester Leong

St Luke's Eldercare, Singapore

Abstract:

St Luke's Eldercare (SLEC) is a Christian healthcare provider poised to meet the needs of elders in the continuum of care between hospital and nursing home. We have a total of 22 senior care centres all over Singapore. Averaged about 40 to 60 elders with dementia in each centre.

In 2017, one major concern arise from care staff is the difficulty in managing behaviours of concern such as restlessness, agitation and decreased activity engagement. The Occupational Therapy (OT) Department then work closely with all centres to form what we called, the 'DCT' or 'Dementia Care Team'. It comprises of a Multidisciplinary Team which includes Centre Manager, Supervisor, OT, Nurse, Social Worker and 2 Care Staff. A PCC training session was provided, followed by quarterly coaching cum mentoring sessions by the Principal OT. Every centre will bring their own cases for discussion. Short sharing sessions on various topics such as use of technology were also presented.

SLEC now have a total of 22 DCTs with over 80 members. As of 2019, the DCT members take on a more active role in conducting assessments and using tools/measures to monitor care for their elders with dementia. One example is use of Pool Activity Level Checklist in prescribing suitable and meaningful activities. In-house DCT meeting is also held monthly.

In 2018, feedback were given by our DCT members to bring the same training to other staff so that they can share "*same line of thought!*" The OT team then initiated 'Centre-based Dementia Care Training' for 6 months. After reviewing the needs, our training materials were modified to be more simplified, bilingual, activity-based and relevant.

A total of 169 staff attended. More than 80% of them have never worked with persons with dementia before. Pre and post test were conducted to find out their perceived sense of competence to care for someone with dementia. About 50.3% indicated from Fair to Good and 20.7% from Poor to Fair or Good. With the good response, we are currently working with the training department to bring the curriculum to all staff who have not attended and eventually to form part of the SLEC On-boarding Programme for all new staff joining our organisation.

In tandem, SLEC embarked on the Eden Alternatives. Staff from various levels of management including CEO were trained to bring the message 'that no matter how old we are or what challenges we live with, life is about continuing to grow' (The Eden Alternatives, 2016). The centre managers then bring the Eden Principles back to their daily practice. One example of how we now make greater effort to know and understand each and every one of our elders is in the introduction of "Knowing Me". Another one would be how our organisation moved from addressing our 'clients' to our 'elders'!

These are some of SLEC efforts in working towards creating a better place in this world for all our elders with dementia so that no one is left out and ALL have a chance to THRIVE AND GROW in spite of dementia!

Poster Presentation Abstracts

ID: 679

Abstract Topic: Genetics

Keywords: single-cell; bioinformatics; atlas; computational biology

A single cell brain atlas in human Alzheimer's disease

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Abstract:

Alzheimer's disease (AD) is a heterogeneous disease that is largely dependent on the complex cellular microenvironment in the brain. This complexity impedes our understanding of how individual cell types contribute to disease progression and outcome. To characterize the molecular and functional cell diversity in the human AD brain we utilized single nuclei RNA-seq in AD and control patient brains in order to map the landscape of cellular heterogeneity in AD. We detail gene expression changes at the level of cells and cell subclusters, highlighting specific cellular contributions to global gene expression patterns between control and Alzheimer's patient brains. We observed distinct cellular regulation of *APOE* which was repressed in oligodendrocyte progenitor cells (OPCs) and astrocyte AD subclusters, and highly enriched in a microglial AD subcluster. In addition, oligodendrocyte and microglia AD subclusters show discordant expression of *APOE*. Integration of transcription factor regulatory modules with downstream GWAS gene targets revealed subcluster-specific control of AD cell fate transitions. For example, this analysis uncovered that astrocyte diversity in AD was under the control of transcription factor EB (TFEB), a master regulator of lysosomal function and which initiated a regulatory cascade containing multiple AD GWAS genes. These results establish functional links between specific cellular sub-populations in AD, and provide new insights into the coordinated control of AD GWAS genes and their cell-type specific contribution to disease susceptibility. Finally, we created an interactive reference web resource (<http://adsn.ddnetbio.com>) which will facilitate brain and AD researchers to explore the molecular architecture of subtype and AD-specific cell identity, molecular and functional diversity at the single cell level.

Poster Presentation Abstracts

ID: 680

Abstract Topic: Informal carers support – pre, during and post

Keywords: Mindfulness, caregiver stress

Introduction of mindfulness practice during dementia nurse counselling session in a memory clinic in Singapore-impact and challenges

Philomena Anthony, Wee Shiong Lim, Siew ling Ang, Poh ling Ong, Noorhazlina Binte Ali
Tan Tock Seng Hospital, Singapore

Abstract:

INTRODUCTION

Mindfulness is a practice of bringing one's attention to the present, on purpose and in a non-judgemental way. Mindfulness Practice (MP) has been shown to alleviate various forms of stressors and improve well-being. This pilot study aims to evaluate the impact and challenges of introducing Mindfulness Practice during Dementia Nurse Counselling sessions.

METHOD

We selected caregivers who scored 3 (quite frequently) or above on questions 7, 8, 14, 17 (representing role strain), 20 and 21 (representing worry about performance) on the Zarit Burden Interview (ZBI). The concept of MP (5 basic Foundational Attitudes and Simple Breathing Exercise) was introduced separately in a 10-minute session by a Nurse (team consisted of a trained Mindfulness Nurse facilitator and 2 other nurses who had attended basic Mindfulness sessions conducted in the Clinic) at the end of a 30-40 minute Dementia Nurse Counselling session (which incorporated non-pharmacological care and management of dementia). Additional reading materials on Mindfulness were given and practical breathing exercises were taught. We then followed up with a telephone interview 2 weeks later to evaluate their responses.

RESULTS

6 suitable caregivers were successfully recruited. They had a mean age of 54 years, were highly educated (more than 10 years of education) and spent an average of 36 hours with the Person with Dementia per week. There was a notable trend in the scoring of ZBI whereby spouses generally scored less on questions 20 and 21 (worry about performance) on the ZBI compared to adult children. Qualitative phone interviews revealed increased awareness of MP as a stress-coping strategy. Caregivers feed backed on the various challenges encountered such as having no time to read through the given materials. Nevertheless, all felt that the clinic session was useful in increasing their awareness of MP. 50% of them felt that MP helped to alleviate their stress. Challenges highlighted by the nurses included poor receptivity of the caregivers in spending time over the phone for a short interview and inertia of caregivers in practising the breathing exercises.

CONCLUSION

Results of this on-going pilot study will better inform us of the target group of caregivers who may most benefit from this intervention, and also the method of implementing MP in a busy memory clinic setting. A more structured Mindfulness session, distinct from a Dementia Nurse Counselling session may be more beneficial and practical for the caregiver and nurse.

Poster Presentation Abstracts

ID: 681

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: mild cognitive impairment, reliability, validity, health belief model, scale

Reliability, validity, and responsiveness of the health belief model based knowledge scale for mild cognitive impairment: a behavioral exploration in cognitive complained subjects.

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Abstract:

Objectives: The gold of our study was to confirm the validity, reliability, and sensitive assessment tool using health belief theory methods in cognitive complain subjects with mild cognitive impairment. The study results explore the behavior consciousness and cognitive attitudes in participants who may risk of MCI or Dementia.

Methods: N=255 cognitive complained MCI adults with no current or past history of dementia were tested on four sequential assessments to examine temporal reliability, stability, and validity of the MCIHB scale. We examined temporal reliability across 2 weeks and stability via two consecutive assessments, validity using exploratory and confirmatory factor analysis (EFA and CFA), comparing the health belief behavioral levels across pre-specified groups, and responsiveness to change.

Result: The modified scale includes four dimensions: susceptibility cognition (8 items), severity cognition (11 items), barrier cognition (7 items), and benefit cognition (8 items), 34 items in total. The Cronbach's alpha coefficient of internal consistency reliability of the overall scale was 0.88, the recalculation reliability was 0.90, and the content validity was 0.91. The correlation coefficient between subscale and total scale scores was 0.63 ~ 0.89. Principal component analysis extracted 1 common factor of 4 factors whose eigenvalue was greater than 1, the contribution rate of each common factor was greater than 52%, and the load value of each item on its common factor was greater than 0.44.

Conclusion: The health belief scale of elderly patients with mild cognitive impairment has good reliability and validity, which can be used to evaluate the health belief level of elderly people with mild cognitive impairment, and provide effective evaluation tools and reference indexes for nursing health education and community health service.

Poster Presentation Abstracts

ID: 683

Abstract Topic: Models of care

Keywords: simplify, cost-saving, measurement, outcomes, complexity

A cost-effective way to measure the complexity and outcomes of patients with dementia managed by a psychogeriatric community team in Singapore

Fengyuan Yao, Rozinah Bachik, Xuan Zheng Jerald Lim, Ze Jia Christ Tan, Jie Jia Ng

Institute of Mental Health (IMH), Singapore

Abstract:

Background:

Elderly with Dementia are often complex - having challenging medical, psychiatric and social issues which have to be managed together (Boustani, 2007). The Aged Psychiatric Community Assessment and Treatment Service (APCATS) is psychogeriatric community team in Singapore who takes care of elderly patients with Dementia who have difficulties accessing outpatient care. They adopted a case management model of care to manage these patients holistically (Some, 2012).

APCATS case management model include:

- Using a standardised approach to identify psychiatric, physical health and social problems
- Collaboration with community partners and primary care to manage elderly clients' problems holistically
- Providing the elderly client with a single point of contact who can help the elderly navigate through the healthcare system

However, it has been a challenge to quantify the complexity of the issues in these patients and measure the outcomes of the patients managed by APCATS to justify the funding of this service. Many scales have to be used to measure the improvement of each problem in these elderly.

Aim:

Since 2015, APCATS had used Health of Nation Outcome Scale 65 (HoNOS65) to quantify the complexity of the problems of the elderly and measure the outcomes of the elderly after they entered APCATS service. APCATS team had also used this tool to allocate appropriate resources to manage these patients. This poster aims to demonstrate how APCATS does the latter effectively.

Methods:

Quantifying the complexity of the problems in this elderly

HoNOS65 has a comprehensive list of problems that the team uses to identify problems in their patients. By counting the average number of problems each elderly has, the team is able to demonstrate the complexity of their patients

Measuring

outcomes

By measuring the total score of HoNOS65 during every home visit, the team is able to demonstrate an improvement in patient's outcome (in terms of HoNOS65 score). The results in most categories of problems are consistent with results measured by other scales. The team also develops a way to ensure the inter-rater reliability of this scale.

Allocating appropriate resources

By using the scores in certain sub-scales within HoNOS65, the team is able to standardise and determine the frequency of home visits according to the needs of the patient.

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Results:

On average, the team addresses 12 problems in each patient, demonstrating the complexity of their problems. More than half of the patients showed improvement in HoNOS65 scores at 6 months after intervention.

Discussion and conclusion:

APCATS team is able to measure the complexity of elderly with dementia and the effectiveness of their case management model of care using just one measurement scale. Multiple measurement scales can be replaced by one scale, thus saving a significant amount of time & manpower needed to complete many measurement scales.

Poster Presentation Abstracts

ID: 685

Abstract Topic: Consumer empowerment

Keywords: empowerment, community, advocacy

Voices for hope

Ruth Wong, Agnes Lee

Alzheimer's Disease Association, Singapore

Abstract:

The Voices for Hope programme is an initiative by Alzheimer's Disease Association (ADA), with the aim to empower persons with dementia and their care partners to share their stories, their needs and their rights with the community. It also aims at creating a network of persons with dementia and care partners who support each other in having their voices heard publicly. As the concept of empowerment is an uncommon concept to many countries in this part of the world, there is no template nor model that we can base on. This is the first of its kind empowerment programme in Asia.

The original idea of having an empowerment programme for persons with dementia was inspired by Kate Swaffer who is a self-advocate and founder of Dementia Alliance International. After a few conversations with her, we felt that there was a need to identify and support potential self-advocates in Singapore.

The programme structure is divided into 4 components: creating familiarity, cultivating self-advocacy skills, stepping-up and contributing. Participants meet once a week for 2.5 to 3 hours over 8 sessions. Participants are made up of persons with dementia and their care partners who have an interest in expressing themselves but may not have the confidence nor platform to do so. We started the first cohort in January and second cohort in May 2019 respectively. A total of 24 participants from both cohorts graduated from the programme. About 50% of the graduates have stepped up and shared their stories with the community. They have also collaborated with community partners such as artistes and food outlets to organize events for other persons with dementia and their families.

As this is an empowerment programme, it provides a platform for participants to share their views in various topics. The long-term goal is for them to embark on the journey as a self-advocacy group. Hence, upon graduation, the participants can choose to join the Forget-Us-Not Network to continue this self-advocacy journey. This network supports participants to take the initiative in organizing activities for persons with dementia and caregivers, volunteer for public talks, symposium, conference and participate in community events.

The Voices for Hope programme is a catalyst to bring persons with dementia and their care partners together to embark on a self-advocacy journey. Although a cohort graduates from the programme at the same time, each participant is at a different starting point. We hope to create a self-advocacy group that is culturally appropriate and meaningful to each of them. Living with dementia may take on a new meaning for this group so that they would continue to empower one another to create a community that they aspire to live in.

Poster Presentation Abstracts

ID: 686

Abstract Topic: Dementia and the Convention on Human Rights of Persons with Disabilities (CPRD) – NEW

Keywords: dementia; care homes; aged care; human rights; Convention on the Rights of Persons with Disabilities

Human rights of people living with dementia in care homes

Linda Roslyn Steele¹, Kate Swaffer^{2,3,4}, Lyn Phillipson⁴, Richard Fleming⁴

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Abstract:

This paper explores how care homes—and, specifically, their common features such as dementia care units and locked doors and gates—impact on the human rights of people living with dementia. We suggest that congregation, separation and confinement of people living with dementia by the care home built environment constitute ‘segregation’. In the specific context of residential aged care facilities in Australia, we draw on the United Nations Convention on the Rights of Persons with Disabilities (‘CRPD’) to frame this segregation as an injustice. We focus on the rights to non-discrimination (Article 5), liberty and security of the person (Article 14), equality before the law (Article 12), accessibility (Article 9), and independent living and community inclusion (Article 19). Our analysis shows that addressing segregation must involve structural and resource reforms that are transformative in bringing about new ways of living and relating to each other. Such reforms are directed towards providing meaningful alternatives and appropriate supports to make choices from a range of alternative residency and support options, and building communities that are free from ableism, ageism and other systems of oppression that contribute to confinement and segregation.

Poster Presentation Abstracts

ID: 695

Abstract Topic: Psychosocial interventions

Keywords: BPSD, behavioural management, SPT, caregiver education, PCC

Individualized simulated presence therapy (SPT) in managing challenging behaviors and role modeling for caregiver: a qualitative case report

Si Huan Lim, Xin Ling Ong, Andrea Lim, Fengyuan Yao

Institute of Mental Health, Singapore

Abstract:

Background

Simulated presence therapy has been used as a non-pharmacological intervention to manage challenging behaviors in dementia (Woods & Ashley, 1995). In Singapore, the “Spending Time with You” (Goshen Rehabilitation and Consultancy, 2011) SPT DVD was developed to engage persons with dementia across various care facilities. It consisted of a simulated presence eliciting conversations and facilitating singing of oldies. The use of this general DVD posed limitations in the heterogeneous presentation of dementia. As such, the use of individualized SPT was explored to manage an 85-year-old lady with moderate dementia, presented with agitation, restlessness, and calling out behaviors.

Methods

The client’s behaviors were formulated to be perpetuated by unmet core psychological needs of occupation and inclusion (Kitwood, 1997). She was assessed for SPT using the DVD. The assessment revealed that she sustained attention longer when the pace was slower, the pauses between conversations were brief, shorter sentences were used, and when sensory seeking behaviors were reinforced (e.g., clapping). An individualized SPT video consisting of these components was created. The caregiver was instructed to play the video on a home television daily. She was also instructed to place familiar items that the client used for sensory stimulation around, as the video specifically included visual cues (e.g., pressing buttons on phone) to reinforce the client’s sensory seeking behaviors with these items (e.g., pressing buttons on her toy phone).

Outcomes were assessed qualitatively, based on caregiver’s reports.

Results

Caregiver reported that the frequency of calling out reduced significantly – “she hardly calls out now”. Agitation and restlessness also reduced significantly – “she could sit and watch the video for one hour instead of pacing”, “she does not really hit out now”. More importantly, the simulated presence in the video served as a role model for the caregiver, in demonstrating the adjustment of communication and interaction approaches to accommodate to the client’s abilities and needs – “I learnt how to interact with her and how my responses could be the reason why she is agitated”, “I will play with her (to meet sensory needs)”.

Conclusions

SPT could be individualized to accommodate to the heterogeneous presentation of dementia, in managing challenging behaviors. Beyond that, it could also be a powerful psychoeducational tool for caregivers, as they observe and model after the simulated presence.

Poster Presentation Abstracts

ID: 696

Abstract Topic: Formal carers education and training

Keywords: dementia education, dementia literacy, nursing homes, staff burnout

Dementia education and training in Singapore nursing homes: effects on literacy and staff burnout

Si Huan Lim, Yvonne Tan, Xin Ling Ong, Puay Sze Soh, Fengyuan Yao

Institute of Mental Health, Singapore

Abstract:

Background

In Singapore, the proportion of persons with dementia residing in nursing homes increased from 25 – 35% in 2006 to 50 – 60% in 2016 (Wyman, 2016). However, training needs analysis with nursing home staff revealed a knowledge gap in dementia care. This gap in knowledge often led to difficulties in managing the challenging behaviors displayed by residents with dementia, which potentially led to staff burnout. Therefore, we aimed to explore the effects of a dementia education and training program on the level of literacy and burnout among the staff in four nursing homes in Singapore.

Method

A seven-week training program consisting of topics on dementia, non-pharmacological management of dementia (person centered dementia care, P.I.E.C.E.S.™ framework [Hamilton, Harris, Le Clair, & Collins, 2008], management of BPSD), and activities planning for residents with dementia was designed. In addition, topics on conditions that could affect dementia care such as general mental health (schizophrenia and anxiety), depression, and delirium, were also included. Last, a practicum session was incorporated in the program to aid consolidation and application of the acquired knowledge to a case scenario. Each session lasted three to four hours. Literacy test for each session (except the practicum session) was designed to assess acquisition of knowledge.

The literacy test was administered before and after each didactic session and the Copenhagen Burnout Inventory (CBI) was administered before and after the training program to assess outcomes. A feedback form was also administered at the end of the training program to obtain qualitative responses from the trainees.

Results

170 trainees across the four nursing homes completed the training program. Paired-samples *t*-tests were conducted to compare the differences in literacy scores before and after each didactic session and burnout scores before and after the seven-week training program. There was a significant decrease in burnout scores across domains (11.62% decrease in personal related burnout score, 11.04% decrease in work related burnout score, and 11.93% decrease in client related burnout score). There was a significant improvement (ranged from 18.90% to 32.89%) in literacy test scores. The main themes elicited from the trainees' qualitative reports on the feedback form included "the training was relevant", "the theoretical knowledge was helpful in understanding the symptoms", "manage behaviors better", "know how to interact and communicate with residents better", and "more empathic towards residents".

Conclusions

Preliminary evaluation of the outcomes of a seven-week dementia education and training program was positive. Specifically, the program narrowed the knowledge gaps in dementia care related topics. More

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importantly, this improvement in knowledge could potentially have an effect on the reduction of staff burnout scores across domains.

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ID: 698

Abstract Topic: Well being and quality of life

Keywords: Dementia, Quality of Life

Eq5d as a measure of health-related quality of life in mild-moderate dementia: comparison between self and caregiver ratings

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¹Institute of Geriatrics and Active Ageing, Tan Tock Seng Hospital, Singapore; ²Department of Geriatrics Medicine, Tan Tock Seng Hospital, Singapore; ³Geriatrics Education and Research Institute, Singapore

Abstract:

Introduction

The EuroQoL 5-Dimensional - three level (EQ5D-3L) is a preference-based health-related quality of life (HRQOL) instrument that has been validated in many health conditions. Given the well documented discordance between self and carer-rated HRQOL in dementia, the use of EQ5D as a brief generic HRQOL instrument in dementia is unclear. Hence, this study aims to study the inter-domain agreement and inter-rater consistency between persons with mild to moderate dementia (PwD) and family carer proxy ratings of EQ5D, and to identify factors associated with discrepancy in EQ5D between PwD-caregiver dyads.

Methods

We studied 165 mild-moderate PwD-caregiver dyads attending a memory clinic. Social demographics, interpersonal relationship, disease-related characteristics and EQ5D-3L from both PwD and caregivers were obtained. PwD and caregiver-rated EQ5D-3L scores were analysed for inter-domain agreement using weighted Kappa, and inter-rater consistency and agreement using intraclass coefficient. Hierarchical multiple linear regression with difference in EQ5D utility score as the dependent variable was performed. Both PwD's and caregivers' age and gender were entered in step 1 (baseline model), and Cornell Scale for Depression in Dementia (CSDD), Neuropsychiatric Inventory Questionnaire (NPIQ) and nature of relationship in step 2.

Results

Amongst 165 dyad ratings in EQ5D utility values, there were 59 concordant ratings, 67 positive (PwD>caregiver) discrepant and 39 negative (caregiver>PwD) discrepant ratings. Comparison of individual domains showed moderate agreement in all domains (Kappa:0.414-0.512, $p<0.001$), except for anxiety/depression (Kappa:0.125, $p=0.055$). Overall intraclass correlation coefficient in both consistency (ICC=0.530, 95% CI= 0.411-0.631) and absolute agreement (ICC=0.516, 95% CI=0.389-0.622) was poor for EQ5D utility scores. In regression analysis, the baseline model explained 1.6% of variance for discrepancy in EQ5D utility score. In step 2, addition of the variables accounted for 17.8% increase in variance, with significant associations found for CSDD ($\beta=0.026$, $p<0.001$) and age of PwD ($\beta=0.008$, $p=0.025$) with increased discrepancy in EQ5D utility scores, and adult child relationship ($\beta=-0.169$, $p=0.011$) with decreased discrepancy in EQ5D utility scores.

Conclusion

Persons with mild to moderate dementia are able to rate their own HRQOL through a brief generic instrument. However, there is overall poor agreement between self and carer-rated EQ5D ratings. Only one-third of dyad ratings show concordance, with lowest agreement for anxiety/depression domain. Presence of depression and older age result in lower self-rated HRQOL, whereas adult child caregivers rated HROL for PwD more positively compared with spouses.

Poster Presentation Abstracts

ID: 704

Abstract Topic: Dementia and human rights – NEW

Keywords: Cross-cultural, adaptation, elder abuse, screening, persons living with dementia

Cross-cultural adaptation of screening measures for elder abuse in south Africa

Roxanne Jacobs¹, Margie Schneider¹, Nicolas Farina²

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Abstract:

Background: Abuse of older persons is a public health, criminal justice and human rights concern that cuts across class, race and socio-geographic lines. Considered a hidden problem due to under-reporting, elder abuse is believed to be on the rise where one in every six older persons aged 60 and over are said to have experienced some form of abuse. Only 4% of cases are reported as fear and feelings of shame and hopelessness lead older persons to deny abuse, or they are unable to disclose due to cognitive impairment. People living with dementia are at increased risk, where two of every three persons have reportedly experienced some form of abuse. Existing tools for care-recipients commonly exclude persons living with dementia due to cognitive impairment, while relying on the reports of perpetrators using confrontational tools that bias disclosure. Elder abuse occurs within a relationship and requires the reports of both caregiver and care-recipient. The status of elder abuse in South Africa is largely unknown, with no available screening measures that are culturally sensitive and appropriate to screen for abuse of older persons, persons living with dementia, and their caregivers. The Elder Abuse Screening Tool (EAST) was developed for the South African context to detect risk and vulnerability among older respondents, but has never been validated. The Caregiver Abuse Screen (CASE), originally developed in Canada, is a measure that specifically words items in a non-blaming and non-confrontational manner to elicit caregiver experiences and feelings rather than confronting caregivers with inferred allegations of abuse. To date these tools (EAST and CASE) have not been culturally adapted in South Africa and such an adaptation is the focus of this study.

Methods: Nested within the STRiDE project (“Strengthening responses to dementia in South Africa”), the EAST and CASE measures were forward- and back-translated to Afrikaans, isiXhosa and Northern Sotho languages, and tested via cognitive interviewing of five older persons (≥65 years) and five caregivers per language. Combining think aloud and verbal probing techniques, each item on these measures were tested on how they perform on their interpretative value. Participant responses were noted for each item and narratives recorded and analysed to synthesise responses, producing thematic maps, and producing conclusions on the performance of each question and the individual instruments as a whole.

Results: This presentation will examine these findings and describe the appropriateness of the EAST and CASE to screen for elder abuse in South Africa.

Conclusion: The use of appropriate screening measures for elder abuse can strengthen protection services for older persons in South Africa and support the promotion of human rights, dignity and respect.

Poster Presentation Abstracts

ID: 706

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Post-diagnostic support; Community; Peer support; Meaningful activities; Realist research

A realist review of sustainable community interventions for people affected by dementia (sci-dem)

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Abstract:

Background and objectives of the study

Socially-situated support for those with dementia and informal/family carers has significant benefits, from combating isolation and maintaining positive self-image, to delaying decline and hospitalisation. However, in many countries, such as the UK, early-stage post-diagnostic support is typically delivered piecemeal by a variety of agencies with inconsistent funding, leading to fragmented provision with significant gaps, and many such schemes discontinue after only a relatively short period. Well-established schemes that have flourished may point the way to how such interventions could be implemented more universally and consistently. This realist review is investigating “What makes a community intervention for people affected by dementia sustainable: in what circumstances and why?” to deepen our understanding of the best ways to provide locally-embedded community support for people affected by dementia, that can be sustained over time.

Methods

This review is utilising a realist approach to gathering and synthesising data, designed to indicate what works for whom, in what circumstances, in what respects and how. Key sources of evidence have been gathered and interrogated to develop an evidence-based programme theory on which to base recommendations. Stakeholders with involvement in a variety of interventions, including people with dementia, were consulted to develop an initial programme theory; this was then tested and developed with data gathered from iterative formal searches of electronic databases and grey literature, together with citation tracking. Data were screened and assessed for relevance and rigour and analysed for themes and patterns, with the aid of NVivo software. After further consultation with stakeholders, this was synthesised to trace context-mechanism-outcome configurations.

Results

The review is due to complete in June 2020. Results will take the form of a detailed and evidence-based programme theory, mapping a range of context-mechanism-outcome configurations regarding various elements of how such interventions are implemented and how people involved with them at all levels tend to act and react to what happens. Early findings indicate a range of key contextual factors associated with funding, planning, ethos, activities, marketing, relationships with other organisations and place in the community, affecting mechanisms associated with psychological, practical and bureaucratic barriers, in turn affecting engagement and sustainability.

Conclusions

Conclusions will focus upon how best to implement community-based interventions, with recommendations to those commissioning, planning or running such schemes. Accessible publications and online materials will be produced, aiming to provide an evidence-based ‘blueprint’ for other community settings. Recommendations about what could be useful at both regional and national policy and infrastructure levels will also be made.

Poster Presentation Abstracts

ID: 707

Abstract Topic: Dementia and human rights – NEW

Keywords: Self-Determination, Supported Decision Making, Protection, Autonomy, Guardianship

State responsibility for dementia in Korea: is it relevant to a supported decision making system?

Cheolung Je, Hyojung Kim

Hanyang University, Korea, Republic of (South Korea)

Abstract:

The number of adults with dementia in Korea has been rapidly increasing. As the breakdown of traditional large extended family structure and urbanization is still in progress, dementia is no longer a problem just for most nuclear family members who used to care for their parents. Accordingly, Korean government developed the National Dementia Comprehensive Plan as a social response to dementia, and that Plan has passed the first and second rounds, and the third plan period is continuing. In addition to that Plan, Moon's Government, which started from May 2017, promised the state responsibility for dementia during his presidency election campaign and began to implement the National Responsibility System for Dementia from 2018. The contents of the state responsibility for dementia policy focus on early detection and medical treatments of dementia, alleviation of family members' financial burden for medical treatments and care, expanding the capability of care hospitals and facilities, and management and administration of dementia at state level.

This presentation criticizes that the policy of state responsibility for dementia in Korea falls short of recognition of adults with dementia as human beings with rights to self-determination and rights to selection of various alternatives for treatments of dementia. This presentation is premised on the social model of disabilities, namely dementia should be classified as a disability in terms of international human rights law, meaning that UN Convention on the Rights of Persons with Disability (UN CRPD), which Korea ratified in 2008, should apply to adults with dementia. Based on this premise, this presentation argues that a supported decision making system required by Article 12 UN CRPD should be introduced and applied for treatments and care of adults with dementia as well. For this purpose, this presentation analyses the definition of supported decision making systems, and suggests that respect to self-determination is to help and assist adults with dementia restore authentic self with their rights, will and preferences respected, and that any supported decision making system cannot be achieved without various alternatives for their treatments and care provided for.

This presentation argues that to introduce a supported decision making system for treatments and care of adults with dementia, alternatives to medical treatment such as nutrition, physical exercise, psychotherapy, change of social environment, supporting self-help organization and advocacy should be provided for. For this purpose, what adults with dementia would want and need is to be firstly considered. Otherwise, it would be difficult to realize a supported decision making system, whereby they can restore and enjoy their own lives with full legal capacity just like others.

Poster Presentation Abstracts

ID: 709

Abstract Topic: Dementia friendliness

Keywords: dementia friendly, peer support, community, memory café

The open door café: powerful, person-driven peer support

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¹Dementia Friendly Nevada; ²University of Nevada, Reno

Abstract:

The biomedical paradigm of conceptualizing dementia has trained people living with dementia and their support partners to navigate the post-diagnostic landscape by searching for interventions, both pharmaceutical and otherwise. Non-pharmaceutical interventions often take the form of structured activities that lack meaningful engagement, and people living with dementia are systematically diverted toward tasks saturated with busywork. These activities—intended to combat cognitive change—do not foster the potential for growth that exists for every individual, including people living with dementia. Growth often follows connection, so it is unsurprising that when asked about their needs in a comprehensive community assessment, people living with dementia across Nevada responded that they needed more peer support.

In response to this expressed need, Dementia Friendly Washoe County (DFWC)—a member of the Dementia Friendly Nevada initiative—launched the Open Door Café (ODC): a monthly gathering place for people living with dementia and their care partners designed and implemented in partnership with people living with dementia. Despite resembling the “memory café” model, the ODC is almost entirely unstructured. The Café therefore supports each participant’s needs as they arise and treats each person as an individual rather than applying a one-size-fits-all solution to a diverse population. The ODC does more than give people living with dementia a way to pass the time; it builds a welcoming and supportive environment where people living with dementia can exist freely, without demands or expectations, and know that they are accepted for who they are in each moment. To ensure that efforts were continuously grounded in the needs and desires of community members living with dementia, focus groups were conducted at six-month intervals to solicit feedback from Café participants.

The first support group demonstrated consensus that the ODC was successful in building a culture of support that makes each person feel valued and that promotes connections which are quickly woven into a cohesive Café community. Two points of improvement were identified. First, the one structured component of the Café—a brief showcase activity—was felt to be too structured and involved. Moving forward, that component was shifted to a friendly icebreaker discussion, and positive feedback was received at the next focus group. Second, participants expressed a desire for a more structured peer support group to be offered in addition to the ODC. This feedback suggests that the question of what program to provide should not be a choice between structured and unstructured; the two complement each other and satisfy separate needs of people living with dementia. DFWC has since launched the evidence-based Java Music Club as a more structured offering. Further focus groups will be conducted to determine whether these programs are meeting the peer support needs of people living with dementia.

Poster Presentation Abstracts

ID: 716

Abstract Topic: Attitudes, awareness and stigma

Keywords: Memories Cafe, Arts, Stigma, Community, Fun

Memories café: breaking through dementia stigma with community arts

Yun Ni, Rachel Lim

Alzheimer's Disease Association, Singapore

Abstract:

Facing stigma is often a primary concern of persons living with dementia and their care partners. The topic of Dementia is often a taboo even among family members; the lack of knowledge and conversations prevents people from living the best quality of life possible and developing a support system in the community.

In early 2014, Alzheimer's Disease Association (ADA), Singapore piloted The Memories Café programme to raise awareness about dementia. Modelled after Dr Bere Miesen's "Alzheimer's Café", the programme is for persons living with dementia and their care partners. The programme provides a normalised café setting for participants to interact through activities and conversations in a safe, supportive and conducive environment.

The two-hour programme is designed with various engagement activities such as sing-alongs, drumming, movement, storytelling and craftwork that are led by community artistes, volunteers and staff. The programme encourages all participants to mingle and interact among the group and members of the public while enjoying light refreshments.

Memories Café aims at minimising the societal stigma on persons living with dementia and to encourage social acceptance through the engagements in a café within a community setting. The programme provides an alternative platform for social interactions and respite to persons living with dementia and their care partners, moving away from long-term care environments and their homes. With organised activities for persons living with dementia and their care partners, Memories Café aims to improve their bonding with each other.

To ensure the sustainability of the programme, we empower volunteers to host Memories Café sessions independently while encouraging their ownership over the programme. With community inclusivity in mind, Memories Café has reached out to the different community groups such as residents' committees and institutions (e.g. community hospital, Kebun Baru precinct) to initiate the concept of Memories Café of their own.

At Memories Café, both persons living with dementia and caregivers are empowered to be creative and express themselves through music, movements and artwork.

Poster Presentation Abstracts

ID: 718

Abstract Topic: Education and training in hospitals – NEW

Keywords: trainer, dementia education, adult learning, hospital, dementia care skills

Journey of dementia care skills training: Brunei hospital experience from trainer's perspective

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Abstract:

Introduction

Brunei has one of the fastest ageing growth rates in ASEAN increasing from 5% in 2007 to 20% by 2050 for population above 60+. The leading causes of death in Brunei in the last 4 decades have largely been non-communicable diseases (NCDs) such as cancers, stroke, coronary disease or diabetes. Dementia is going to be a major disease burden due to aging population and prevalence of NCDs which pose increased dementia risk. All Bruneian receive free healthcare currently but majority of aged care burden remains fallen on families as informal caregivers in community. Majority of care for patients with dementia particularly those with Behaviours and Psychological Symptoms of Dementia (BPSDs) may first present to hospital mimicking other disease(s) or more commonly at crisis points due to families not coping. Little is known about hospital professional's capacity in dementia caregiving.

Methodology

Dementia Care Skills (DCS) from Alzheimer Disease International (ADI) was first introduced with intention for capacity building in 2017. Five trainers have been conducting DCS workshops with regularity totaling 4 sessions since 2018. Each session was limited to 25 persons with total of ninety signed up, but only 77 completed for the duration. We adopt the modified 12 hours / 6 modules to fit into a 2 full days. Appropriate changes was made to reflect local cultural values. Major modification was made in Module 6 with liberal use of real clinical cases to depict patient with dementia or challenges faced by caregivers to highlight previously covered key concepts. Videos and experiential activity remain an important parts of the course. General feedbacks outlined below were collected at the end of the workshop.

Results

98.7% agree to improved overall understanding of dementia and benefitted from the program. Meanwhile 1.3% are neutral about this. 100% agree to acquisition of knowledge about the topic and how it will helps to prepare or enhance their dementia caregiving skills. Nearly 97% appeared satisfied with the overall administrative logistics and efficiency with facilities set up. Meanwhile, 96.5% are satisfied with our trainers' command of content and effective delivery while 3.5% remain neutral about our trainers. Free text feedbacks were obtained on the common theme of dementia they have learnt, what they liked about the dementia workshop and their reflections on their experience.

Conclusions

Delivery of dementia caregiving for healthcare staffs should involve case studies and experiential activity to facilitate application of core concepts as part of effective adult learning method to promote concepts retention.

Poster Presentation Abstracts

ID: 720

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: Dance/Movement Therapy, quality of life, elderly, mild cognitive impairment

An exploration of dance/movement therapy on the improvement of quality of life in the elderly with mild cognitive impairment

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Abstract:

Introduction

Neurodegenerative disorders (NDs) such as dementia, Parkinson disease (PD) affect patients' cognitive functions (e.g. cognitive deterioration in visuospatial function, short term memory, and social cognition), motor control (e.g. gait disturbance, balance difficulty, and falls) and social interaction. Behavioral and psychological symptoms of dementia (BPSD) and non-motor symptoms in PD patients significantly affect patients' quality of life (QOL) and impact the supporting of the individuals. Research on non-pharmacological therapies has been studied to support patients with NDs, especially on physical exercise or embodied practice. Dance/Movement therapy (DMT), based on the premise of body-mind interconnectedness, is an embodied psychotherapy which supports the participants to cultivate their physical, cognitive, emotional, and social integration. The results of a meta-analysis in 2014 have suggested that DMT is effective in improving QOL and decreasing clinical symptoms, as well as enhancing subjective well-being, positive mood, affect, and body image. DMT is also applicable to patients with dementia and PD; recent research findings are favorable.

Objectives

To explore the effects of DMT on QOL in elderly individuals with mild cognitive impairment.

Methods

Medical staff recruited patients with mild cognitive impairment or dementia from the dementia clinic and adult psychiatric outpatient clinic of Taipei City Hospital, Songde branch [HY1] to form a DMT group. It was a one-hour weekly group, in a total of 10 sessions. The group was led by a board-certified dance/movement therapist with 3-6 coleaders of health care professionals [HY2]. The interventions were developed based on Laban Movement Analysis in the Chacian approach. Qualitative analysis of the therapist's clinical notes was studied to extract relevant findings on aspects of cognition, motor abilities, emotionality, and social interaction.

Results

22 patients with NDs participated in the DMT group from July 2018 to September 2018. The improvements were observed in various domains, e.g. stamina, orientation in the space and time, cognitive and motor abilities, initiation of movement and social interaction, creativity in kinesthetic expression, verbal and non-verbal communications, and positive mood/affect.

Conclusions

DMT fosters patients' social interaction and helps alleviate emotional disturbances by cultivating their motor and cognitive functions. The improvement of QOL is promising in the patients with NDs through the implementation of DMT.

Poster Presentation Abstracts

ID: 722

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: caregiver burden, mild cognitive impairment, dementia

Caregiver burden in mild cognitive impairment: burden profile and associated factors

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Abstract:

Introduction: The physical, behavioral, and psychological needs of persons living with varying degrees of cognitive impairment bring about substantial strain on the well being of their caregivers. Mild cognitive impairment (MCI) is viewed as a transitional phase between normal cognitive function and dementia. Given the increased risk of developing dementia in MCI, early interventions in the care-cycle can potentially reduce morbidity of caregiver burden. This study aims to compare caregiver burden profile of MCI with severity spectrum of dementia and examine caregiver and patient-related factors associated with higher burden within the MCI group.

Methods: We studied 909 dyads of family caregivers and patients living with cognitive impairment. MCI was diagnosed according to revised Petersen criteria. Patients were stratified into MCI, very mild, mild, moderate, and severe dementia according to the Clinical Dementia Rating scale. Caregiver burden was measured using the 22-item Zarit Burden Interview (ZBI) questionnaire. The multidimensionality of ZBI was embraced with analysis via a validated 4-factor structure: role strain from demands of care (F1) or lack of control (F2); personal strain (F3); and worry about performance (F4). We further defined high and low burden groups within MCI using the quintile cutoff (ZBI 35), and compared caregiver and patient characteristics between these groups. Descriptive and inferential statistics were performed using SPSS.

Results: Total ZBI scores were comparable between MCI and very mild dementia, and significantly lower than mild through to severe stages of dementia. In post-hoc analyses comparing factor scores between MCI and other groups, F1 was significantly higher from mild dementia onwards, with F2-3 correspondingly higher from moderate dementia onwards. Notably, there was no significant difference in F4 between MCI with different dementia severity. Within the MCI group, total and F1-4 ZBI scores were significantly higher for high burden compared to low burden group. Within the high burden group, caregivers were majority female, with a higher proportion being adult children as opposed to spouses. In addition, significantly higher Neuropsychiatric Inventory-Questionnaire severity scores, lower Chinese Mini-Mental State Examination scores, and impaired activities of daily living (Barthel and Lawton) were observed in this group.

Conclusion: Our study affirms previous evidence of significant caregiver burden in the pre-dementia MCI stage. Total caregiver burden increased with severity of cognitive impairment, with the exception of worry about performance which was significantly endorsed even in MCI stage. The presence of cognitive, behavioral and functional issues is associated with caregiver burden in MCI. Early recognition of factors contributing to burden in MCI facilitates opportunities for selective preventive intervention, potentially reducing psychiatric and physical morbidity in these caregivers.

Poster Presentation Abstracts

ID: 723

Abstract Topic: Non-pharmacological interventions

Keywords: Cognitive stimulation therapy, functional connectivity

Putative brain mechanisms of cognitive stimulation therapy (CST)

Gloria Wong, Bridget Liu

The University of Hong Kong

Abstract:

BACKGROUND: Group-based cognitive stimulation therapy (CST) has proven effects on enhancing cognitive performance in people with dementia, with modest efficacy comparable to AChEIs. It is currently recommended by the NICE guidelines for all people with mild to moderate dementia. However, not everyone responds to CST, and the mechanisms of action is not well understood. Based on the biopsychosocial model of dementia, interventions may improve symptoms by reducing excessive disability, and people with higher brain reserve are predicted to respond better. On the other hand, social cognitive processing and language use involved in group CST, as compared with other cognitive intervention approaches, would predict changes in related large-scale brain networks, such as the default mode network (DMN). This pilot study examined the neural correlates of cognitive performance in people with mild dementia receiving CST.

METHODS: People with mild dementia recruited from the community who underwent CST (n=16) or usual care (n=13) received baseline and follow-up brain 3T MRI. Cognitive functioning was assessed using Alzheimer's Disease Assessment Scale (ADAS-Cog). Brain reserve was assessed using the total brain volume (TBV)/total intracranial volume (TICV) ratio on voxel-based morphometry (VBM) analysis. Functional connectivity of the DMN was analysed using the Functional Connectivity toolbox (CONN).

RESULTS: The CST group (age=81.5±5.9 years, 70% female) and control group (age=81.1±5.0 years, 65% female) were matched at baseline in age, gender, education, work years, TBV, and cognitive functioning. At follow-up, the CST group maintained in TBV ($t(16)=.83$, $p=.42$) while the control group had significant decrease ($t(16)=4.39$, $p<.05$). Changes in ADAS-Cog total scores were significantly correlated with baseline TBV ($r=0.60$, $p<0.01$) in CST group. The CST group showed greater DMN connectivity change than control group. Specially, increased connectivity in BA39 angular gyrus, and area associated with complex language function, was observed in the DMN.

CONCLUSION: Initial evidence supports the excessive disability theory by showing that a higher brain reserve at baseline predicted better response to CST, and the enhancement in cognitive performance in CST is related to changes in the large-scale brain network of DMN, which suggests a mechanism through social cognitive processing and language use. Further, larger-scale replication study is needed.

Poster Presentation Abstracts

ID: 724

Abstract Topic: Dementia policies and public policy

Keywords: Situation analysis, Chinese, Hong Kong, dementia policy

Tools to inform policy: Chinese communities' action in response to dementia (tip-card) – the situation of Hong Kong special administrative region

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Abstract:

Background: Chinese communities will be a major driving force in the continued growth of dementia prevalence, with an estimate of 9.5 million people with dementia in mainland China, Hong Kong, and Taiwan. These communities are ageing at a speed that no western countries have experienced, with a rapidly shrinking work force that strains the society's care infrastructure and economic development. To identify sustainable solutions to the unique challenges faced by Chinese, well-informed policies based on solid evidence, strong stakeholder engagement, and careful considerations of the lessons learned from international dementia care and service development are needed. This research aims to build on existing data, fill gaps in evidence, and consolidate findings with stakeholders to provide the policy tools to inform the best strategies for dementia care in Chinese communities.

METHODS: The research include: (1) a situation analysis and theory-of-change analysis involving key stakeholders; (2) a cost of dementia study using existing database and newly collected data (n=1,000); and (3) a simulation modelling analysis.

Results: Preliminary findings from a rapid situation analysis showed that Hong Kong is one of the most rapidly ageing societies in the world. Percentage of citizens aged 65 years or above is expected to increase sharply from 17% in 2018 to 31% in 2036. The estimated cost of dementia will increase from HK\$12,220 million in 2010 to HK\$31,810 million in 2036. Apart from a relatively well-developed public healthcare and long-term care system, the government recently introduced in 2018 a 3-year Dementia Friendly Community Campaign, and in 2019 a Dementia Community Support Scheme. There is no existing dementia-specific policy in Hong Kong, although the Elderly Services Programme Plan of the government has stated that services for people with dementia should be an integral part in services for older persons adopting a multidisciplinary approach. Nearly 300 dementia-related studies in Hong Kong have been published, majority focusing on screening instruments and interventions. In the 2017 Mental Health Review Report of the government, research priorities specified were (1) up-to-date, territory-wide epidemiological studies to gauge prevalence and make reliable estimates for service planning and (2) to assess regularly the effectiveness of prevention programmes and dementia care strategies.

Discussion: Hong Kong as one of the world's most rapidly ageing societies has a relatively comprehensive healthcare and social care infrastructure, active research on dementia, and the government has recently initiated programmes/campaigns to provide community support and raise public awareness of dementia. The rapid situation analysis suggests a high readiness for the development of dementia-specific policy using an evidence-based approach co-developed with stakeholders, to ensure equitable and sustainable strategies in dementia care.

Poster Presentation Abstracts

ID: 725

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Cognitive Performance, Ethnicity, Education Level, Dementia, MoCA Test

Sociodemographic factors determining cognitive performance among participants of the Malaysian elders longitudinal research (MELOR) study

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Abstract:

Introduction

The National Health and Morbidity Survey on Older Malaysians published in 2018 suggested that 8.5% of individuals aged 60 years and over have dementia. Published studies on geographically specific factors which may influence cognitive decline in our population remain limited. The objective of our study was therefore to determine sociodemographic influence on cognitive performance among individuals aged 55 years and over residing in the Klang Valley of Malaysia.

Methods

Cognitive performance was evaluated using the English, Malay, Traditional Chinese and Tamil versions of the Montreal Cognitive Assessment (MoCA) tool among 1394 participants recruited to the Malaysian Elders Longitudinal Research (MELoR) study. Participants were selected through random sampling from the electoral rolls of three parliamentary constituencies in Petaling Jaya and Kuala Lumpur stratified by age deciles and the three major ethnic groups of Malay, Chinese and Indian. Comparisons were made between sociodemographic factors and MoCA scores categorized into probable dementia, probable mild cognitive impairment (MCI) and probable normal ageing using cut-off scores of 20 and 25 for dementia and MCI respectively.

Results

Significant differences between groups were observed for total MoCA scores for age categories, ethnicity and education level ($p < 0.001$). There was no gender differences in MoCA scores. Additional analyses using linear regression with dummy variables demonstrated significant differences in total MoCA scores between ethnic Malays and Chinese (mean difference, MD (95% confidence intervals, CI) = -2.84 (-3.33- (-2.34)) and ethnic Indians and Chinese (MD (95%CI) = -1.88 (-2.36- (-1.40)) after adjustment for difference in age and educational level.

Conclusion

Initial analysis of MoCA scores among participants of the MELoR cohort suggested that performance in cognitive testing at baseline varied with ethnicity, and this was not explained by differences in age or educational attainment. This may reflect genuine difference in cognitive decline with ethnicity or it may also be due to potential cultural bias of the MoCA test. Further analysis will seek to determine factors mediating these differences, and future follow-up studies will identify factors which will contribute to cognitive decline in this cohort.

Poster Presentation Abstracts

ID: 726

Abstract Topic: End of life and palliative care

Keywords: family caregivers, end-of-life care, ACP, dementia

Perspectives of family caregivers in EOL care for people with dementia (PWD)

Lay Ling Tan

Changi General Hospital, Singapore

Abstract:

Background and objectives

In many Asian countries, family caregivers are intimately involved in the care of older adults. Our family caregivers in Singapore struggled with their caregiving responsibilities with a high prevalence of depressive symptoms. A recent local study suggested that most people with early cognitive impairment declined advanced care planning (ACP) discussions. Decisions on care delivery often have to be made by family caregivers on behalf of persons with dementia (PWD) who lack capacity. Family members often report psychological distress in making care decisions on their behalf. This study attempted to understand the perspectives and experiences of family caregivers in making EOL care decisions for PWD.

Methods

A qualitative study of a purposive sample of 14 subjects with dementia and availability of a family caregiver were included. Semi-structured interviews were conducted, recorded and transcribed verbatim. Thematic analysis was used to identify common themes with regards to the experiences and perspectives of family caregivers towards EOL care.

Results

Half of our family carers would avoid care decision discussions with their loved ones. A common theme was the perception that their loved ones with dementia would trust them in making decisions. Caregivers would also prefer to allow nature to take its course. Most caregivers did not consider dementia as a terminal illness. They had difficulty understanding the deteriorating and life-limiting nature of dementia, Caregivers were unfamiliar with lasting power of attorney (LPA) and ACP. They would prefer to follow the doctors' recommendations when the time comes and not discuss these with their loved ones prior. There was a perceived refusal of PWD to cooperate with treatment options and family carers felt helpless with regards to their caregiving role. Caregivers highlighted challenges regarding practical care and yearned for more support in understanding care needs of PWD.

Conclusions

Family carers tended to rely on doctors for EOL care decisions. There was lack of understanding of dementia as a terminal illness and discussions about EOL decisions were not perceived as urgent. Raising awareness that dementia is a life-limiting illness may help facilitate discussions of ACP and EOL care.

Poster Presentation Abstracts

ID: 727

Abstract Topic: Risk factors

Keywords: cognition, depressive symptoms, social frailty

Associations of social frailty with cognition and mood in healthy community-dwelling older adults

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Abstract:

Background

Social engagement and behaviour have been found to predict adverse health-related outcomes such as cognitive outcomes and depressive symptoms. In many Asian societies, commensality (eating together) provides social opportunities for older adults. We adapted the NCGG-Social Frailty (SF) scale to incorporate a question on 'eating alone', and examined association of SF with cognition and mood amongst healthy community-dwelling older adults.

Methods

SF was defined by responses to 5 questions (live alone, go out less often, rarely visit friends, feel unhelpful to friends/family, not eat with someone at least once a day). The scale score ranged from 0-5 points: a 0-score indicated social non-frail; 1 indicated social pre-frail; and ≥ 2 indicated social frail.

Cognition was measured using Chinese Mini-Mental State Examination (CMMSE) and Chinese Frontal Assessment Battery (CFAB) and mood with 15-item Geriatric Depression Scale (GDS). We also assessed nutritional status with Mini Nutrition Assessment (MNA); functional performance with basic and instrumental activities of daily living (ADL) and Frenchay Activities Index (FAI); and life-space mobility using Level 5 of Life-Space Assessment (LSA-5).

We performed cross-sectional analysis of 230 community-dwelling older adults from the GeriLABS2 study. We assessed correlation between each question in SF scale against cognition and mood, and performed linear regression analyses to evaluate the impact of SF on cognition and mood adjusted for age, gender, MNA and LSA-5.

Results

The mean age was 67.19 ± 7.43 yrs, with 72.6% females and 10.75 ± 4.36 yrs of education. SF prevalence was: non-frail, 51.7% (n=119); pre-frail [PF] 34.8% (n=80); and frail [F] 13.5% (n=31). CFAB, GDS, MNA and LSA-5 were significantly different between SF groups (all $p \leq 0.05$), but not CMMSE, basic and instrumental ADL, and FAI ($p = 0.08-0.74$).

Amongst the 5 questions, 'feel unhelpful to friends/family' was least endorsed in both PF (0%) and F groups (19.4%), whilst 'eat alone' was most endorsed (PF 42.5%; F 71.0%). For all questions, there was no significant correlation with CFAB and CMMSE. Mood, however, was significantly correlated with 'go out less often', 'rarely visit friends', and 'feel unhelpful to friends/family' ($r = 0.19-0.27$, $p < 0.05$).

In linear regression, SF was an independent predictor for mood in both PF ($\beta = 0.56$, $p = 0.01$) and F groups ($\beta = 1.65$, $p = 0.00$), but not for CFAB (PF $\beta = -0.43$, $p = 0.11$; F $\beta = -0.55$, $p = 0.14$) or CMMSE (PF $\beta = 0.06$, $p = 0.81$; F $\beta = -0.09$, $p = 0.80$).

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Poster Presentation Abstracts

Discussion

'Eating alone' was common in socially pre-frail and frail groups, albeit not significantly correlated with mood. Our results support the associations of SF with depressive symptoms but not cognition amongst healthy community-dwelling older adults with no dementia. This highlights the imperative need for meaningful social engagements in older adults, with commensality a possible avenue as a preventive approach. Future study should explore the longitudinal impact of SF on these health areas.

Poster Presentation Abstracts

ID: 728

Abstract Topic: Well being and quality of life

Keywords: Quality of life, Transitions, Depression

Longitudinal changes in self versus proxy-rated quality of life in mild-moderate dementia: factors associated with positive and negative transitions

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Abstract:

Discrepant ratings in health-related quality of life (HRQOL) by persons with dementia (PwD) vis-a-vis family carers have been associated with depression and neuropsychiatric symptoms. However, longitudinal changes in dyad ratings and attendant factors which affect transitions from better to poorer self-rated HRQOL, and vice versa, are not well established. We sought to ascertain baseline factors which predict these transitions of self- and proxy-rated HRQOL over a 1-year interval.

We recruited and followed up 144 PwD-caregiver dyads with mild-moderate dementia over 1 year. Interviews were administered separately to PwD and family caregivers for self- and proxy-rated Quality of Life in Alzheimer's Disease scale (QoL-AD) at baseline and 1-year. We also administered Cornell Scale for Depression in Dementia (CSDD), Zarit Burden Interview (ZBI) and Neuropsychiatric Inventory Questionnaire (NPI-Q). Dyads were classified into 3 groups by comparing self versus proxy-rated QoL-AD scores at baseline and 1-year: i) transitions from higher/equivalent baseline self-rated (compared to proxy-rated) to lower self-rated QoL-AD (Negative Transition, NT), ii) transitions from lower/equivalent baseline self-rated to better self-rated QoL-AD (Positive Transition, PT), iii) no change in status (Unchanged, UC). We compared baseline PwD and caregiver characteristics between the 3 groups; ZBI was analysed using a validated 4-factor structure. We then performed logistic regression to determine predictors of negative and positive transition, adjusted for PwD gender and education.

There were 17(11.7%) dyads in NT, 24(16.5%) dyads in PT and 104(71.7%) dyads in UC. There was a trend towards difference in NPI-distress scores between the 3 groups ($p < 0.1$), with PT group having lowest NPI-distress score. Of the 4 factors of ZBI, factor 3(personal strain) and factor 4(worry about performance) were significantly different between the 3 groups ($p < 0.05$). Logistic regression showed that lower PwD educational attainment ($OR = 1.15$, $p < 0.05$) and ZBI factor 3(personal strain) ($OR = 0.81$, $p < 0.05$) significantly predicted transition to poorer self-rated QoL-AD, whilst lower NPI-distress ($OR = 1.22$, $p < 0.05$) and higher factor 4(worry about performance) ($OR = 1.51$, $p < 0.05$) predicted transition to better self-rated QoL-AD. CSDD did not predict transitions between groups.

This study demonstrates that factors predicting transitions to poorer self-rated QoL-AD or better self-rated QoL-AD are different. Besides low educational attainment, the other factors which significantly predicted transitions are caregiver rated scores of NPI-distress scores, Zarit personal strain and worry about performance factors. This suggest the significant influence of caregiver burden and distress from neuropsychiatric manifestations on how caregivers rate care-recipients' QoL-AD. Future studies should examine how caregivers' self-rating of their quality of life influence the discrepancy of self-rated QoL-AD and proxy-related QoL-AD.

Poster Presentation Abstracts

ID: 729

Abstract Topic: Epidemiology

Keywords: dementia, survival, all-cause mortality, Hong Kong, CDARS

Survival of people with clinical diagnosis of dementia in Hong Kong: a population-based study

Hao Luo, Yi Chai, Gloria H.Y. Wong, Jennifer Y.M. Tang, Gary Lau, Terry Lum

The University of Hong Kong, Hong Kong S.A.R. (China)

Abstract:

Objectives: Studies on survival of people with clinical diagnosis of dementia can provide estimates of care outcomes of a health system and offer real-life insights on how to provide better support for the target population. This study aims to estimate survival from the point of recorded diagnosis of dementia, compared with people without dementia.

Methods: This case-control study used data from Clinical Data Analysis and Reporting System (CDARS), a population-wide databased managed by Hong Kong Hospital Authority. All patients aged 60 years or over with a first-ever code for dementia from 2001 and 2010 (N=24,250) were matched with patients without dementia by sex and index date at a 1: 2 ratio. We adopted Cox proportional hazard model to estimate hazard ratios, with and without adjustment for age, sex, and comorbidities (diabetes, cardiovascular disease, hypertension, cerebrovascular disease, and high cholesterol).

Results: A total of 5,847 patients have a diagnosis of Alzheimer's disease (AD), and 7,729 have vascular dementia (VaD). The median survival time, calculated based on the Kaplan-Meier estimator, for patients with dementia of any kind, AD, and VaD were 1163, 2448, and 1268 days, respectively. Compared with the control group, the raw and adjusted hazard ratios for dementia were 2.78 (95% CI, 2.71-2.84) and 1.14 (1.13-1.17), respectively.

Conclusions: Median survival times were much lower than figures reported by other regions and in screened populations. The high risk of death may be an indicator of late diagnosis and hence call for promoting early diagnosis to ensure timely intervention.

Poster Presentation Abstracts

ID: 730

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: MCI, mild cognitive impairment, neuropsychiatric symptoms, subjective cognitive decline, mild behavioural impairment

Mild behavioural impairment (MBI) in subjective cognitive decline (SCD) and mild cognitive impairment (mci): prevalence and association with longitudinal cognitive decline in a memory clinic cohort

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Department of Geriatric Medicine, Tan Tock Seng Hospital, Singapore

Abstract:

Background:

MBI is characterized by neuropsychiatric symptoms not attributable to existing dementia, psychiatric or medical causes. These symptoms are associated with increased risk of disease progression in established dementia. However, the prevalence of NPS within the construct of MBI, and its association with cognitive decline in pre-dementia states are not well established. We aim to investigate the prevalence of MBI in SCD and MCI, and its association with longitudinal cognitive decline in a memory clinic cohort.

Methods:

We evaluated 42 subjects with SCD and 233 subjects with MCI over a median follow-up time of 24 months. MCI was defined as (i) global Clinical Dementia Rating (CDR) score=0.5; (ii) neuropsychological test performance ≥ 1 SD below age- and education-adjusted means. SCD was defined as (i) CDR ≤ 0.5 (only if the memory domain was endorsed) and (ii) unimpaired neuropsychological test performance. We operationalized MBI using the Neuropsychiatric Inventory Questionnaire. Cox proportional hazards models were used to evaluate the effect of MBI on the risk of cognitive decline, defined as CMMSE below age- and education-adjusted cut-offs for dementia.

Results:

75.1% MCI and 64.3% SCD subjects fulfilled criteria for MBI (≥ 1 MBI domain present). Prevalence estimates across MBI domains were: affective dysregulation (MCI: 53.0%, SCD: 43.2%); impulse control (MCI: 54.4%, SCD: 44.4%); decreased motivation (MCI: 23.7%, SCD: 15.9%); social inappropriateness (MCI: 4.5%, SCD: 0%); and abnormal perception or thought content (MCI: 15.2%, SCD: 9.1%). Higher risk of cognitive decline were observed in MCI subjects with decreased motivation (hazard ratio [HR] adjusted for age, gender, education and baseline neuropsychological test performance: 2.01, 95% CI: 1.06–4.08) and abnormal perception (adjusted HR: 2.16, 95% CI: 1.03–4.52). There was an incrementally higher risk of cognitive decline amongst individuals with ≥ 2 MBI domains (adjusted HR: 1.98, 95% CI: 1.05–3.75) and ≥ 3 MBI domains present (adjusted HR: 2.51, 95% CI: 1.14–5.14).

Conclusions:

MBI is common in SCD and MCI and is associated with longitudinal cognitive decline in subjects with MCI. The risk of cognitive decline increased with number of MBI domains involved. Further studies are warranted to examine the utility of MBI as a early clinical biomarker of neurodegenerative disease and as a potential target for treatment.

Poster Presentation Abstracts

ID: 731

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: cognitive intervention program, dementia, occupational therapy

Occupational therapy at long-term care services for people with dementia and their families

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²School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan

Abstract:

Introduction

Based on the Long-Term Care 2.0 policy in Taiwan, the Taipei City Psychiatric Center has a comprehensive and continuous care system from hospital to community for people with dementia. This care model includes acute wards, day care centers, memory integrated clinics, Integrated Dementia Care Centers, and Support centers for People with Dementia and their Families (SPDF). Occupational therapists are members of the psychiatric teams and use non-pharmacological treatments to provide quality accessible, affordable services. Using the Model Of Human Occupation (MOHO) theory, occupational therapists assist people with dementia with participating in and adapting to social life. The MOHO theory examines the 4 systems of volition, habituation, performance, and environment from a holistic perspective. Through occupational adaptation, including occupational identity and occupational competence, the MOHO theory emphasizes understanding the persons and their narratives.

Methods

We examined the values and interests of people with dementia, understood their roles and habits, and assessed their performance skills and environmental resources. According to the MOHO theory, we tried to understand a person's life story and designed non-pharmacological treatments for people with dementia at acute wards, day care centers, and SPDFs with a 60-minute session from Monday to Friday. Additionally, we had a series of cognitive intervention activities for cognition and daily function maintenance.

Positive impact

We designed 12 sessions of cognitive intervention activities once a week from May to July 2019 for people with mild or moderate dementia in the community. Thirty-seven people joined the group, with the average age being 79 years. The activities were focused on attention, memory, visual perception, calculation, executive function, and problem solving. After the sessions, we developed a learning checklist and went to the National Taiwan Museum for learning food preparation and to establish their real-life experiences. Occupational therapists and volunteers led the people with dementia on these general visits and allowed them to observe and touch the displayed objects. The occupational therapists also strengthened their tone, movements, and expressions to revitalize their life experiences in their memories. One person in the group used to be a grocery store owner. Through the process of displaying familiar items, she shared her experience of running a grocery store in the market when she was young and also asked other group members to share their own stories.

Perspectives

By understanding the key relationships of the group members with their past life roles and valuable careers and also their preferences for support with their daily habits, we designed an appropriate occupational therapy for people with dementia. The three major themes of the experience of volition in dementia are volition, modified occupation, and social environment.

Poster Presentation Abstracts

ID: 733

Abstract Topic: Mild Cognitive Impairment (MCI)

Keywords: MILD BEHAVIOURAL IMPAIRMENT, MILD COGNITIVE IMPAIRMENT

Mild behavioural impairment in mild cognitive impairment and healthy controls

Fennie Choy Chin Wong¹, Kok Pin Ng¹, Audrey Low², Russell Jude Chander³, Benjamin Wong¹, Sheng Chun Ng¹, Nagaendran Kandiah¹

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Abstract:

Objectives/Background:

Mild behavioural impairment (MBI) is a new construct illustrating the relationship between early neuropsychiatric symptoms and behavioural changes at late-life; and the risk of cognitive decline and dementia. However, the frequency and characteristics of MBI among healthy controls (HC) and mild cognitive impairment (MCI) remains unclear. This study aims to investigate and contrast MBI frequency amongst HC and MCI subjects while relating MBI scores to cognitive performance.

Methods:

123 subjects ($M_{age}=65.66$ years, $SD=9.08$) underwent neuropsychological assessments and were categorised into HC and MCI (MMSE cut-off score ≤ 26). All completed the MBI-Checklist (34 items; 5 behavioural subdomains). In line with existing literature, MBI cut-off scores of 8.5 and 6.5 were used for HC and MCI respectively.

Results:

The cohort comprised 48 HC ($M_{age}=62.87$ years, $SD=7.72$) and 75 MCI ($M_{age}=67.45$ years, $SD=9.47$). MBI is almost twice as frequently reported in MCI than HC (32.0% vs 16.7%, $p=.059$). In the total cohort, those with MBI performed significantly poorer in global cognition (MMSE: $p=.035$; MoCA: $p=.013$; VCAT: $p=.012$) and episodic memory (ADAS story immediate recall 2: $p=.048$) and in all cognitive domains trend-wise, corrected for age. MCI+MBI had poorer cognitive performance than MCI-MBI in all cognitive domains, which was significantly worse in global cognition (MoCA: $p=.031$; VCAT: $p=.018$).

Conclusion:

MBI is more frequent in MCI than HC and is associated with poorer cognitive performance. Prompt detection of MBI among MCI patients would allow timely behavioural interventions that can improve quality of life and clinical outcomes.

Poster Presentation Abstracts

ID: 734

Abstract Topic: Dementia and spirituality

Keywords: Singapore, Spirituality, Religion, Case Studies

Attending to spiritual needs in dementia care: a Singapore experience

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Abstract:

There is no one definition for Spirituality. Professional chaplains describe spirituality as an awareness of relationships with all creation; an appreciation of presence and purpose that includes a sense of meaning. It is also not uncommon to conceptualise spirituality in terms of being at the core of who we are. The notion of spirituality as an integral component of the total well-being of older adults with dementia is being increasingly recognised. For many, spiritual connection provides a source of reassurance, hope and meaning in their lives. In the midst of the debilitating cognitive and physical changes brought on by their disease, those living with dementia and their carers, might turn to spirituality for comfort, or connection with the transcendent.

People with dementia typically retain older memories for longer periods than recent memories. Hence they may respond to items or scenes they recall from the distant past including photos, religious readings, objects, scents or songs. As such, each person's spiritual needs are unique, and these include personal questions about meaning, faith and belief. These needs ought to be addressed and respected as much as the medical, physical or psychosocial aspects of dementia care. By attending to these needs in persons with dementia, healthcare professionals may minimize the risk of spiritual distress, which is the impaired ability to connect with others or to derive meaning in life. This presentation highlights two individuals with examples of the impact of spiritual and religious encounters on their dementia journeys in unique ways.

Case Study 1:

Mr. Chan is a 70-year-old widower with advanced dementia who grew up in a strong Buddhist-Taoist tradition. His current speech is limited to only several single words, and he usually responds with one or two short sentences. Due to his limited language abilities, he struggles to verbally express his needs and preferences. Being attentive and responding to his spiritual needs intimately and communicating them non-verbally, our encounters facilitated this individual to use his spiritual beliefs and religious objects in making sense of his existential issues.

Case Study 2:

A devout Catholic lady in her mid 80's, Mrs. Moh was diagnosed with dementia four years ago. Although she may not be fully cognizant of her present reality and has a poor memory of the recent past, she has specific religious themes and hopes which she desires. Having met these spiritual needs through personalized exploration and reminiscence, her almost obsessive and repetitive conversations related to this topic faded over time. Spiritual care has helped her discover hope, create new meaning in her life and affirm her self-identity.

(Names and personal details in the case studies have been changed to protect their identities.)

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Poster Presentation Abstracts

ID: 736

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: advocacy, policy, grassroots

Lessons learned from dementia advocacy Canada

Lisa Poole

Dementia Advocacy Canada, Canada

Abstract:

This presentation would explore the importance of grassroots advocacy and detail the lessons learned from Dementia Advocacy Canada including participation at the policy level.

Poster Presentation Abstracts

ID: 737

Abstract Topic: Epidemiology

Keywords: Research; developing countries; Mexico

A roadmap of dementia research in Mexico

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¹Psychiatric Care Services, Ministry of Health, Mexico; ²National Institute of Neurology and Neurosurgery, Mexico; ³National Institute of Geriatrics, Mexico; ⁴Personal Social Services Research Unit, London School of Economics and Political Science

Abstract:

Background and objectives of the study:

Incentivizing national research on dementia (basic, clinical, epidemiological and social) is essential to generate new knowledge that promotes better management of the disease and to optimize the quality of life of people with dementia and their families. Increasing and strengthening research on dementia, through collaborations and inter-institutional links with national and international scientific groups, is therefore an important task that must be carried out to achieve these aims. Therefore, the objective of this research is to conduct a comprehensive review of the literature on the state of dementia research in Mexico at the state level, as well as to determine the issues with the greatest production

Methods:

A search was conducted for original articles on dementias in Mexico in the electronic databases of Pubmed, Redalyc, Medigraphic, Lilacs, Scielo, Conricyt and Google Scholar, using the keywords "dementia", "Mexico" and "Mexican", published during the period 2005-2018. At the same time, another search was carried out in the repositories of the main public universities of the country. The articles and theses are described by category, as well as the geographic location of the place where the principal investigator is assigned.

Results:

We identified 108 original investigations on dementia, mainly focused on clinical and intervention aspects (37%), followed by those of an epidemiological character (13%), and those dedicated to basic research (13%). Subsequently, there are those focused on the evaluation of informal care and the impact of the caregiver. There was less research on non-pharmacological interventions.

On the other hand, 134 theses were identified, almost half of them focused on clinical and intervention factors (49%), followed by the evaluation of some aspect of informal care or caregiver impact (13%), as well as non-pharmacological interventions.

By state, only 17 of the 32 states in the country have at least one publication on dementias (53%). Of the 111 publications identified with ascription of the first author in Mexico, 70% have as the main author a researcher from Mexico City.

Perspectives:

Although research on dementias in Mexico has been increasing, some limitations are identified in certain areas, both geographic as well as thematic. As such there is a need for more research in the evaluation of research on the effectiveness of interventions, on the impact of dementia, as well as on other areas such as stigma. It is therefore necessary to use a variety of approaches to understand the needs of people with dementia and their families.

Poster Presentation Abstracts

ID: 738

Abstract Topic: Formal carers education and training

Keywords: Undergraduate Education, lived experience, healthcare student

Time for Dementia: Understanding student experience

Stephanie Daley, Molly Hebditch, Yvonne Feeney, Sube Banerjee

Brighton and Sussex Medical School

Abstract:

Introduction

The Time for Dementia study has been set up to ensure that the future healthcare workforce have the necessary knowledge and skills to deliver high quality person-centred care to the increasing number of people living with dementia. It is an undergraduate education programme which aims to improve student knowledge, attitudes and empathy towards those living with dementia. In the programme, students (nursing, medical and paramedic) visit a family (person with dementia and their carer) in pairs over a two year period in order to understand what it is like to live with the condition.

A mixed methods research design has been used to evaluate the impact of the programme upon student attitudes, understanding, knowledge and behaviours towards dementia. This has included quantitative assessment of student outcomes (Banerjee et al, 2019) which has shown statistically significant improvement dementia knowledge and attitude in intervention group students compared to controls. However, we have been keen to understand more about the wider student learning experiences from the programme, and therefore undertook this qualitative study to explore student experience further.

Methods

Participants were undergraduate students who were undertaking the Time for Dementia at either the Brighton and Sussex Medical School or the University of Surrey, UK. We sampled for variation in the student participants in order to generate a framework for understanding the student experience of Time for Dementia. Interviews and focus group transcripts were analysed using thematic analysis.

Results

39 student participants took part in individual in-depth qualitative interviews and 38 took part in five focus groups. Four key themes were identified from the analysis; Insight and understanding, Challenging attitudes and stigma, Relational learning and Enhanced dementia practice. Specifically, students identified that their original perceptions of dementia had changed throughout the visits. Students felt able to see beyond negative stereotypes about dementia, and instead recognise that a person with dementia could remain intelligent, humorous, and continue to make decisions and accomplish challenges and tasks. Students also reported applying broader dementia skills and awareness into practice, this included improved communication, involving families in care, exploring carer's wellbeing, adapting hospital procedures, being aware of possible signs and symptoms of undiagnosed memory problems.

Discussion

Our qualitative research has demonstrated the positive impacts upon the undergraduate healthcare students that have been through the programme. Our students have received an education programme which will equip them to understand the needs of patients with dementia, regardless of the area of healthcare which they practice in.

Poster Presentation Abstracts

ID: 740

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: Undergraduate Education, lived experience, healthcare student, community engagement

Participating in Undergraduate Dementia Education: The Experience of People with Dementia and their Carers

Stephanie Daley, Molly Hebditch, Yvonne Feeney, Zoe Cashin, Sube Banerjee

Brighton and Sussex Medical School

Abstract:

Introduction

The aim of the Time for Dementia programme is to equip undergraduate healthcare professionals with the necessary skills, attitudes and knowledge to work effectively with people with dementia and their carers. The programme has been established at the Brighton and Sussex Medical School and University of Surrey, whereby medical, nursing and paramedic students visit a family (person with dementia and their carer) in pairs over a two year period. The programme has involved 2600 students and over 1000 families since its inception in 2014.

Overall, there is a dearth of literature about the subjective experience of people with dementia and their carers in dementia education. We were therefore keen to understand more about the experience of those families taking part, as well as their motivation to engage in the programme.

Methods

In addition to satisfaction surveys, in-depth interviews were carried out with families (a person with dementia and their carer). Interviews took place at mid-way (12 months) and at the end (24 months) of the programme. We sampled for variation in participants, and sought to explore factors underpinning motivation to join the programme, on-going engagement and the experience of/and satisfaction with the programme. Interviews were audio recorded, transcribed verbatim and analysed using thematic analysis techniques.

Results

Qualitative interviews were undertaken with 37 families. Four core themes, each with subthemes, were identified from the analysis; motivators, value to family, value to person with dementia, and student factors. Significant factors in the experience of families included the perception of 'making a difference', enjoyment and a perceived benefit to the person with dementia, student attributes and 'fit with students'. Motivation to join and remain in the programme was most commonly linked to a desire to improve dementia care and altruism.

Discussion

Time for Dementia, and other similar programmes are only feasible if widespread engagement by people with dementia and carers is possible. These findings help us to understand the positive outcomes for families, as well as the factors which need to be addressed in the recruitment and on-going engagement of families within dementia education.

Poster Presentation Abstracts

ID: 742

Abstract Topic: Risk reduction and prevention (including clinical trials)

Keywords: Pilot study, Multimodal intervention, Focus Group Interviews, Relatives' experiences

Study partners' experiences of participating in a multidomain intervention for individuals with prodromal Alzheimer's disease

Charlotta Thunborg^{1,5}, Ulrika Akenine¹, Gerd Faxèl-Irving¹, Miia Kivipelto^{1,2,3,4}

¹Karolinska Institutet, Sweden; ²Stockholms Sjukhem, Sweden; ³Imperial College, London; ⁴University of Eastern Finland, Kuopio; ⁵Mälardalen University, Västerås

Abstract:

Background: FINGER (i.e., The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability) was the first long-time and multi-domain based lifestyle intervention with benefits on cognition in at-risk older people. The MIND-AD, a multimodal preventive trial for Alzheimer's disease: towards multinational strategies, was adapted from the FINGER model to fit individuals with prodromal Alzheimer's disease (AD). The term prodromal AD means memory impairment, not severe enough to interfere significantly with activities of daily living, the person have biological markers without having dementia. The primary outcome of MIND-AD was to evaluate the feasibility and adherence. This presentation will focus on a sub-study, a Focus Group (FG) study with study partners (i.e., a family member or a friend) who participated in the MIND-AD intervention. The purpose of this sub-study was to examine how study partners living with persons newly diagnosed with prodromal AD experienced participating in MIND-AD.

Method: All study partners who accepted to participate in the larger MIND-AD study in the memory clinic were eligible and was invited to participate in the FGs. Semi-structured FGs using targeted probes was used to provide insight into study-partners' experiences of the MIND-AD. FGs were audio-recorded and transcribed verbatim. The data were entered into Atlas.ti version 8.0 for the coding and analysis. A qualitative analysis was applied to report the patterns of experiences of study-partners, referred to as "categories" in this abstract.

Results: Two FGs with in total 9 study partners were performed. The preliminary results included four categories: 1) *the importance to have social connections*, 2) *to understand early signs of Alzheimer's disease*, 3) *to change approach to early signs of forgetfulness*, 4) *to find structure in chaos*. Results indicated that being in social situations had been different for them recently. It was identified through the study partners' focus on how the impact of early signs of Alzheimer's and living life as usual was impacted. Study partners were not comfortable sharing the diagnosis with friends in social situations. Furthermore, the process of adaptation included a changed approach to deal with forgetfulness. A wide spectrum of perceived benefits from participating was noted, not only improvements in physical, mental, and social factors but also the impact of the study time, that gave structure to a chaotic time after the diagnosis.

Conclusion: Study partners' experiences should be taken into account when designing multi-domain life style interventions for individuals with prodromal AD. We are currently completing the recruitment and carrying out further analysis. Implications to research and clinical practice will be discussed in relation to current evidence on dementia risk reduction.

Poster Presentation Abstracts

ID: 744

Abstract Topic: Psychosocial interventions

Keywords: cognitive stimulation, cognition, quality of life, psychosocial intervention

Effectiveness of cognitive stimulation for dementia: a systematic review and meta-analysis

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¹Centre for Dementia Studies, United Kingdom; ²Sheffield University, United Kingdom

Abstract:

Background and objective:

Non-pharmacological or psychosocial interventions are now considered a core component of dementia care. Cognitive stimulation (CS) is one such intervention that is used internationally to provide general stimulation of cognitive abilities and treat cognitive decline in people with dementia. Despite its popularity, recent work assessing its benefits for people with dementia has been limited. This presentation will discuss a pre-registered, systematic review and meta-analysis that aimed to update previous work conducted in 2013 by Aguirre and colleagues, and so provide an overview of the current state of evidence on the effectiveness of CS for the cognition (primary outcome) and quality of life, activities of daily living, and psychological symptoms (secondary outcomes) of people with dementia.

Method:

A systematic search of the literature was conducted in June 2018 across multiple healthcare databases (Medline, Cinahl, Psycinfo, and Lilacs), trial registers and grey literature sources to elicit randomised control trials using CS with people with dementia. The search revealed 91 full texts that were assessed against the inclusion criteria and 33 of these were included in the final meta-analysis, covering reported data from 2066 participants (experimental $n = 1104$, control $n = 962$). To gauge the strength of evidence for the effectiveness of CS, we complemented effect size estimates with Bayes Factors analysis.

Results:

A medium-sized effect of CS on global cognition was found immediately post the intervention and evidence for this was supported by decisive Bayesian evidence. However, these benefits were not maintained long-term suggesting a drop-off effect. CS was also found to significantly improve activities of daily living, depressive symptoms, and dementia ratings; however, this was only supported by ambiguous Bayesian evidence. No significant CS benefits were found for memory, language, quality of life, anxiety, and behaviour ratings. Furthermore, a review of study bias highlighted that most studies lacked active, double-blinded controls, potentially leading to an overestimation of the effect and making it difficult to conclusively attribute the observed improvements to the CS intervention.

Conclusion:

As the popularity of CS interventions continues to increase across the globe, it is important to ensure that its clinical use within dementia care is supported by conclusive evidence. This systematic review and meta-analysis of the current body of literature suggests positive short-term effects of CS on indicators of global cognition of people with dementia. However, the lack of adequate control groups and the at best ambiguous evidence for any other outcome highlights the need for better controlled future studies that can provide more robust and compelling evidence.

Poster Presentation Abstracts

ID: 745

Abstract Topic: Non-pharmacological interventions

Keywords: ketosis, ketones, ketone ester, ketone salts, medium-chain triglycerides

Strategies to achieve mild nutritional ketosis for Alzheimer's, dementia, and healthy brain aging

Mary Newport

Spring Hill Neonatology, Inc, United States of America

Abstract:

BACKGROUND/INTRODUCTION: Insulin resistance, insulin deficiency, resulting in abnormal glucose uptake in the brain, and inflammation are important pathological factors in Alzheimer's disease (AD) and other dementias. Once thought to be harmful byproducts of metabolism, at physiological levels, ketones may provide therapeutic benefits through several mechanisms. Ketones are an alternative fuel to glucose for the brain, naturally increasing during even short-term overnight fasting. Ketone PET scans show ketone uptake is normal in brain regions affected by abnormal glucose uptake in AD. Ketones are anti-inflammatory and prevent build-up of toxic beta amyloid and tau tangles in animal models.

METHODS: Doctor's approval and monitoring is important. One or more strategies can be used to achieve mild nutritional ketosis defined as betahydroxybutyrate levels of 0.5-2 mmol/L: (1) Fast overnight for at least 10-14 hours. (2) Consume coconut oil and/or MCT oil with meals, aiming for 20 to 90 grams per day. (3) Adopt a low-carb ketogenic diet (KD): Gradually reduce carbohydrates to <60 grams per day and increase healthy fats to 50-60% of calories. (4) Consider ketone salts or esters, monitored by doctor to further enhance results.

RESULTS: Positive clinical trials and case studies are published using MCT oil, coconut oil, KD, or ketone ester in people with mild cognitive impairment or AD. Studies of the KD in people with type 2 diabetes, which carries a 30% risk of dementia, report complete reversal of biomarkers of insulin resistance in 8 weeks. Two case studies of people with mild AD report reversal of insulin-resistance biomarkers and significant improvement in MoCA test to near normal scores after 10 weeks on KD in mild nutritional ketosis. There are anecdotal reports of people in the later stages of AD having improvement in symptoms with nutritional ketosis, such as recognizing, making eye contact with, and speaking again to family members. For some, the improvements are noted within days and, for others, become more obvious over several weeks to months.

CONCLUSIONS/PERSPECTIVES: Adopting a lifestyle of mild nutritional ketosis requires acceptance and cooperation by the person living with dementia, caregivers, and other family members who may be directing care. Careful planning and consistency are key to achieving the best results, and this could require considerable time and effort to get underway and then maintain, particularly when a ketogenic diet is part of the plan. Given the lack of success in developing any new drug to improve the lives of people living with Alzheimer's, much less cure the disease, accumulating evidence suggests that adopting strategies to achieve mild nutritional ketosis could be beneficial and possibly preventive. Even small improvements may enhance the quality of life for people living with dementia, their caregivers, and other family members.

Poster Presentation Abstracts

ID: 750

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: Occupational therapy, group therapy, dementia, nursing home

Effectiveness of a structured occupational therapy group therapy programme for nursing home residents with dementia: a retrospective cross sectional study

Yoke Chuan Lee

Econ Healthcare Group, Singapore

Abstract:

Background: Groups treatment is widely used in Occupational Therapy practice. Group activities are carefully planned to maximise the residents' interaction with other group members and to focus on specific treatment goals.

Objectives: The goal of developing the group therapy programme is to provide cognitive, emotional and functional benefits to the nursing home residents with dementia. The aim of this study is to evaluate the effectiveness of a weekly thematic group therapy which led by Occupational Therapist (OT) for people with dementia in residential care.

Methods: Mini Mental State Exam (MMSE) is a test of cognitive functions among the elderly. Modified Barthel Index (MBI) is used to assess an individual's functional independence. The Geriatric Depression Scale (GDS) Short Form is used to measure depression. All residents in a local nursing home are continually assessed 6-monthly by OT using MMSE, MBI and GDS. 20 group activities were planned under 4 categories which are cognition, Activities of Daily Living (ADL), psychosocial and leisure. A standardised training was provided to therapy assistant to administer MBI, MMSE and GDS before and after 6-months group therapy. 21 residents with mild to moderate dementia in the nursing home were included in the study but only 13 residents were included in the analysis as the rest either refused Occupational Therapy or were medically unwell during the study period.

Results: An increase in MMSE and MBI score was observed for residents with dementia who attended the group therapy sessions. However, this study shows that the group sessions had limited effect to prevent depression among the group participants.

Conclusion: The group therapy programme can potentially maintain or improve cognition and functional independence of nursing home residents with dementia. A large-scale group therapy implementation may be useful to clarify long-term benefits of group therapy for elderly with dementia.

Poster Presentation Abstracts

ID: 752

Abstract Topic: Post diagnostic support for people with dementia and carers – NEW

Keywords: Meeting Centres, post-diagnosis, community, engagement

Meeting centres support programme: evidence of transferability to different countries for providing effective community post-diagnostic support

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Abstract:

Background: The MEETINGDEM research was funded through the JPND with the aim of adapting, implementing and evaluating the Dutch Meeting Centres Support Programme (MCSP) model in UK, Italy and Poland. The focus of MCSP is on both the person living with dementia and their family who provide care at home. They meet in a relaxed small group on an on-going regular basis in easily accessible community facility. Evidence-based post-diagnostic interventions are provided geared up to the needs of local members. It is facilitated by a small team of staff and volunteers trained in the ethos of person centred dementia care and the Adaptation-Coping Model. There is a well-developed community process for developing new MCSPs that engages all local stakeholders.

Method. After exploring pathways to care, the three countries established initiative groups of organizational collaborators and user representatives; inventoried facilitators/barriers to implementing MCSP; and developed implementation plans, practical guides and toolkits, utilizing and adapting Dutch materials. Staff were trained and 9 Meeting Centres (MC) established (Italy-5, Poland-2, UK-2). The first 9 MC participated in the study into MCSP's impact on people with dementia (behaviour, mood, quality of life/ QoL) and carers (sense of competence, mental health, loneliness, distress, experienced burden), its cost-effectiveness and user satisfaction.

Results: Overall MCSP components and vision were maintained in all countries/centres. Country specific requirements resulted in variations in inclusion criteria, frequency of programme components, culture specific activities. Factors facilitating implementation were: added value of MCSP and evidence of its effectiveness, matching needs of the target group, enthusiastic local stakeholders, suitable staff and project-manager. Barriers included competition with care/welfare organizations, scarce funding. MCSP appeared more effective on QoL (feelings of belonging, self-esteem, positive affect; with medium to large effect sizes) of people with dementia than usual care. Higher attendance levels were associated with greater neuropsychiatric symptom reduction and increased feelings of support. Carers experienced less burden than those receiving usual care. In Italy, carers experienced better mental health and less distress by mood/behaviour symptoms of people with dementia. People with dementia and carers were highly satisfied with MCSP. Carers felt the activities for people with dementia are functionally activating, and provide an important means for social and emotional interaction.

Conclusion: MCSP is transferable across countries and shows improved quality of life and mental health benefits for people with dementia and carers against reasonable additional costs. Meeting Centres have been maintained in all participating countries and are proving a popular means of actively supporting people and families in the post-diagnostic stage.

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Poster Presentation Abstracts

ID: 754

Abstract Topic: Psychosocial interventions

Keywords: auto ethnography, narrative therapy, dementia, psychosocial interventions

Autoethnography and narrative therapy: interventions for dementia

Kate Swaffer

University of South Australia, Australia

Abstract:

The purpose of this presentation is to present auto ethnography (AE), supported by narrative therapy, as new and unique psychosocial interventions for dementia when introduced together. It will discuss this as an approach to better understand the lived experience of dementia, and also as a method of therapeutic healing following a diagnosis of dementia. It is an ethical exploratory research approach and practice, which so far has been found to be an investigative method, which engages with the theory of AE, with the express purpose of understanding if there is utility and value in this methodology for the understanding of the lived experience of dementia. An initial examination of auto ethnography as a psychosocial intervention suggests that auto ethnographic writing practice is affective, critical and extremely informative and informative. Coupled with narrative therapy, it holds the possibility of a new way to help create change in nursing practice, as well as reduce self-stigma. Creating improved quality of life and well being and providing a new use of narrative that health care professionals can use, as an intervention for dementia is critical to change. Investigating the deeper understanding of the lived experience of dementia through auto ethnography, this presentation also elucidates a greater ethical understanding of whose story the lived experience of dementia is to share. I will also discuss this relatively new methodology and its use in not only exploring more genuinely the lived experience of dementia, and my presence inside that domain most others define as a critical illness, but how it fits within the spectrum of disability. Finally, through the lens of auto ethnography, I will discuss the value of self-advocacy, self-help and peer-to-peer support, in terms of a more positive response to a critical illness, and if this methodology is of real value to people diagnosed with any type of dementia.

Poster Presentation Abstracts

ID: 755

Abstract Topic: Well being and quality of life

Keywords: Exercise, Wellbeing, Gym, Strength, Mobility

Benefits of gym exercises

Alister Robertson

Dementia Alliance International

Abstract:

There's growing evidence that exercise is not just good for the body, but also the brain, boosting memory and overall brain health. This presentation is not based on a formal research project, but on observations made by participants and trainers of the benefits from the various activities undertaken. The gym program includes the use of free weights and resistance apparatus, core strength, stretches and relaxation exercises.

Exercise appears to endow a wealth of benefits, from the release of happiness-inducing hormones to higher physical fitness. It has long been known to provide several health benefits, both physical and mental. There's growing evidence that exercise is not just good for the body, but also the brain, boosting memory and overall brain health. To take this evidence and put it into practise, a small group of 10 people living with dementia attend a gym for a weekly one-hour session.

As part of the program, we incorporate resistance training which can increase muscle, tendon and ligament strength, flexibility and postural support. It can also assist with strength and balance which is known to help with the prevention of falls. In addition, the use of Tai Chi type movements helps gain control of arms and legs and use of opposite sides of the body helps challenge the brain. By incorporating core and breathing control into the movements it allows the body to calm and enables us to complete the task, giving a sense of achievement rather than failure.

Observations: When introduced to the program, some participants found it extremely difficult to identify and follow instructions including the safe operation of weight resistance apparatus. After some months, we were all able to identify and safely operate the apparatus without verbal instructions being necessary.

There has been a noticeable improvement in strength, flexibility, co-ordination, as well as balance and mobility for all of us. This has been achieved as participants experience and deal individually with their varying dementia degradation. A bonus to our wellbeing is that the gym outing provides good social interaction not only within the group but with other gym participants. We also see it as another opportunity to raise awareness of dementia in the community.

Poster Presentation Abstracts

ID: 756

Abstract Topic: Non-pharmacological interventions

Keywords: dementia, cocoa, *Caenorhabditis elegans*, Alzheimer's disease, amyloid- β

Long-term consumption of cocoa prevents dementia induced by amyloid- β 1-42 in *caenorhabditis elegans* (c. Elegans)

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Abstract:

Background and objectives of the study

Alzheimer's disease (AD) is an irreversible neurodegenerative disorder characterized by a progressive decline in memory, cognition and motor function. Pathological hallmarks of AD include accumulation of A β peptides and aggregation of tau protein. Due to the progressive aging of the population and lack of an effective cure, AD is becoming a healthcare burden. Epidemiological studies suggest that the diets rich in polyphenols can play a protective role in neurodegenerative diseases. Consumption of cocoa, one of the most popular food products rich in polyphenols, is associated with many health benefits, including a lower risk of cognitive decline in elderly population (Moreira et al 2016). The objective of this study was to determine the effects of long-term consumption of cocoa on short-term memory in a transgenic model of *C. elegans* with pan-neuronal expression of human A β ₁₋₄₂.

Methods

Control (GRU101) and the transgenic strain (GRU102) expressing constitutive pan-neuronal A β ₁₋₄₂ were grown on Nematode Growth Medium (NGM) plates with *Escherichia coli* (*E. coli*) OP50 diet. Starting from L1 larval stage, the cocoa supplemented worms received unsweetened cocoa powder suspended in M9 buffer (5mg/ml), spread on the lawn of *E. coli*. Naive chemotaxis, learning and dementia index (short-term memory loss) were measured at day 4 (young age) and day 8 (middle age).

Results

Both strains exhibited an age-related decline in both chemotaxis index and learning index. In addition, GRU102 worms showed a higher dementia index at day 8 at both 1 hour and 2 hours after conditioning. Cocoa supplementation reversed the age-related decline in chemotaxis index in both strains, improved learning at day 4 in GRU102 worms and decreased the dementia index in GRU102 worms at day 8 to reach similar levels to GRU101.

Conclusions

Long-term cocoa supplementation of diet of transgenic *C. elegans* expressing human A β ₁₋₄₂ prevented the onset of dementia in later life. The results indicate that dietary intervention at an early age may prevent / delay onset of AD in later life.

Poster Presentation Abstracts

ID: 758

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Caregiver app, communication strategies.

To build up the communication skills of caregivers of persons with dementia using “play to care” application

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Abstract:

Background & objectives of the study

Aged Psychiatry Community Assessment & Treatment Service (APCATS) is a community-oriented psychogeriatric outreach service in Singapore which does home visits for elderly patients who have psychiatric illness. 35% of our patients (86 out of 246 who entered our service since 2015) have dementia with challenging behaviours. In these cases, many challenging behaviours can actually be managed non-pharmacologically by modifying communication approaches and engagement in activities. However, many caregivers do not have knowledge in these areas, resulting in caregiver burnout when they struggle to manage the challenging behaviours. A research has shown positive responses and engagement from the MESSAGE communication strategies (Liddle et al., 2012). Many of the caregivers cannot attend caregivers' training programmes due to their caregiving commitments. Research by ADA in 2006 and 2008 (2017) indicated half of their caregivers in the study were tied down with full time caregiving and never utilized dementia services. As such, we aim to develop an app by offering flexibility and convenience to help caregivers learn to communicate effectively with PWD, through playing the scenario based games during their preferred times.

Methods

APCATS had developed a prototype of the app, called “Play to Care”. This interactive app includes “Scenario Based” games for caregivers. The scenario games will present four common challenging behaviours. These behaviours include aggressive behaviour, restless and wandering, resistance to showering, sleep wake reversal. For example, in aggressive behaviour, the player will have to select from the given options the most appropriate way to communicate with PWD. So, in the process of playing, the caregivers will pick up tips on the positive engagement with PWD. There is also another option button in the app which allows players to learn about the

MESSAGE strategies of communication through playing the games and collecting the correct badges to complete the game. The app was piloted and used by a few clients (PWD) in APCATS service and their caregivers. Feedbacks were gathered from these caregivers.

Results/Positive impact

Feedbacks from the caregivers were positive. The scenario-based games teach them useful communication tips on how to approach a challenging behaviour in PWDs. Some caregivers find the app a little challenging to play initially but after a few trials they began to understand more about the MESSAGE strategies and able to remember a few of them.

Conclusions

With this favourable pilot, APCATS plans to spread the app to all caregivers within the service and eventually to the general public. With the strategic communication platform, caregiving experience with PWD can be enhanced. In the pipeline, a study can be done to evaluate the learning and application

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of MESSAGE strategies through the use of app as well as the amount of positive engagement between the caregivers and PWD.

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ID: 760

Abstract Topic: Education and training in hospitals – NEW

Keywords: dementia, hospital, environment, education

Do hospitals harm or heal? A lived experience review of hospital environments and how they may impact a person living with dementia

Lyntara Quirke, Kim-Huong Nguyen

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Abstract:

Despite significant improvements in acute care, people with dementia still face challenges in receiving appropriate care in this setting. In Australia, one in four people with dementia require hospital services annually. In hospital, dementia may go unrecorded, contributing to the needs of the person with dementia not being adequately met. It is well known that hospital environments are often unfriendly for people with dementia, who are more prone to adverse outcomes, such as delirium, falls and mental distress caused by unfamiliar environments. This can lead to extended stays and increased frailty which may result in an increased risk of discharge to long-term care, as opposed to returning home or to live independently in the community. It is essential to raise awareness on the vulnerability of people with dementia in acute care environments and the provision of education programs to improve their outcomes and experiences.

We present a discussion drawn from the literature and lived experience. First, we provide a summary of evidence on the outcomes for people with dementia in acute care from a rapid literature review. We show how inappropriate hospital environments may trigger a cascade of complications for people with dementia during their hospital stay.

Second, we present a lived consumer experience of a carer who has cared for two family members with dementia, highlighting the challenges in navigating the environment for people with dementia. With backgrounds in nursing education and hospital management, our consumer representative was drawn to learn more about dementia when her father was diagnosed with Alzheimer's disease. As his primary caregivers, she and her husband recorded his wayfinding difficulties in new environments. From this experience, she sought to understand how environments impact people with dementia and used it to support the application of the "principles for dementia design" in multiple research projects across Australia. She became an advocate and environmental consultant with Dementia Training Australia and contributed as a consumer representative to many projects, including the "Dementia Enabling Environment Project". In 2018, her husband developed a rapid and rare form of dementia and experienced acute delirium episodes, primarily exacerbated by the hospital environment. The design principles became even more relevant to them and this lived experience account will demonstrate the need to improve acute care environments for people with dementia.

In conclusion, creating appropriate physical hospital environments for people with dementia is essential to high-quality care. It requires ongoing education and training for clinical and care staff in hospital, including architects and designers. With this knowledge, people with dementia would have improved outcomes and reduced acute care stays, leading to a more efficient use of healthcare resources.

Poster Presentation Abstracts

ID: 763

Abstract Topic: Non-pharmacological interventions

Keywords: massage therapy, behavioural and psychological symptoms, dementia, mild cognitive impairment, caregivers

Massage and technology: a potential synergy for behavioural and psychological symptoms of cognitive impairment

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Abstract:

Introduction: Dementia and Mild Cognitive Impairment (MCI) are common ailments facing the fast-growing elderly population in Singapore. Behavioural and Psychological Symptoms (BPS) affects up to 80% of persons with dementia (Lyketsos, et. al., 2002; Vaingankar, et. al., 2017) and 35 to 85% of individuals with MCI (Lyketsos, et. al., 2002; Gallagher, Fischer & Iaboni, 2017). BPS includes anxiety, agitation and aggressive behaviours and at times, may cause more distress than the cognitive impairment itself. Additionally, it is a source of stress for their caregivers (Tan, Wong & Allen, 2005). Thus, BPS constitutes a significant proportion of the burden of the disease and it is important to develop more evidence-based therapy options. Non-pharmacological therapies are usually the preferred first line treatment (Tible, Riese, Savaskan & Gunten, 2017). One such therapy is massage therapy although current evidence are insufficient. It is found to be particularly useful in helping to curb aggressive behaviours but evidence is less consistent for anxiety and mood symptoms (Wu, Wang & Wang, 2017).

Methods: In our study, we aim to investigate the feasibility and utility of a massage jacket on persons with dementia or MCI. 44 Singaporean elderly over 65 years old with either condition and exhibits BPS will be recruited for this pilot randomized controlled trial with their caregiver. They will be from SengKang General Hospital, National University Hospital and the CHI study by NUS Mind-Science Centre. Baseline data of MMSE, CDR, NPI-Q, ZBI and Eq-VAS will be collected. In the control group, caregivers will deal with the behavioural distress of the participants as they usually would. The intervention group will be given the massage jacket for 6 weeks. Following which, post-intervention assessments of NPI-Q, ZBI and Eq-VAS will be administered within 2 weeks.

Potential results/Conclusion: We hypothesize that participants in the massage jacket group will do better in domains of BPS and caregiver stress. This could prove beneficial to both the participant and their caregiver by reducing their distress associated with cognitive impairments with a simple home-based treatment. As noted by Tible and colleagues (2017), BPS cannot be fully treated but merely managed well. The provision of an option for self-management will be more feasible and sustainable for the long term. With dementia being a rising problem, we hope that the massage jacket will be an additional treatment modality in the currently limited armamentarium to reduce the cost of the illness, burden of care and well-being of persons with dementia or mild cognitive impairment and their caregivers.

Poster Presentation Abstracts

ID: 766

Abstract Topic: Dementia and labour laws – NEW

Keywords: employment support, job accommodation, dementia

Employment support in people with dementia: a cases analysis in Taiwan

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Abstract:

The impact of dementia on employment is increasingly an important topic in people with dementia (PWD). Continuing work is an effective method of maintaining self-esteem and alleviating functional decline among PWD, both of which may help improve their quality of life. There are many different types of dementia, including Alzheimer's disease, vascular dementia and fronto-temporal dementia. Symptoms include memory impairment, reduced ability to learn new material, sensory impairments, speech and communication problems, and personality changes may affect the work efficiency and quality. However, there is a dearth of research focusing on the experiences and the process of PWD employment support services. It is thought that some accommodation strategies or assistant technology such as using memory aids, providing written information and quiet work areas could be useful; nevertheless, this would be dependent on the type of job the PWD does, and the different types and severities of dementia.

To date, there has been relatively little research about how to manage and support PWD through the vocational assessment, job accommodation, sheltered employment, and supported employment. The workforce development policy in Taiwan had developed a service system in vocational rehabilitation for people with disabilities, but how to utilize in PWD and integrate with senior employment program needs further exploration. In addition, the connection of employment support and dementia care is the resolution of this cases analysis.

The aim of this study was to explore the multiple strategies of employment support in PWD, and analyze the experiences of PWD, caregivers, colleagues and managers.

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ID: 768

Abstract Topic: Dementia and NCDs, SDGs, UHC and ageing – NEW

Keywords: Coronary Artery Disease, Cognitive Dysfunction, Aged, Metabolic Risk factors

Association of history of coronary artery disease with cognitive impairment: data from birjand longitudinal aging study (BLAS)

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Abstract:

Introduction

Cognitive impairment and coronary artery diseases are common diseases in older adults that both impose a significant burden on health systems. Association between cognitive impairment and history of CAD was not clearly defined. This large study, with a representative sample of older adults, revealed this association.

Methods

The Birjand Longitudinal Aging Study is an ongoing community-dwelling study on aged population ≥ 60 years old residents in both urban and rural areas of Birjand County in Iran. The primary outcomes of this study are cognitive impairment, cardiovascular disease, and geriatric syndromes. Using a multistage stratified cluster sampling based on geographic blocks in the urban population and a simple random sampling in the rural community the participants were selected. Cognitive impairment was assessed by Abbreviated Mental Test Score (AMTS) and Mini-Mental State Examination (MMSE). Cognitive impairment defined if impairment in cognitive function detected by each tools (MMSE < 24 or AMTS < 8). History of acute Myocardial Infarction (MI), Coronary Artery Bypass Graft (CABG), or Percutaneous Coronary Intervention (PCI) defined as Coronary Artery Disease (CAD). Demographic data and of smoking status (current smoker and ex-smoker) and past medical history were gathered by interviewing with the participants and one of their informants. Systolic and diastolic blood pressure were measured according to standard protocol. Hypertension was defined based on mean systolic blood pressure ≥ 140 mmHg or mean diastolic blood pressure ≥ 90 mmHg or history of hypertension. Twelve-hour overnight fasting blood sample were taken and fasting blood glucose (FBS) were measured by an auto-analyzer. Subjects with history of diabetes or FBS ≥ 126 mg/dl considered as had diabetes. Univariate and multivariable logistic regression models were used to reveal the association.

Results

Finally, data of 1613 older adults were analyzed by a cross-sectional approach. Mean age of the participants was 70.89 ± 7.55 . Of total, 838 (51.95%) were female. Cognitive impairment were detected in 925 (57.35%) of the participants. History of CAD reported in 287 (17.79%) subjects. In multivariable

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logistic regression model after adjustment for age, sex, education, smoking, history of cerebrovascular accident (CVA), diabetes, hyperlipidemia, and hypertension, the history of CAD associated with cognitive status (Odds Ratio = 1.42; 95% confidence interval = 1.00 – 2.02). Moreover, there was a positive association between cognitive impairment and age, female gender, and Cerebrovascular Accident (CVA).

Conclusion

Cognitive impairment was more prevalent in subjects with CAD (\geq than 40%). This association was independent of the history of having metabolic risk factors and CVA. History of CAD seems to be a marker for clinically significant atherosclerosis which also affects the microvascular that supplied the brain.

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ID: 769

Abstract Topic: Environment and architecture for dementia

Keywords: Alzheimer disease, dementia, nursing home, recommendations for planning

Recommendations for optimizing and planning homes for people with dementia in Croatia

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Abstract:

About 4.1 million people live in Croatia, and 26% are over 60 years old. According to ADI and WHO estimations, there are 100,000 persons with dementia (PWD) in Croatia. The capacities of nursing homes in Croatia are modest with under 18,000 beds in total. Only 2% of the Croatian population over the age of 65 live in nursery homes, and more than 70,000 people are waiting for the accommodation that will follow in 10-15 years. Only a few nursing homes have wards for people with dementia.

Current standards for nursing homes in Croatia mainly determine only the minimum of spatial and technical conditions and the number of carers. Fortunately, the new wards for people with dementia significantly exceed these standards, but still do not follow all the possibilities that modern architecture can provide. In many old homes, such as the Domus Christi Nursing Home in Dubrovnik, which has been in operation since 1347, modern adaptations are not even possible. That is why Alzheimer Croatia and partners, during the implementation of the European Cross-Border Project to Improve the Quality of Life of People with Dementia Interreg VA - Slovenia-Croatia, "Dementia aCROsSLO", made our first modern "Recommendations for the optimization and planning of nursery homes for people with dementia".

Based on today's scientific knowledge, the 170-page A4 format handbook provides an overview of regulations, reports, and studies on the architectural design of homes, outlines the environmental principles of people with dementia and practical planning tips, and shows specific types of construction and open spaces suitable for people with dementia. Among the design principles, these recommendations emphasize the need to facilitate decision-making by people with dementia by reducing unnecessary stimulation and clearer communication, creating a home-like atmosphere and delimiting private and social spaces, reducing anxiety and fear (e.g. by facilitating orientation and determining the direction of movement), the need to foster independence and social interaction as well as security by building and designing a protected and secure environment.

The professional chambers of architects, social workers and others have found this Handbook extremely useful, especially simple written recommendations that point to the many improvements in homes that can be made with minimal investment, as well as expert advice from architects who should be respected when building new or renovating existing nursing homes. The manual was also presented to the relevant ministries in Croatia and Slovenia, who evaluated it as a very good basis for developing new standards.

In addition, the growing number of Dementia Friendly Communities - cities in Croatia has accepted the Alzheimer Croatia initiative to make these Recommendations one of the key foundations for the development of nursing homes that are becoming Dementia Friendly Institutions.

Poster Presentation Abstracts

ID: 770

Abstract Topic: Informal carers support – pre, during and post

Keywords: support group, dementia, informal caregivers, participatory action research

Empowering informal caregivers of people with dementia through the support groups: A participatory action research

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Abstract:

Introduction. The increase in the number of people with dementia (PwD) challenges the role of informal caregivers who support them. Over the past years, the topic of dementia has been on the agenda more than ever before and has started to reduce the informal caregivers' burden. Caregivers' increased care burden was triggered by their insufficient information, lack of awareness and support.

Study design. In Estonia, there has not been any support groups for informal caregivers of PwD. To support and empower the informal caregivers, the participatory action research (PAR) was implemented between October 2016 and May 2019 in 3 cycles. The members of the non-profit organization "Living with Dementia" defined the problems in the community, created plans and solutions. This study aimed to explore the issues arising from launching support groups for informal caregivers of PwD and facilitators. The study used mixed methods.

Results. The PAR lasted 30 months and at the end of the study, 17 support groups were launched in different regions in Estonia during the 3 cycles. The best format of the support group was a tailored support group according to the needs of caregivers which included fragments of education, information, and peer-support aspects to empower informal caregivers.

Poster Presentation Abstracts

ID: 771

Abstract Topic: Dementia and human rights – NEW

Keywords: Dementia, missing, safety, independence, freedom

Staying safe 'going out'- the experience of people with dementia

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Abstract:

Going outdoors is an important part of living well with dementia but people with dementia are at a high risk of going missing. High complex cases have a high mortality rate, place a high burden on police and result in immense stress for all involved. Often the concern about going missing leads to taking preventative measures, which can negatively affect quality of life. This research aims find out more about the experience of 'going out' for people with dementia and their families and to explore how it affects their sense of identity, control and independence. Focus groups and walking interviews with people with dementia and their carers investigate how they engage with 'going out' and prevent being missing. One aim of this research is to inform police search strategies when people with dementia are reported missing. A wider aim is to understand the experience so we can support people with dementia to safely live independently in their communities.

Poster Presentation Abstracts

ID: 772

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: Mobile Health, mHealth, People with Dementia, Family Caregivers

The use of mHealth for people with dementia and caregivers: an integrative literature review

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Abstract:

Background and objectives of the study: Dementia has become one of the most significant public health priorities in the world, and it is estimated that someone in the world develops dementia every 3 seconds. Dementia affects not only the people who have it but also their family caregivers, and which can significantly affect to physical and emotional burdens. Mobile health (mHealth) has been used in combination with a traditional approach in several health conditions, such as people with chronic illnesses and mental health problems. However, little is known about the use of mHealth in persons with dementia and their family caregivers in Thailand. This article aims to identify and synthesize whether the use of mHealth technology, such as smartphone applications, mobile phones, tablets, and innovative technologies.

Methods: An integrative literature review approach using the framework of Whittemore and Knaf (2005) was guided. The authors performed an integrative review of seven databases were searched to capsule what research has done on the use of mHealth in people with dementia and their family caregivers.

Results: 10 studies were met the inclusion criteria. Three categories emerged from the literature, including the type of mHealth devices, the effectiveness, and the limitations related to the use of mHealth for people with dementia and their family caregivers. Most studies examined the use of mHealth technologies from various devices, such as an iPad app, smartphones, and tablets (both Android and Apple). These devices were suitable and easy to use for people with dementia and their caregivers, particularly, touchscreen-based programs. One study reported that mobile devices could help the caregivers to receive significant information of dementia in decision making for diagnosis, treatment, and complementary and alternative medicine. Fortunately, mHealth could reduce caregiver burden and improve an ability to cope with challenging situations. It was also used to monitor the movements and activities of people with dementia. On the other hand, mHealth still has limitations for the users, including a lack of information and support from the health care services about how to access devices. People with dementia did not feel comfortable to use, particularly people with visual and sensory perception impairments.

Conclusions: The use of mHealth technologies seems to be a feasible intervention for people with dementia and their family caregivers for improving well-being and the quality of life and reducing physically and emotionally family caregivers' burdens. Nevertheless, mHealth still has limitations for users who have cognitive function impairments.

Poster Presentation Abstracts

ID: 777

Abstract Topic: Non-pharmacological interventions

Keywords: cognitive training, computerized training, cognitive impairment, heart failure

Can computerized cognitive training improve cognition in patients with heart failure?

Zhong Jie Kua¹, Michael Valenzuela², YanHong Dong³

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Abstract:

Background and Objectives: Cognitive impairment is highly prevalent in patients with heart failure (HF), negatively impacting self-care and consequently increasing mortality. Although computerized cognitive training (CCT) has been found to be efficacious in improving cognition in older adults, little is known about the efficacy of CCT in patients with HF. This brief systematic review examined the feasibility and efficacy of CCT on cognitive functioning in patients with HF.

Methods: PubMed, Embase, and PsychINFO electronic databases were searched to identify randomized controlled trials (RCTs) of CCT in patients with HF published from January 1, 2000, to December 31, 2017. A narrative synthesis of intervention effectiveness on individual cognitive domains and functional outcomes was provided. Risk of bias of the studies was also rated.

Results: The search yielded 4 RCTs describing 3 cognitive training interventions (n = 138). Preliminary evidence indicated that CCT may enhance the processing speed and working memory of patients with HF. Intervention effects also seemed to confer transferrable benefits to functional outcomes of daily living. The outcomes of the assembled studies were assessed using the Grades of Recommendation, Assessment, Development and Evaluation system, and the quality of the evidence was found to be of moderate to low quality.

Conclusions: Computerized cognitive trainings show promise in enhancing the cognition of patients with HF. The stability of the current findings would need to be tested in RCTs with larger sample sizes to validate the use of CCTs in targeting cognitive impairment and self-care abilities for patients with HF.

Poster Presentation Abstracts

ID: 778

Abstract Topic: Diagnostic tools

Keywords: Brief cognitive tests, Screening tools, Cognitive impairment, Type 2 diabetes mellitus

The utility of brief cognitive tests for patients with type 2 diabetes mellitus: a systematic review

YanHong Dong¹, Zhong Jie Kua², Eric Y.H. Khoo³, Edward H.M. Koo⁴, Reshma A. Merchant⁵

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Abstract:

Background and Objective: Type 2 Diabetes Mellitus (T2DM) is associated with an increased risk for mild cognitive impairment and dementia in both middle-aged and older individuals. Brief cognitive tests can potentially serve as a reliable and cost effective approach to detect for cognitive decrements in clinical practice. This systematic review examined the utility of brief cognitive tests in studies with patients with T2DM.

Method: This systematic review was conducted according to guidelines of the Preferred Reporting Items for Systematic Reviews and Meta-Analyses. "PubMed," "PsychINFO," "ScienceDirect," and "ProQuest" electronic databases were searched to identify articles published from January 1, 2005 to December 31, 2015.

Results: The search yielded 22 studies, with only 8 using brief tests as a cognitive screening tool, whereas the majority using these tests as a measure of global cognitive functions. In regard to cognitive screening studies, most had failed to fulfil the standard reporting of diagnostic test accuracy criteria such as Standards for Reporting of Diagnostic Accuracy for dementia and cognitive impairment. Moreover, few studies reported discriminant indices such as sensitivity, specificity, and positive and negative predictive values of brief cognitive tests in detecting cognitive impairment in patients with T2DM. Among studies which used brief cognitive tests as a measure of global cognitive function, patients with diabetes tended to perform worse than patients without diabetes. Processing speed appeared to be particularly impaired among patients with diabetes, therefore, measures of processing speed such as the Digit Symbol Substitution may add value to brief cognitive tests such as the Montreal Cognitive Assessment.

Conclusions: The Montreal Cognitive Assessment supplemented by the Digit Symbol Substitution Test indicate initial promise in screening for cognitive impairment in T2DM.

Poster Presentation Abstracts

ID: 779

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: cognition, intervention implementation, barriers, facilitators, LMIC

A thematic analysis of the barriers to and facilitators of the implementation of cognitive stimulation therapy (CST) in Delhi

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¹Atal Bihari Vajpayee Institute of Medical Sciences and Dr Ram Manohar Lohia Hospital, New Delhi, India; ²University College London, London, UK

Abstract:

Introduction:

This work forms part of the CST-International research programme.

Cognitive Stimulation Therapy (CST) is an evidence based non-pharmacological intervention for Persons with Dementia (PwD). A culturally validated model of CST can address the treatment gap for dementia on account of paucity of trained mental health professionals in low and middle-income countries (LMICs) including India. Exploration of the barriers to and facilitators of CST implementation is the key to successful implementation of CST as a low cost, community owned and sustainable intervention for PwD in LMICs like India.

Methods:

Using novel methodology developed from the Consolidated Framework for Implementation Research (CFIR) for the CST-International project, open ended questions for diverse stakeholders were prepared to capture the postulated challenges and supports for implementation of CST at community level. The potential stakeholders were divided into three groups. The first group comprised of policy makers including decision makers in various programs related to PwD in Ministry of Health and Family Welfare, Non-Governmental and charitable organisations associated with dementia care. The second group of stakeholders comprised of potential CST facilitators including Psychiatry residents, Clinical Psychology trainees and nurses while the third group of stakeholders were potential recipients of CST/ interested parties e.g. PwD, carers, community leaders and members of the general public.

Stakeholder responses were sought on the different aspects of CST implementation like intervention characteristics (complexity, adaptability, evidence strength and quality, design quality and packaging), characteristics of individuals (knowledge and belief about intervention), inner settings (structural characteristics, implementation climate, networks and communication) and outer setting (peer pressure, patient needs and resources, external policies and incentives) and a thematic analysis was conducted on audio recorded transcripts.

Results:

Stakeholders opined that availability of local infrastructure and healthcare workers can facilitate culturally adapted CST implementation at community level in and around Delhi. However, insufficient evidence base of CST efficacy in Indian context and lack of a network of trained and certified CST providers ensuring fidelity of the intervention over time and across sites, could act as barriers for scaling up of CST in multiple sites by multiple agencies. Detailed results of the thematic analysis will be presented at the conference.

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Conclusion:

CST implementation in and around Delhi lacks any major site or community specific barriers. However, upscaling of CST may be hindered by paucity of evidence base of CST efficacy in Indian context and lack of network of trained and certified CST providers.

Poster Presentation Abstracts

ID: 781

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: Self-advocacy, inclusion, capacity-building, global partnership

The many voices of dementia advocacy

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¹Dementia Alliance International; ²Alzheimer's Society

Abstract:

Dementia Alliance International (DAI), 3 Nations Dementia Working Group (3NDWG) and Alzheimer's Society UK worked as partners to deliver a small capacity building project for self-advocacy and inclusion on dementia.

The project aimed to identify the barriers as well as tools to support inclusion of people impacted by dementia in campaign activity and self-advocacy. The project partners consulted with dementia working groups in various countries and with individuals, identifying that barriers to self-advocacy can include: confidence, accessibility, discriminatory language, stigma and lack of engagement from others.

This session will present the project, including:

1. Analysis of the barriers and solutions to increasing self-advocacy on dementia, including the work of dementia working groups worldwide.
1. A Directory which collates relevant existing resources that support inclusive working, including tools to support self-advocacy and to help organisations work more inclusively.
2. A short film of and by people living with dementia aimed at supporting and encouraging self-advocacy by sharing their experiences, motivation and tips on speaking out.

Participants of the film said:

"The driving force for me becoming a self-advocate on dementia is there is so much I want to do and share and just like my physical health I want to do as much as I can while I can because the day will come when I can't." Kris, USA.

"The first few times that you speak out publicly you're terrified of not remembering what you want to say but then you find out every speaker is the same and that even people without dementia are like that." Kate, Australia.

"To someone who is thinking should I advocate or shouldn't I - try and see!" Agnes, Scotland.

The project and resources have been positively received. There has already been interest to translate the film into different languages and participants have reflected positively on the process and resources on different platforms:

"It is good that we share information with each other around the globe. The same problems such as stigma, affect our lives in many ways. When speaking at meetings, in the media and at various events, we can change the perceptions of living with dementia." Petri, Finland on the Alzheimer Europe newsletter.

"I'm very pleased to have been involved in the development of these resources and very happy to see the advocacy knowledge and activity happening around the world being pulled together." Hilary on 3NDWG blog

Poster Presentation Abstracts

ID: 783

Abstract Topic: Innovation, entrepreneurship and technology

Keywords: digital, technology, innovation, solutions

The role of digital technology in enhancing the lives of people with dementia

Charlotte Swarbrick, Barbara Sharp, Joyce Gray, Gillian Fyfe, Nicola Cooper

Alzheimer Scotland, United Kingdom

Abstract:

Digital technology solutions have the capacity to transform the experience of living with dementia and help people to take control of aspects of their lives despite the many changes and challenges dementia brings. Working closely with people with dementia, families and carers, the Alzheimer Scotland digital team are breaking down many myths and misconceptions about people with dementia and their use of technology. Technological support solutions are founded on a rights-based technical charter in Scotland to ensure people with dementia experience fair and equal opportunity to benefit from this rapidly moving area of innovation.

Engaging people with dementia and their families directly in the processes of development helps to ensure that technical solutions are informed by lived experience and tested in real world situations. In face of the ever-increasing range of products and options, it is not only essential that the active voice of people with dementia and families influence these developments but that an informed and person-centred focused workforce is there to support their use. There are no 'one size fits all' type solutions and the Alzheimer Scotland team are leading the way in bringing together the skills required to work effectively with individuals whose lives are affected by dementia and in exploring digital support options with them.

The work of the Alzheimer Scotland team and an insight into the digital offering in dementia care will be explored through the personal stories and experiences of people with dementia and families who have embraced the potential benefit to their lives of this area of innovation. A range of good outcomes for people with dementia and their families will be presented, alongside messages of caution in terms of appropriateness and risk. The role of partnership working will be explained and how this has realised greater progress than might otherwise have been possible.

Technological solutions in the support of people with dementia need not be complex or expensive but they must be a 'good fit' for the person and situation. Get these aspects right and they offer a whole new world of possibilities for people living with dementia in activity, safety and self-management.

Poster Presentation Abstracts

ID: 787

Abstract Topic: Attitudes, awareness and stigma

Keywords: stigma, healthcare practitioners, dementia awareness

Perspectives and experiences of healthcare practitioners in Indonesia

Tara Puspitarini Sani^{1,2}, Imelda Theresia², Aditya Putra¹, Yuda Turana^{1,2}, Nicolas Farina³, Sara Evans-Lacko⁴

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Abstract:

Background:

Dementia is a growing public health challenge in low-and-middle income countries (LMICs). To best address this challenge it is important to understand a range of perspectives –including those who use and those who deliver services. Non-specialist health workers are the first line of an integrated care. This study aims to explore the experience of healthcare practitioners in diagnosing and caring for people with dementia in Indonesia.

Methods:

Data are collected via two focus groups as part of the stigma work package of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project. Participants included: neurologists, general practitioners, clinical psychologists and nurses working in primary care and specialty care and both private and public institutions

Results:

At the hospital level, cognitive screening, lab, and imaging examinations were performed to patients with chief complaint of cognitive problems and those treated for other conditions but showing signs of dementia. It was described that dementia is not commonly discussed in the clinical psychology practice; however, dementia awareness has started to rise and push further discussion among Indonesian psychologists.

Nurses reported that approximately 75% of the private nursing home clients have dementia, and in many cases, this is revealed only after a screening before moving into nursing home. It was identified that private care homes' staff have better access to information, as they receive various training related to geriatrics and dementia and have started implementing cognitive-stimulation therapy principles in the nursing home activities. In the government-owned nursing home, the only source of information about dementia is through Alzheimer Indonesia. Government nursing home staff reported difficulties in differentiating dementia from other psychiatric problems.

Conclusion:

Healthcare practitioners varied in their awareness of dementia. Some healthcare facilities reported the availability of skilled staffs to provide service for those with dementia. Key areas for improvement were; 1) better access to information about dementia from all stakeholders involved, 2) availability of care skills training for health and social workers, and 3) increase of research initiatives on dementia and ageing in Indonesia.

Poster Presentation Abstracts

ID: 791

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Program development, model programs, cultural competency, residential care, staff and family training

Creating a center of excellence in a residential memory care setting

Darrick Lam¹, Kyle Fredrickson¹, Scott Okamoto¹, David Troxel²

¹ACC Senior Services, United States of America; ²Best Friends Approach, Sacramento CA

Abstract:

Established in 1972, ACC Senior Services (formerly known as the Asian Community Center of Sacramento Valley, Inc.) is a private non-profit organization located in Sacramento, California whose mission is to promote the general welfare and enhance the quality of life for our community by identifying, developing, and providing culturally sensitive health and social services for older adults. Our programs include a (US Government rated) five-star rated skilled nursing facility, an assisted living community, a senior apartment complex and a senior center. ACC also offers other programs to enrich the lives of seniors and caregivers, including transportation, caregiver support services, senior employment and training, as well as congregate nutrition and home-delivered meals.

In 2019, ACC Senior Services is opening its first dementia specific residential program called Maple Tree Village (MTV) which will serve 30 residents living with Alzheimer's disease and other dementia at the assisted living level of care (generally early to middle "stage" dementia).

This workshop will share the organizational game plan to create an innovative, life-affirming program for the 30 residents living with dementia that will be rich in art, music, conversation, life story work and creative care management. Keeping with our history of serving the active and diverse Asian community living in Sacramento, programs will also offer activities that support a cultural connection such as movement classes, Tai Chi, and diverse spiritual activities and activities relating to our resident's individual histories that include favorite music and food.

Seeking a larger impact, ACC will also discuss its vision and implementation of a local Dementia Center of Excellence that will not only enhance care among the residents of MTV but also offer a broad range of services for the thousands of Sacramento area families living with dementia and/or serving as active care partners. The Center of Excellence will include support groups, a dementia café for persons with dementia, care management, workshops and conferences and a teaching/learning program where family and professional care partners will be able to learn and practice skills within residential care settings using an innovative model that we believe will replicate a "teaching hospital" model.

Participants will leave with a step by step outline and idea sheet to help them replicate the program in their own care or service setting and the presentation will include early results of program activity and evaluation.

Poster Presentation Abstracts

ID: 795

Abstract Topic: Dementia friendliness

Keywords: awareness raising, social inclusion, informal education, caregivers support, dementia friendly community

»Dementia friendly spots« a national awareness raising campaign and support network in local communities

Štefanija Lukič Zlobec, David Krivec, Maša Bastarda

Spominčica - Alzheimer Slovenija, Slovenia

Abstract:

Introduction

In 2016 Spominčica developed the idea of "Dementia Friendly Spots" (DFS), a national awareness raising programme involving services providing organizations. Rising awareness about dementia is still one of the priorities in all countries and it is one of the major contributing factors for shifting the paradigm towards timely diagnosis and dementia friendly society.

Methods

The first DFS was opened in July 2017 at the Human Rights Ombudsman office after the training of employees. The opening was covered by national media, TV, radio and newspapers. Member of EWGPD presented his life with dementia after the diagnosis and stressed the importance of building dementia inclusive society. DFS stands for help, information and support for different target groups related to dementia: persons with dementia and their caregivers, public workers, volunteers and other residents. Since there has been a growing interest in DFS from organizations all around the country. The programme is supported by the Ministry of social affairs and Ministry of Health. The education programmes for organizations cover the topics about dementia and first signs, communication with persons with dementia, the importance of timely diagnosis, post-diagnostic support and rights of persons with dementia. Then, an official opening with culture programme is organized, where all important stakeholders from the local community are present and is covered by media.

Positive impact

The organization is presented with a DFS sticker, a certificate and put on web map. Activities are evaluated, and trainings are periodically renewed. Spominčica already opened more than 150 DFS in nursing homes, community health centres, centres for social work, Red Cross, libraries, police and fire stations, hospitals, pharmacies, shops, hairdressers, Ministry for Labour, Faculty for Social Work, National Institute for Public Health, Traffic Safety Agency, etc. With DFS we aim to raise public awareness about dementia and reduce stigma, improve accessibility to information about dementia. Organizations in the network can provide user friendly and more accessible use for persons with dementia in local facilities and services (banks, posts, pharmacies, libraries, public transport) with trainings for organizations staff in recognition of first signs, use of dementia friendly language, proactive and assertive communication with persons with dementia, decent approach to them. Above all, we improve social inclusion of persons with dementia, support their autonomy as an active member/citizen in society.

Perspectives

DFS are an innovative way of implementing a Dementia Management Strategy, adopted by the Ministry of Health in May 2016. DFS main goal is to provide information about dementia and support to PwD and their families in local communities. With DFS Spominčica is building support networks in all local communities in the country.

Poster Presentation Abstracts

ID: 797

Abstract Topic: Other syndromes and dementia – NEW

Keywords: Progressive Supranuclear Palsy (PSP), Psychosis, dementia

A case of progressive supranuclear palsy with an initial acute psychiatric presentation.

TOLULOLA TAIWO

Red Deer Regional Health Centre/Alberta Health Services, Canada

Abstract:

INTRODUCTION: Progressive Supranuclear Palsy (PSP) is a neurocognitive and neurodegenerative disorder. The predominant features of PSP are atypical Parkinsonism, vertical (supranuclear) nerve palsy and dysexecutive syndrome.

METHODS:

We report on the case of a 67 year old right-handed male pilot without any prior psychiatric history who presented to his community hospital with reports of bizarre behaviors. He was verbally and physically aggressive, making demands to be evaluated by the medical staff. He incorrectly believed that he was scheduled to have some laboratory investigations. The patient was formally certified and transferred to a Psychiatric Hospital for further evaluation.

The patient was referred to our program (Specialized Geriatric Services) for an evaluation of his Parkinsonism features which were initially discovered during his admission to the Psychiatric Hospital.

DISCUSSION: The patient's cognitive evaluation revealed impaired delayed recall, partial environmental orientation and normal scores on the 3 step command (executive function) on the Mini Mental Status Examination (MMSE). The Montreal Cognitive Assessment (MoCA) version 7.1 revealed visuospatial deficits. He had language impairments with poor verbal fluency (F,A,S words) and poor semantic/categorical fluency, anomia, hypophonia and poor articulation. He had poor conceptualization and unable to correctly interpret proverbs. He provided concrete responses for object similarities.

The patient had subjective reports of depression. He endorsed positive responses on the Geriatric Depression Scale (GDS) and Geriatric Anxiety Inventory (GAI). There were subjective reports of impulsive behaviors and compulsive actions.

Neurological evaluation revealed slow vertical and horizontal saccades, hypomimia and hypophonia. No vertical gaze palsy was elicited. Frontal release signs (Hoffman's palmomental and snout reflexes) were positive. Babinski response was elicited bilaterally. Fine resting, postural and action tremors were present in both hands. He had cogwheeling rigidity in both upper limbs which was brought on by using distraction techniques.

A provisional diagnosis of Progressive Supranuclear Palsy (PSP) was made.

T2 weighted MRI brain scan revealed midbrain atrophy with preservation of the pons.

18F-Fluorodeoxyglucose (FDG)-PET scan revealed extensive hypometabolism in both frontal lobes including the mesial frontal lobes and anterior cingulate gyrus. Metabolism in the posterior cingulate gyrus was normal.

The patient's Risperidone was discontinued and substituted with Quetiapine (to reduce the likelihood for extrapyramidal symptoms).

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CONCLUSION:

This case reflects the variability in presentation of PSP. The initial presentation of PSP with neuropsychiatric symptoms of delusions, agitation, irritability, verbal and physical aggression highlights the variable initial presentation of this neurocognitive disorder.

Poster Presentation Abstracts

ID: 803

Abstract Topic: Education and training in hospitals – NEW

Keywords: Dementia Delirium Course, Healthcare professionals, Multidisciplinary

Intensive practical course in dementia and delirium care – an Asian hospital's experience

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¹Institute of Geriatrics and Active Ageing, Tan Tock Seng Hospital, Singapore; ²Department of Nursing Service, Tan Tock Seng Hospital, Singapore; ³Department of Geriatric Medicine, Tan Tock Seng Hospital, Singapore

Abstract:

Background:

The Institute of Geriatrics and Active Ageing (IGA) was officially established in 2013, to be at the forefront of Tan Tock Seng Hospital's expansion of geriatrics research and education initiatives. IGA has organised a 3-week Intensive Practical Course in Dementia and Delirium Care since 2014, involving a multidisciplinary team of speakers and facilitators, to equip healthcare professionals with essential skills and knowledge to deliver good dementia care. We aim to describe the evaluations of the course and results of surveys conducted over 6 years.

Methods:

From 2014 – 2019, a total of seven runs was conducted with 199 healthcare professionals from various healthcare settings attending the 20-hour intensive course. The curriculum was designed to include a blend of didactics, interactive discussions, role plays and case studies, complemented with evidence-based practice. The variety of topics comprised diagnosis, assessment and management of dementia and delirium; person-centred care and effective communications; managing challenging behaviors; engagement therapy; safe living and rehabilitation for person with dementia; dementia-friendly environment in various care settings; community resources for older person with dementia and advance care planning. Pre- and post-course MCQ quizzes were administered to assess knowledge in dementia and delirium care, in addition to a course evaluation on the contents and delivery. We performed a descriptive analysis of the data.

Results:

The participant profile comprised 111 (55.78%) nurses, 55 (27.64%) doctors, 27 (13.57%) allied health professionals and 6 (3.02%) others. Their care settings included 87 (43.72%) from acute hospital, 35 (17.59%) community hospital, 34 (17.09%) nursing home, 25 (12.56%) primary care, 6 (3.02%) home care service, 6 (3.02%) hospice, 4 (2.01%) day care/family service centre and 2 (1.01%) others.

Of the post-course responses by 187 participants, 184 (98.40%) expressed higher level of confidence in managing dementia/delirious patients, with 186 (99.47%) likely to recommend the course to others. 190 participants completed both the pre- and post-course MCQ quizzes, with 140 (73.68%) reported an improvement in their dementia and delirium care knowledge.

Overall, participants provided positive qualitative comments on the holistic coverage of the course, and appreciated the multidisciplinary approach. They enjoyed the good blend of didactic and practical sessions, in particular the cementing of theories through applications such as interactive case discussions, reflection and sharing, and role plays.

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Conclusion:

As a course provider, the findings are encouraging and serves as a strengthener for us to continuously enhance course contents and practicality. There is an impetus for our course contents to be updated with trends in dementia/delirium care and aligned with local context, in order for healthcare professionals to provide better care to this population of older adults.

Poster Presentation Abstracts

ID: 805

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: employment, work, partnership, community, occupation

Making it work: partnership models for therapy through work (TTW) for people with young onset & early stage (yes) dementia

Dian Karnina, Sion Teng, Mee Choo Soh

Apex Harmony Lodge, Singapore

Abstract:

According to Kitwood (1997), occupation is one of the six aspects critical in delivering person-centered dementia care. By meeting one's need for occupation, meaningful engagement could be created through stimulating tasks and social interaction.

Globally, efforts in providing work-based interventions for dementia clients are still limited, although pilot research in Australia, USA, and the UK have seen positive impacts on the PwDs' wellbeing. In Singapore, Apex Harmony Lodge (AHL) started its Therapy through Work (TTW) program for its long-term care facility residents in 2013 and identified higher average wellbeing scores of residents who participated in outside work activities than those who did not (Soh, Goh, Koh, & Fusek, 2017). Responding to the greater need for early dementia care in Singapore, AHL then expanded the TTW program to reach out to clients with young onset and early-stage (YES) dementia based in the community. This program would not have been possible without the involvement of various stakeholders and partners that not only created the opportunities, but also facilitate the employment process.

Since 2018, AHL was tasked to pilot the TTW program -first of its kind in Singapore- and recruit 100 YES PwD into employment in three years. While employment-based rehabilitative programs are common for people with special needs and disability, such programs were largely unheard of in the dementia field. Hence, the process of winning the support of employer partners, as well as making the work partnership mutually beneficial was uncharted territory.

The outreach to potential partners, collaboration initiation, onboarding, as well as the expansion were done through a mix of the existing community and social employment platforms. Community support coming from volunteers as well as caregivers has also been invaluable.

AHL started TTW with one employer partner in July 2018 and managed to garner the support of six employers by July 2019 in the area of laundry, food preparation, as well as hydroponic farming. Employment models have been diversified to meet the different needs of clients and employers.

These preliminary learning points outline how a community-based intervention program is best supported by tapping on inherent resources from the community itself. This presentation will outline the process, success factors, and challenges in pathfinding and building community partnership for the benefit of people with dementia.

Poster Presentation Abstracts

ID: 807

Abstract Topic: Dementia friendliness

Keywords: dementia café, people with dementia and their families

A survey of dementia café in local areas of japan

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¹Yamaguchi University Graduate School of Medicine, Japan; ²Alzheimer's Association Japan, Yamaguchi, Japan; ³Senior Citizen's Welfare Division, Public Health and Welfare Department, Yamaguchi Prefectural Government, Japan

Abstract:

Background: As a result of the development of policies for dementia in Japan, dementia cafés have been established throughout the country for people with dementia and their families. However, dementia cafés are diverse, and little is known about management methods and how they operate.

Objective: To investigate dementia cafés in Yamaguchi Prefecture and understand how they operate.

Method: In July 2018, questionnaire surveys were conducted for all 71 dementia café operators. Questions were related to management entity, frequency, availability of pick-up services, number of participants, participation fee, operating funds, subsidies, presence of holding programs (e.g. lecture, activity, recreation, etc.), staffing, and management problems.

Results: The number of valid responses was 58 and the recovery rate was 81.7%. Many social welfare organizations, non-profit organizations, and regional networks participated in the survey, and the frequency of holding a café occurring once a month was the highest at 83%. Fourteen percent of cafés had pick-up services, and many cafés had less than 20 participants per session. Participation fees in most cases was 100 yen and the annual operating funds varied from less than 20,000 yen to 550,000 yen. Sixty-two percent of cafés received subsidies and grants. In total, 43 cafés had activity programs, most of which were physical exercise, outdoor activities, recreation, and lectures. Staff were mainly medical and nursing personnel. We identified some issues, in that there were few participants, the participants were the same persons every time, and it was difficult to secure operational staff. We also found that operational costs were low.

Conclusion: Dementia cafés were operated mainly by local residents and organizations. It is clear that they were struggling to obtain participants, including people with dementia. The issues highlighted by this study are the needs to how to inform about the café and secure operational staff.

Poster Presentation Abstracts

ID: 808

Abstract Topic: Non-pharmacological interventions

Keywords: Therapeutic Cooking, non-pharmacological therapy, behavioral and psychological symptoms of dementia, Japanese Canadian older adults

Examination of methodologies for introducing volunteer-led “therapeutic cooking” program to Japanese Canadian older adults with dementia in Canada

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¹Kindai University, Japan; ²Nikkei Seniors Health Care and Housing Society, Canada; ³Saintpaulia Ainosato, Japan; ⁴Kyoto University of Education, Japan

Abstract:

[Object]

Cooking is a task familiar to many older adults, and it is also an activity that has demonstrated to activate the prefrontal cortex and to reduce behavioral and psychological symptoms of dementia (BPSD). Cooking is expected to not only have a relaxing effect but it also serves as a form of non-pharmacological intervention. We have proposed “Therapeutic Cooking” and have conducted field research. The purpose of this study was to investigate the methodology for introducing a volunteer-led Therapeutic Cooking program for Japanese Canadian older adults with dementia in Canada, where such program does not yet exist.

[Methods]

From May to July 2018, Cooking Therapy workshops were held twice a month targeting residents of an assisted living facility in Burnaby, British Columbia, Canada, and residents of the neighborhood. There were 6 to 8 participants and 8 to 10 volunteers at each session. The menu included curry and rice, dumplings, chirashi sushi, and sushi rolls. Prior to the implementation, a lecture was given to volunteers on how to support participants in Therapeutic Cooking activities, and a handout and meeting on ways to support the participants were provided before each session. The evaluation was conducted by volunteers for individual participants at each session. In addition, participants were asked to describe their impressions of the cooking activities, and their level of satisfaction was evaluated using face icons. We conducted surveys with volunteers before and after the intervention on their awareness and learning on cooking activities.

[Ethical considerations]

The purpose and content of this study, and ethical considerations were explained to the participants and the facility manager verbally and in writing.

[Results]

We selected volunteers who had prior volunteer experience with Japanese Canadian older adults with dementia. Pre-training for volunteers covered the purpose of Therapeutic Cooking, its philosophy, ways to support the participants, the evaluation method, precautions, etc. Also, a file including the menu, schedule, precautions, tips for communication, etc. was sent by e-mail at least a day prior, and a 10-minute meeting was held before the day's cooking activities. Each participant had one volunteer, and the volunteers supported the participants in accordance to the approach proposed by Therapeutic Cooking. Individual participant evaluation was performed by each volunteer, but it was challenging for them to do a comparative evaluation against the participant's state of daily living. However, the participants were highly satisfied with their cooking activities, and there were many comments such as, “I enjoyed it very much,” and “I want to participate again.” It was suggested that further investigations

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into volunteer training methods and evaluation methods are necessary for the introduction of volunteer-led Therapeutic Cooking program.

Poster Presentation Abstracts

ID: 809

Abstract Topic: Attitudes, awareness and stigma

Keywords: Dementia, Surgical menopause, Risk factors, Awareness

Raising awareness of the link between surgical menopause and dementia

Emily Ong

Alzheimer's Disease Association, Singapore, Singapore

Abstract:

My mum has a superb memory even though she is 78 years old, and I have always prided myself for inheriting that excellent memory from her. So, what has happened along the way? Why am I having a neurocognitive disorder at 49?

Based on the standard risk factors for dementia, I should be at very low risk since I have none of the modifiable risk factors like high blood pressure, high cholesterol, or diabetes. Hence, I started reading many medical research findings in the hope of finding a more rational explanation that puts me at a higher risk of neurocognitive disorder and YOD as a woman.

Recent studies have suggested a link between surgical menopause and dementia, with increased risk for hysterectomies performed at a younger age. According to a study¹, women with short reproductive spans (14-20 years) have 55 percent higher risk of dementia, compared to those with spans of 34 years and more. The surgical removal of the ovaries increases the risk up to 70 percent. Based on this statistic, I have more than 70 percent risk of dementia!

I underwent early hysterectomy with bilateral salpingo-oophorectomy (BSO) at the age of 30 because of severe endometriosis. Though I was put on hormone replacement therapy right after the surgery, it had to be terminated after 3 years because a lump was discovered on my left breast. I have always wondered about the long term impact of my shortened reproductive span on my body, besides the typical menopausal symptoms – but it has never crossed my mind that the shorter span may be linked to a higher risk of early-onset dementia.

Without the awareness of this risk factor for women, receiving a diagnosis of dementia can be upsetting and confusing, especially among otherwise healthy younger women who do not have the more widely-known risk factors for it. In this talk, I would like to share my experience on the path to a diagnosis, and how increasing awareness of this risk can help women who have or will undergo surgical menopause.

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Poster Presentation Abstracts

ID: 815

Abstract Topic: Informal carers support – pre, during and post

Keywords: Mindfulness, Dementia Family Caregiver, Burden, Anxiety, Depression

Mindfulness-based intervention in alleviating burden and negative emotions for dementia family caregivers

Hui-Hsuan Ku¹, Chih-Pang Chu¹, Chun-Yu Chen², Chuan-Yueh Hsu³

¹Taipei City Hospital Songde Branch, Taiwan; ²Taiwan Catholic Foundation of Alzheimer's disease and Related Dementia; ³Chinese Mindfulness-Based Stress Reduction (MBSR) Center

Abstract:

Introduction

Mindfulness is defined as “paying attention in a particular way: on purpose, in the present moment, and non-judgementally”. The aim of mindfulness-based intervention (MBI) is to help people develop a sense of self, detect their emotions and thoughts, avoid unhealthy stress coping mechanism, and choose wisely in the interpersonal relationships by a series of mindfulness exercises. In systemic review, MBI can alleviate negative emotion, make a reduces psychophysical stress, and enhance life satisfaction. Dementia family caregivers have to face lots of stress every day. MBI reduce their stress-related negative emotions and help them make wise choose. Most of the family caregivers are middle-aged women and their stress is associated with memory decline in old ages. Therefore, we designed a MBI course to help family caregivers to reduce their burden and to alleviate negative emotions, such as depression and anxiety.

Method

The mindfulness-based intervention course in our study was run by two leaders. The participants were recruited by advertisement in the dementia care centers, or referral from doctors or social workers. To reduce drop-out rate and increase counseling effectiveness, participants were interviewed individually by psychologists to evaluate their psychophysical status and feasibility of enrollment, introduce what the mindfulness is and how it could help caregivers. The enrolled subjects received 9-week training including a day of mindful practice. The effectiveness of the intervention was assessed by questionnaires including Burden Scale for Family Caregivers (BSFC), Beck Anxiety Inventory (BAI) and Beck Depression Inventory (BDI) before and after the MBI course.

Results

37 dementia caregivers completed our MBI course. 92% were female and the average age was 52 years-old. Most of the care givers were daughters (58%), followed by spouses (15%). The most frequently-used mindfulness practices at home during the course were breathing space, followed by mindful breathing and body scan. 41% of participants' self-reported time spent on caregiving were less than 4hr while 31% reported more than 8 hour per day. All of the participants completed BSFC and caregiver burden improved significantly (before vs after: 56.1 ± 18.9 vs 48.0 ± 15.1 , $p=0.03$). 13 participants complete BAI and BDI. Although the result of BAI was not significant (before vs after: 13.5 ± 8.9 vs 10.3 ± 7.4 , $p=0.31$), trend of improving BDI score was noted (before vs after: 15.1 ± 11.7 vs 10.3 ± 8.8 , $p=0.08$).

Discussion and conclusion

The pilot study showed that MBI can reduce dementia family caregiver burden. Further investigation with more participants is required to confirm its beneficial effects on negative emotions. Moreover, studies comparing MBI to other interventions on caregivers are needed to ascertain its role on dementia care. Nevertheless, MBI may be a fascinating method in supporting stressful dementia family caregivers.

Poster Presentation Abstracts

ID: 816

Abstract Topic: Well being and quality of life

Keywords: well-being, vocation, meaningful activity, engaged

Title: engaging persons with dementia in a café setting- a case study

Ying Ying Chong

Alzheimer's Disease Association, Singapore

Abstract:

Introduction

In 2016, National Neuroscience Institute (NNI) reported that an estimated 4,000 people in Singapore have young-onset dementia. It is an inevitable circumstance where some may lose his or her job, resulting to social and financial problems.

A day are serving a generally older profile of persons with dementia may not be able to fulfil the needs of a person with young-onset dementia and mild stage dementia.

ADA Cafe was set up in October 2016 with a new concept of providing vocational activities for persons with dementia of young-onset and mild stage. The Cafe offers opportunities through tasks such as taking orders, serving customers and helping out in general cleaning duties. It also aims to support persons with dementia to continue living well within their community which they are most familiar and comfortable in.

The following case study aims to evaluate if participation in vocational activities in a cafe setting helps to maintain the well-being and quality of life of persons with dementia.

Methods

Two persons diagnosed with Alzheimer's Disease of mild stage and who are engaged in the Cafe's activities were interviewed face-to-face whilst a telephone interview was conducted with their care partners using a questionnaire.

A total of 19 questions were asked comprising knowledge of diagnosis of dementia, how they came into contact with ADA Cafe, their activities carried out at ADA Cafe and what was most fulfilling for them in helping out in ADA Cafe.

A Bradford Well-being profile assessment was used to assess the participants' well-being at baseline and after six months to assess if their level of well-being had decreased, maintained or increased after engaging in vocational activities at the Cafe.

Questionnaire for the care partners included 7 questions which encompassed on how they came into contact with ADA Cafe, the changes they noticed after the participants started helping out in the Cafe and their wish for the future for both participants. This was supplemented with a Quality Of Life questionnaire based on their observations if there were any positive changes in the participants' attachment at the Cafe.

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Results

Overall, the feedback from the interviews and questionnaires showed positive impact on the two participants- their well being was maintained, their quality of life improved, their self-esteem was enhanced, they had greater sense of responsibility and purpose and looked forward to going to the Cafe daily. The improvements in their physical health was also noticed by their care partners- they were able to sleep better and gained more weight. Relationships in the family also improved as there was lesser friction.

The presentation will provide an overview of ADA Cafe for persons with dementia, describe how persons with dementia are engaged in the Cafe and the impact of the programme on persons with dementia and their care partners.

Poster Presentation Abstracts

ID: 820

Abstract Topic: Psychosocial interventions

Keywords: Mobile application games, Memorie, SenzeBand, cognitively stimulating activity

An evaluation of the impact of cognitive stimulating mobile application games on the cognitive function and well-being of persons living with dementia

LI LENG EUNICE TAN, WEITING JIANG, HWAN JING KOH

ALZHEIMER'S DISEASE ASSOCIATION, Singapore

Abstract:

Family of Wisdom (FOW) is a new care model that Alzheimer's Disease Association has started in Singapore since September 2013. Running at shorter hours than a full day daycare center, the FOW programme is an avenue for persons with dementia living at home and their full-time caregivers to leave their house and engage in meaningful activities for three hours every week. These activities are cognitively and physically stimulating, individualized to the clients, and foster interaction among them; with the aims to improve their well-being and cognitive function, and provide their caregivers with some respite. The FOW programme is conducted in a small group setting, with 1 to 12 clients of similar stage of dementia, spoken language, age and educational profile in the same group.

However, the number of table-top games the FOW programme can acquire and the amount of mental stimulation these activities can provide are limited. Most mobile application games are not designed for persons with dementia too. Thus in May 2019, the FOW (Bendemeer) programme introduced a new cognitive stimulating activity developed by a local company named Neeuro, where users wear a non-invasive electroencephalogram headband that safely measures their brain signals, called SenzeBand, while playing games in a mobile application called Memorie. The activity has been chosen for its versatility, progressive training of five cognitive skills (attention, memory, decision making, spatial ability, and cognitive flexibility), the numerous games to train each cognitive domain, and feature to track clients' progress. Most clients, around 50 of them, have been and will continue to engage in this activity for at least 30 minutes every session, over a period of 6 months; whereas those who cannot stand wearing the SenzeBand and/or do not enjoy the Memorie mobile application have been excluded.

The presentation will discuss findings from the estimated 50 clients' pre- and post-cognitive assessments of the 6-months period. Preliminary findings of 5 clients, who have engaged in the activity for at least 6 hours thus far, show that they have been training their attention skill well with positive development, achieving the highest game level, and spending the most number of sessions and longest duration in an attention-training game. In contrast, only 2 clients were able to play a flexibility-training game. They spent the least number of session and shortest duration spent in this game, and made no progression to the second level. Staff have also observed that clients can best engage in attention-training games without any verbal and non-verbal indications to stop, but struggle to start and sit through flexibility-training ones.

Based on the preliminary findings, the new cognitive stimulating activity developed by Neeuro can be a plausible emerging programme that help to maintain or improve some cognitive abilities of persons with dementia.

Poster Presentation Abstracts

ID: 822

Abstract Topic: Public health campaigning – NEW

Keywords: awareness, dementia, project based learning

Youth movement initiative in raising awareness of dementia in community: a project based learning

Sri Mulyani, Azam Saifullah

Faculty of Medicine, Public Health and Nursing. Universitas Gadjah Mada, Indonesia

Abstract:

Background: Dementia has become the global leading cause of disability among elder population. WHO has set seven actions plan on dementia globally, and one of them is dementia risk reduction. Risk reduction in dementia has to be set as early as possible starting from young generation. Thus, it is essential to increase awareness of dementia in community by applying youth movement initiative project.

Methods: This is a project based learning of an elective dementia care course, voluntary followed by 42 nursing students during Feb-March 2019 in one of nursing School in Yogyakarta Indonesia. During the course, a group of eight to nine students was given a project to raise awareness of dementia among community members. There were five groups in this occasion. The project was funded by Faculty of Medicine, Public Health and Nursing, Universitas Gadjah Mada Yogyakarta. At the end of the project students were ask to rate their experience about the project from one to ten.

Results/ Positive impact: Students organised various methods in delivering dementia awareness in community. They reach around five hundreds population in five different public spaces. Various activities were applied, such as direct educational approach, interactive games, quizzes and give away pin or sticker about dementia. Student reflect that this project was enjoyable (scored 7.4 of 10), relatively easy (scored 5.2 of 10), and motivate them to learn more (scored 8.4 of 10). In addition, this project inspire to establish a facebook and an instagram account namely @Yogya_YouthMovement to maintain their program for a bigger audience. Futhermore, even a semester after the course has ended, they still continue to raise awareness of dementia during their community service program in the last year of their study.

Conclusion: This project can be beneficial for community as well as students in learning new skills. Students learnt well from the project and such project was helpful to motivate learning for students especially about dementia.

Poster Presentation Abstracts

ID: 824

Abstract Topic: Attitudes, awareness and stigma

Keywords: Stigma, Dementia, India, LMIC, QoL

Stigma related to dementia in India: current status and challenges

Saadiya Hurzuk¹, Suvarna Alladi², Meera Pattabiraman¹, Narendhar R¹, Priya Treasa Thomas², Sarah Evans-Lacko³, Adelina Comas-Herrera³, Klara Lorenz³

¹Alzheimer's and Related Disorder Society of India, India; ²National Institute of Mental Health and Neuro Sciences, India; ³London School of Economics and Political Science, UK

Abstract:

Background and objectives of the study / Introduction – While approximately 5.12 million people with dementia live in India, there are several obstacles to delivering care and providing adequate support. Stigmatisation of persons with dementia in society is one of the major factors that contribute to low diagnostic rates as well as to poor quality of care. However, there is inadequate understanding of dementia-related stigma and its impact in the Indian context. One of the primary aims of the STRiDE project is to address this evidence gap and conduct a research study that focuses on understanding stigmatisation of dementia in India.

Methods – An exploratory study will be conducted among people with dementia and carers, general public and stakeholders working with people with dementia in India. Initially an extensive review of the dementia related stigma literature will be performed as a part of a situational analysis. Based on this, key themes will be developed, which will be used as prompts in the focus group discussions to be conducted in Chennai and Delhi. The two Indian cities are chosen as they vary in cultural, geographic and socio-demographic characteristics, to provide a wider range of perspectives. Three focus groups will be identified to understand the attitudes and impressions of different stakeholder groups that include persons with dementia and their caregivers, health care professionals and members of the public.

Results / Positive impact – The literature review done as a part of STRiDE situational analysis indicated that people with dementia experience stigmatisation in society as well as neglect from their families (Das, Ghosal, & Pal, 2012). Dementia-related stigma was found to negatively affect personal relationships and the quality of life which can in turn have an effect on dementia care (Sathianathan & Kantipudi, 2018). We hypothesize that the qualitative results based on the various focus group interviews will reveal the different experiences related to stigma among the three groups and also highlight the impact of stigma on their lifestyles.

Conclusions / Perspectives- This in-depth study of dementia-related stigma across different stakeholder groups will yield insights regarding knowledge, awareness and understanding of dementia in Indian context. These efforts of the STRiDE project are likely to promote dementia awareness across diverse sections of society and help fight stigma and discrimination, thereby improve the quality of life of people living with dementia in India.

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Poster Presentation Abstracts

ID: 827

Abstract Topic: Rehabilitation (physical and cognitive)

Keywords: Occupational therapy, geriatric, cognitive intervention

Occupational therapy in a geriatric psychiatric inpatient unit

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¹Department of Occupational Therapy, Taipei City Hospital, Taipei City Psychiatric Center, Taiwan;

²School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan

Abstract:

With an increase in the number of elderly people, the demand for medical and social welfare programs in their service is also growing. Earlier, medical interventions in the aged mostly dealt with issues of physical pain; currently, however, with the rising proportion of elderly population, their psychological problems require more attention. The acute psychiatric inpatient unit at the Songde Branch of Taipei City Hospital is a multi-disciplinary team that provides comprehensive medical care for patients. The majority of cases that are admitted involve patients with elderly dementia, depression, schizophrenia, Parkinson's disease, organic brain syndrome, and delirium.

Occupational therapy involves the use of purposeful and therapeutic activities to promote rehabilitation and maintenance of daily life, leisure, work, and psychosocial functions. An occupational therapist (OT) here plans and arranges for occupational activities for 90 minutes from Monday to Friday. The goal is to maintain a daily routine, sustain appropriate interests and hobbies, maintain interpersonal relationships, moderately engage in social activities, and develop habits of light exercise. The activity on Monday is a cognitive intervention program; the content is based on six cognitive domains defined by DSM-5. On Tuesday, a craft activity that comprises making thank-you cards, accessories and photo frames for the patient's family helps to maintain fine motor function of the upper limbs, enhances sensory stimulation, gives an opportunity to use simple tools, enhances creative experience, and improves self-confidence and interpersonal interactions. On Wednesday, a cooking program combined with other related activities of daily living is organized; this motivates and encourages patient participation, thereby allowing elderly patients to experience a variety of sensory stimuli in a pleasant atmosphere. In addition, patients are provided with opportunities for interpersonal interactions. The activity on Thursday consists of organizing a reminiscence group, whereby the OT leads the patient to recall past life experiences and affirms the value of those experiences. Both through discussion and sharing of their past life experiences, the patients perceive a sense of identity and generally feel happier. The activity on Friday is an exercise training program; the focus here is to maintain a range of motion in the upper limbs, preserve muscle strength of the upper and lower limbs, maintain flexibility of the ankle, improve blood circulation in the lower limbs, and maintain the alertness of patients by using fun components. All individuals go through the process of aging in the course of their life. OTs consider personal development as a primary concern; this includes allowing the elderly to use their existing abilities to function through the aging process, to live a life of dignity and quality, and reducing the level of burden for the caregivers.

Poster Presentation Abstracts

ID: 829

Abstract Topic: Social isolation, loneliness, depression and the consequences for people with dementia and carers – NEW

Keywords: Dementia, Dementia caregiving, Burden, Zarit Caregiver Burden Interview, Dementia severity

Caregiver burden among caregivers for patients with dementia in national brain center hospital Jakarta, Indonesia in 2019

Made Ayu Wedariani, Nanda Adhitama, Ratih Puspa, Asnelia Devicaesaria, Silvia Lumempouw
National Brain Center Hospital, Jakarta, Indonesia

Abstract:

Background: Caregiver has an important role in managing patients with dementia. Caregiver burden has not been evaluated frequently in Indonesia. Dementia is one of the diseases that we found frequently in National Brain Center Hospital, Jakarta. In 2018, we found 123 cases of Vascular Dementia, 24 cases of Alzheimer Dementia, and 16 cases of Mixed Type Dementia.

Objective: This study aimed to measure caregiver burden using Zarit Burden Interview (ZBI) in Dementia patients. Examine correlations between ZBI scores and patient clinical conditions (disease onset, severity, neuropsychiatry symptoms).

Methods: This was a cross-sectional study included 54 patients with dementia, included vascular dementia (66,7%), mixed dementia (20,4%), Alzheimer Dementia (11,1%), and Frontotemporal dementia (1,9%) and their caregivers. The caregivers were interviewed with ZBI. Demographic data and data regarding the patients' illness were collected. The patients are classified into the mild, moderate, and severe stage of dementia, we also measure the Activities of Daily Living Score (ADL score) and Instrumental Activities of Daily living score (IADL).

Results: ZBI mean score is $25,56 \pm 14,2$. Whereas 45 (83,3%) participants get a low burden score (0-40), and the rest of 9 participants (16,7%) have High Burden score (41-88). There are 31 participants (57,4%) have neuropsychiatry symptoms, with the major symptoms are Irritability (18,5%), Visual Hallucinations (13%), Abnormal Motoric Behaviour (9,3%) and others (16,8%). We found no significant correlation of caregiver gender, age, educational level, tribes, relationship with patients, caregiving onset, type of dementia, stage of dementia, and neuropsychiatric symptoms in patients that related to caregiver burden score.

Conclusion: Dementia patients need special care and sometimes give a burden for their caregiver. We found 16,7% caregiver that has a High Burden score, measured by the ZBI Score. Although no other factors we find that are significantly correlated to the burden score. This study has some limitations, some of the patients' caregiver were difficult to contact and not all come to the clinic escorted by their regular caregiver so that only a few meet the study requirements, and causing inadequate samples.

Poster Presentation Abstracts

ID: 839

Abstract Topic: Dementia and equitable society – NEW

Keywords: social participation, occupational therapy, dementia

Benefits of carnival games for people with dementia and their families in the community

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²School of Occupational Therapy, College of Medicine, National Taiwan University, Taipei, Taiwan;

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Abstract:

– Introduction

To launch the World Alzheimer's Month in Taiwan, the Taipei City Hospital held the Carnival Games for Dementia with a series of activities for residents, people with dementia and their families. These activities included memory puzzles, dressing cooperation, attention response, ring toss, and bingo. Similar to healthy older adults, people with dementia enjoy using public spaces for daily exercise. During the carnival games, our team members assisted patients with dementia and their families.

– Methods

We invited people with dementia and their families in the community through the Xinyi District Health Center, Taipei City. For safety, patients and their families were instructed to stay together, especially for people using a wheelchair. In addition, our team included an occupational therapist and a psychiatrist to assist people with dementia and their families.

– Positive impact

The Carnival Games for Dementia was held at the University of Taipei. A total of 250 people attended the carnival including residents, volunteers, people with dementia and their families. We recruited 7 people with dementia, of whom 4 were in the mild, and 3 were in the moderate stages of dementia. Participants were aged between 70 to 91, with an average age of 80.4 years. Of the family members that attended with the patients, 3 were the patients' spouses, 3 were their children, and 1 was an older sibling. The people with dementia independently completed most games with their families, except for the memory puzzle, where people with mild dementia were given oral instructions.

– Perspectives

The Carnival Games for Dementia offered significant benefits for people with Alzheimer's or other dementias. Specifically, it helped with interaction and cooperation between people with dementia and their families, as well as increased social participation. People with dementia and their families, as general healthy adults, should have equitable access to using the public institutes and spaces. In addition, the participants enjoyed and had a meaningful experience at the Carnival Games for Dementia during the World Alzheimer's Month.

Poster Presentation Abstracts

ID: 845

Abstract Topic: Attitudes, awareness and stigma

Keywords: Demensia stigma, Family stigma, Caregiver burden, Indonesia

Family Stigma and Caregiver Burden in Dementia care in Indonesia

Imelda Theresia¹, Tara P. Sani^{1,2}, Patricia Tumbelaka¹, Lisye Konny², Aditya Putra², Sara Evans-Lacko³, Nicolas Farina⁴, Yuda Turana^{1,2}

¹Alzheimer's Indonesia, Indonesia; ²School of Medicine and Health Sciences, Atma Jaya Catholic University of Indonesia; ³Care Policy and Evaluation Centre, London School of Economics and Political Science; ⁴Centre for Dementia Studies, Brighton and Sussex Medical School

Abstract:

Background:

The majority of people with dementia rely on family caregivers to provide daily care in order to maintain quality of life and dignity. Family members and friends who care for people with dementia are affected in a variety of ways and degrees. This study aims to understand the experiences of people with dementia and their caregivers.

Methods:

This qualitative study is a part of the Strengthening Responses to Dementia in Developing Countries (STRiDE) project, which is focused on better understanding stigma towards dementia. Participants were recruited from a diverse education and professional background.

Results:

Thirteen family carers of people with dementia, living in Indonesia, participated in a focus group that explored their experiences of providing dementia care. Respondents' ages ranged from 35 to 74 years old, three males and ten females. Their relation to a person with dementia varied; respondents comprised: seven adult children, two husbands, two wives, one daughter in law and one grandchild. The duration of being a caregiver varied from six months to five years.

The caregivers experienced several obstacles, such as difficulty in finding a balance between work and taking care of their family member who lives with dementia. One of them ended up resigning from her job as a kindergarten teacher and reported the responsibility of caring for her mother full time leads to no social life. The first-born children respondents complained about the lack of emotional and financial supports from other family members. Misconceptions about the symptoms being attributed to spiritual or supernatural causes further add to the distress and confusion of the carers.

Conclusion:

Family caregivers experienced lack of work-life balance, emotional distress, financial burden, lack of support networks, social exclusion, and stigma. These findings highlight the need for interventions to support not only people with dementia but also their carers.

Poster Presentation Abstracts

ID: 847

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: Korean social security systems, community care services, guardianship, decision making, individuals with dementia

Social security systems and care services for individuals with dementia in Korea: the missing links

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¹Seoul National University, Korea, Republic of (South Korea); ²Kyungpook National University;

³Daegu University; ⁴Hanyang University

Abstract:

The number of older adults aged 65 and over in Korea has been rapidly increasing. As a consequence, the number of older adults with dementia is estimated at 0.7 million as of 2018, which comprise 10% of total Korean individuals aged 65 and over. The number of older adults with dementia will be over 1 million by the year 2024 and is estimated to be over 3 million by the year 2050. Given the recent dramatic demographic changes and increasing care burden for older adults with dementia, the Korean government launched the National Long-term Care Insurance in 2008 and developed the National Dementia Comprehensive Plan in 2018. Owing to these recent changes, the current Korean government has been developing the National Responsibility System for Dementia since 2018, which focuses on early detection and treatment for dementia, alleviating family care burden, expanding infrastructures such as hospitals and community care services, and managing dementia-related issues at national level. However, there are a few missing links to be addressed to have the Korean dementia welfare systems operated effectively. The current presentation focuses on two dimensions of missing links including limitations in community care infrastructures and the lack of a mechanism to support self-decision making for individuals with dementia. To address these issues, the presentation will address the following. First, we will share the developmental overview and introduce the current national care and support systems for individuals with dementia in Korea. Second, we will discuss the current legal procedures of long-term care service use in terms of its applications and decisions. Third, we will not only discuss the shortage of community service alternatives due to the lack of community care infrastructures but also point out possible violations of human rights of individuals with dementia due to the lack of self-decision making of the guardianship that is the base of decision making for individuals with cognitive disabilities in Korea. Fourth, based on these discussions, future directions will be discussed with specific focuses on establishing community care infrastructures and developing supported decision making will be discussed.

Poster Presentation Abstracts

ID: 848

Abstract Topic: Models of care

Keywords: responsive behaviours; BPSD; primary care

Management of responsive behaviours in primary care

Constance Dimity Pond, Jenny Day, Karen McNeil

University of Newcastle, Australia

Abstract:

Background and objectives of the study/Introduction

At some stage in the course of dementia, people living with this illness may develop responsive behaviours, also known as behavioural and psychological symptoms of dementia (BPSD), which can be of considerable concern to those caring for them. Our aim was to provide a description of new primary care guidelines which detail strategies for identification of the causes of responsive behaviours and ways of managing them in primary care. Funding support was received from the Cognitive Decline Partnership Centre (CDPC) in Australia.

Methods

Our team performed a narrative review of the literature focused on identification of the causes of responsive behaviours and ways of managing these. Taking into account the busy nature of primary care practice, we developed a three-part guideline addressing responsive behaviours. The first section summarised the issues from the literature review in a short series of dot point 'key messages' and then illustrated them using a diagram. In the second section, we wrote dot points which translated the key messages into statements guiding 'what to do in practice' and included examples. In the third section, we wrote a more formal narrative review, intended to be read more commonly by those with a more academic interest in the topic.

Results/Positive impact

This poster will present the diagram summarising a primary care approach to identifying the causes of BPSD and ways of managing these responsive behaviours. It is proposed that this diagram could provide a useful summary of evidence-based clinical care for busy primary care team members.

Conclusions/Perspectives

Responsive behaviours, also known as BPSD, can cause distress to both families and people living with dementia. This poster presents a diagrammatic guideline, in an accessible format, taken from new primary care dementia guidelines published by the Cognitive Decline Partnership Centre

Poster Presentation Abstracts

ID: 850

Abstract Topic: Clinical trials – NEW

Keywords: Drug utilization study; Inappropriate use; Multiple patch use; Risk minimization tools; Rivastigmine; Transdermal patch

Impact of risk minimization tools on drug utilization of rivastigmine transdermal patch in patients with dementia in a real-world setting

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⁴Novartis Healthcare Private Limited, Hyderabad, India

Abstract:

Background: Rivastigmine (oral or transdermal) is indicated for treatment of patients with mild to moderate Alzheimer's disease. However, post-marketing reports of inappropriate use (IU) and medication errors that includes multiple patch use (MPU) of rivastigmine resulting in overdose have been documented. This led the European Medicines Agency to request the development of risk management tools such as a patient reminder card consisting of instructions for use and a medication record sheet (MRS) to minimize IU. This drug utilization study (DUS) was conducted for rivastigmine transdermal patch (4.6 mg [5 cm²], 9.5 mg [10 cm²], 13.3 mg [15 cm²]/day) to evaluate the effectiveness of risk management tools in reducing the MPU/IU.

Objectives: To estimate the incidence of IU (including medication misuse and error) and titration patterns for 3 doses of rivastigmine patch.

Method: It was a prospective, non-interventional, multicenter, cohort field, post-authorization safety study in patients using or evaluated to be ready to initiate rivastigmine patch, and with a patient assistant willing to participate. The MRS was filled by patient's assistant each day for first 28 days and mailed to the site. The physician/designated personnel conducted a telephone interview with a follow-up questionnaire to the patients' assistants at Day 28 and bimonthly for 10 months during the study. Descriptive statistics was used to describe study results.

Results: The 28-day observational period was completed by 614 patients. The overall IU and MPU decreased from 27.7% to 17.8% and 3.4% to 2.9% from prior to during the study, respectively. Incorrect patch placement notably decreased from 7.2% (prior) to 3.1% during the study. In the current DUS, the components of IU, both (MPU [6.6% vs 2.3%] and incorrect patch placement [35% vs 2%]), were lower as compared to a previous DUS. At study initiation, 258, 182 and 168 patients were on 4.6, 9.5 and 13.3 mg/day patch, respectively. Mean duration of titration from 4.6 to 9.5 mg/day dose was 58 and 115 days for 9.5 to 13.3 mg/day dose. Of the 429 patients completing the study, ~21% were on 4.6 mg/day and ~79% on 9.5/13.3 mg/day dose. Majority (99.7%) of patients/assistants complied with using MRS and most of them (73.3%) found it extremely/somewhat helpful. Instructions for use was referred by 37.9% of patients/assistants, of which 35.3% rated it as extremely/somewhat helpful. Overall, 36.4% and 8.5% of patients reported adverse event (AE) and serious AE, respectively.

Conclusions: The study establishes the effectiveness of the risk management tools in reducing the IU of rivastigmine patches in patients with dementia for all doses. The titration patterns for rivastigmine patches from a lower to higher dose was largely maintained in line with the recommended dosage guidelines. Safety findings from this study were consistent with established safety profile for rivastigmine patch.

Poster Presentation Abstracts

ID: 856

Abstract Topic: Young onset dementia

Keywords: family caregiving experience , young-onset dementia , grounded theory, qualitative research

Family caregiving experiences for persons with young-onset dementia in Taiwan

Li-Hua Chen¹, Yea-Ing Lotus Shyu², Huey-Jane Lee³

¹Chang Gung University, Taiwan; ²Chang Gung University, Taiwan; ³Taiwan Alzheimer's Disease Association;

Abstract:

Background: Most of the studies on family caregiving have been focusing on family caregiving experiences of older persons with dementia, and little is known regarding experiences of family caregivers of persons with young onset dementia. Since the function of persons with young onset dementia is often more rapidly deteriorated and the family is usually in different phase of development from those of the older persons with dementia, the experiences of their family caregivers may be very different from those of older persons with dementia. This knowledge is an important prerequisite for the development of appropriate interventions and personalized care to address their specific needs and problems. Therefore, the purpose of this study was to explore the family caregiving experiences for persons with young-onset dementia in Taiwan.

Method: Caregivers were introduced to this research from The Home of Young People with Dementia located in North Taiwan. A total of thirteen family caregivers were recruited and interviewed individually. Interviews were tape recorded and transcribed verbatim. Constant comparative analysis of grounded theory method was used to analyzed the data. The researchers coded and analysed the transcripts independently then jointly. Substantive and theoretical coding were used to develop the core concepts.

Results: "Striving to provide the best care" was emerged as the core category. Five related concepts were: (1) Excessive load on care responsibility, (2) Loss in daily life, (3) Adaptation with hopelessness, (4) Intimacy changes to alienated relationship, (5) Considering using Palliative Care.

Conclusion: Family caregivers of persons with young onset dementia in Taiwan have been struggling to provide best quality of home care, despite their experiences of excessive care burden and difficulties. Related policies and community services to support these family caregivers are suggested to be developed based on the findings of this study.

Poster Presentation Abstracts

ID: 859

Abstract Topic: Young onset dementia

Keywords: People with Young Onset Dementia; Family Caregiver; Service Needs.

Service needs of people with young onset dementia and their family caregivers: the perspective from professional worker

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Taiwan Alzheimer Disease Association, Taiwan

Abstract:

This research focuses on the people with young onset dementia (abbreviated as YOD in the following text) and family caregivers to discuss their service needs. It also studies services provided by different fields to serve people with YOD and their family caregivers (including current situation, difficulties, challenges and suggestions offered by professionals).

This research uses the methodology of in-depth interview and purposive sampling, by interviewing professionals in different fields, to understand the service needs of people with YOD and their family caregivers. These professionals are from social work, nurse, medicine (neurology department), occupational therapy, physiotherapy and psychology.

By analyzing the interview materials, this research comes up with the conclusion as follows:

1. The issue of people with YOD includes (1) difficulty of making a definite diagnosis; (2) hard to cope with the symptom and therapeutic isn't satisfying; (3) hard to achieve mental adaptation; (4) lacking of social support; (5) losing social connection; (6) patients' rights and interests are easy to be neglected.
2. The issue of family caregivers includes (1) hard to achieve mental adaptation; (2) the burden of caring is huge; (3) confronting financial problems; (4) facing challenge from the family; (5) decreasing of social connection; (6) lacking of service resource.
3. The needs of people with YOD and their family caregivers: (1) their situation and needs need to be seen; (2) developing related professional service; (3) service based on community; (4) postponing the time that they quit the job; (5) developing service for people with YOD and their family caregivers.
4. By studying the services provided by The Home of Young People with Dementia, Long-Term Care Policy 2.0 and other organizations, this research demonstrates the difficulties and challenges of service providing and executing in different fields.
5. Advice for services for people with YOD and their family caregivers: (1) improve family's reaction speed and strengthen the connection with medical organizations; (2) protect the rights and interests of the people with YOD; (3) offer enough support to family caregivers; (4) develop proper services for people with YOD and their family caregivers; (5) promote the services which are mentioned above.

In the end, the researcher comes up with some suggestions based on the conclusions above to help develop service for the people with YOD and their family caregivers: (1) improve patients' and family caregivers' reaction speed; (2) make a proposal to protect the rights and interests for the people with YOD; (3) develop proper services for people with YOD and their family caregivers; (4) related professions and human resource need to be instructed; (5) service should be people oriented; (6) service mode should be multi-disciplinary; (7) pay attention to the career planning issue of the people with YOD.

Poster Presentation Abstracts

ID: 861

Abstract Topic: Psychosocial interventions

Keywords: Simulated Presence Therapy, SPT, Agitation, dementia

Improving management of agitation in persons with dementia (PWD) with simulated presence therapy (SPT) in an Acute Geriatric Ward

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Nursing Department, Changi General Hospital, Singapore

Abstract:

Introduction

Dementia is a progressive and degenerative disorder which is associated with impairment in cognition and function in elderly population. Behavioral and Psychological Symptoms of Dementia (BPSD) is present in up to 80% of the patients with dementia, with agitation as one of the more common occurring behaviors among them. Agitation is often associated with heightened caregiver burden, disease acceleration and early nursing home placement. It is also a major clinical problem for the nurses and their caregivers or family to cope with.

This pilot project aims to investigate the effectiveness of simulated presence therapy in managing patients with agitation in an acute geriatric ward and ultimately benefit for the persons with dementia by reducing hospital associated complication such as fall.

Methods

Simulated presence therapy was implemented for persons with dementia with presentation of agitation in our project. This therapy involves the use of a DVD with videos to mimic the engagement or interaction with persons with dementia through conversations and songs. The DVD is called "Spending Time with You", which comes with five languages: English, Mandarin, Hokkien, Cantonese and Malay. Plan-Do-Study-Act (PDSA) cycle was adopted during the implementation phase. Pittsburg Agitation Scale (PAS), which is a validated assessment tool being used to measure the severity of agitation in persons with dementia before and after the simulated presence therapy was carried out. The Pittsburg Agitation Scale measures four behavior groups, namely aberrant vocalization, motor agitation, aggressiveness and resisting care. On the Pittsburg Agitation Scale rating sheet, a scale of 0 (not present) to 4 (most severe) is used to measure the severity of agitation in each behavior group. The ratings of the four behavior groups were compared before and after the simulated presence therapy to evaluate the effectiveness. The reduction in the rating in each behavior group immediate and 4 hours after engagement of simulated presence therapy indicate the improvement in managing agitation in persons with dementia.

Results

Simulated presence therapy was implemented for 48 patients with dementia. Out of these patients, 93.8% of them presented with agitation and 6.2% of them manifested with depressive symptom. The duration of engagement for the SPT ranged from 3 mins to 30 mins. Out of 48 patients, 87.5% of them were able to respond well to the session. Among those responded well, the rating of agitation on Pittsburg Agitation Scale (PAS) improved immediate and 4 hours after simulated presence therapy (SPT). None of these patients had fall incidences during hospital stay.

Conclusion

SPT is able to generate a good response and effective in managing agitation in persons with dementia. However it was less effective in patients with depressive symptom or aggressive with Pittsburg Agitation Scale rated as 4 on all behavior groups.

Poster Presentation Abstracts

ID: 864

Abstract Topic: Models of care

Keywords: Dementia care provision risk reduction Active Ageing

The compression of needs model

Eef Hogervorst

Loughborough University, United Kingdom

Abstract:

The Active Ageing Index (AAI) is a tool developed to enable combining various quantitative survey data to show the contribution older people could make to society (Zaidi et al., 2012/13). Active Ageing is a positive concept, demonstrating that older people can be active players in optimising their ability to remain independent and experience a sense of well-being and identity, rather than being passive recipients of the passing of time, invariably resulting in poor health.

However, the concept has been criticised for its domains and indicators having been chosen in a rather arbitrary fashion by an Expert Panel without a clear theoretical model and respect for cultural differences (Sao Jose, et al., 2017). Variability in functionality in ageing is its most defining characteristic, ranging from highly independent to having severe dementia with high care needs. One of the other criticisms (Sao Jose, et al., 2017) was that the AAI model does not allow for this variability by including dependency, disability, ill health and need, which can come with age. Mapping older people's needs and finding solutions to fulfil these needs in a cost-effective, self-empowering and dignified manner is important, as people worldwide are ageing. Ageing is thus a global issue, with the majority of older people living in Low and Middle-Income Countries (LMIC). This is also where the majority of people with dementia is expected to live.

We adapted the Active Ageing index (AAI) to also include other predictors of in/decreased needs in older people due to dementia and frailty, which often go hand in hand. In this talk we present data on the relationship between the AAI indicators and dementia prevalence in 3 different areas in Indonesia. These data can help policy makers make decisions in how to best assist Active Ageing to reduce care needs and dementia.

We also included data on off-setting of care needs through the relative contribution of formal and informal care provisions in different ethnic populations in Indonesia. This novel model of compression of need will be discussed to aid data analyses related to dementia care needs and offsetting through available physical and psychosocial resources, as well as formal and informal care provision.

Poster Presentation Abstracts

ID: 870

Abstract Topic: Engaging people with dementia and carers in policy

Keywords: caregivers, dementia, Qatar, NGO, participatory, research, policy

Caregivers' insights for policy and practice: an NGO-funded study on dementia care

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Abstract:

Dementia is a disease that should not be viewed solely as a medical problem: its social and economic burden cannot be overlooked (Rubinstein et. al., 2016). With a sizeable proportion of the burden falling on the shoulders of 'invisible' caregivers within nuclear families, the role and needs of these caregivers also require deeper scrutiny. In addition to the support caregiving families deserve and need in their difficult journey with dementia, the WHO has urged that they also be engaged in service design and policy formulation. Given the impact of public misinformation about the disease and role of socio-cultural beliefs in hindering help-seeking, it is vital to seek context-sensitive insight to ensure that solutions are context-appropriate and effective to the local socio-cultural fabric. However, this dimension remains largely overlooked in Qatar where the family role is taken for granted in the care of older persons and the stigma of cognitive and mental disease remains high. Professional service providers within NGOs and medical home care visit teams continue to work closely with families encountering PWD in the absence of a robust knowledge base.

Reflecting Qatar's explicit commitment towards responding to dementia- its recently launched National Dementia Strategy, its Global Dementia Observatory Team, and dedicated committees and campaigns, the present paper provides an overview of one of the first qualitative studies conducted in Qatar to gain insight into dementia care and produce an evidence base to inform policy and practice. This study was commissioned by the one NGO in the country whose mission is to empower and care for this older population group in Qatar's society- Ehsan Centre for the Empowerment and Care of the Elderly The research was conducted over two years 2017/18 in collaboration with Qatar University and involved a three-stage incremental process of: scoping and systematic review, exploratory interviews with institutional key informant interviews and focus group discussions with frontline social workers and caregiving professionals from Ehsan, religious leaders; the bulk of data was focused on insights from caregiving families. Intentional to enhance communication and exchange between key stakeholders in the sector, the study followed a Participatory Action Research approach from the outset and was also intentional in translating into actionable recommendations and context-relevant advice geared towards the sector generally and Ehsan Centre specifically. The findings and outcomes of this study will be shared in this presentation, indicating the central role of community-based NGOs such as Ehsan in supporting families that care for persons with dementia and ways that their role can be made more effective. It highlights the voices and needs of caregivers themselves as partners in research and dementia care which is why they must always be consulted and guided by formal service providers.

Poster Presentation Abstracts

ID: 871

Abstract Topic: Diverse populations – inclusion, equality, cultural issues

Keywords: Qualitative research, cultural, family care, collaborative caregiving team, cognitive impairment

Research on family care system of the disabled elderly and family negotiation process

HUI-CHIN TENG, Yea-Ing Lotus Shyu

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Abstract:

Background

Elderly care is one of the important traditional duties of Chinese family culture. Due to social changes, weakening of resources inside and outside the family, the concept of family care is also changing. When the family develops to an aging stage, most of the children of the elderly have each formed their own nuclear family. This study focuses on how to manage business in the Chinese community to meet the care needs of the disabled elderly, and focus of the study is the types of collaborative care teams that will emerge and what methods will often be used to resolve conflicts among members.

Methods

In this study, the "family" was used as a research object. Six face-to-face interviews were conducted with four families to collect information. Exploring how the family negotiates and distributes care responsibilities within one year of discharge from an elderly person with a hip fracture to clarify the nature of the family as the basic unit of care. In this study, two disabled elderly people had cognitive impairment.

Results

This research found (1) The formation factors of caregivers are related to cultural norms and role expectations. (2) The reasons why family members participate in the care system each have their own unique family context. (3) The type of family care can be divided into a competitive collaborative caregiving team, divides labor or labor outsourcing collaborative caregiving team, and an alternative supportive collaborative caregiving team. (4) The process of family negotiation and the power in it must be restored in the family context. (5) Competing collaborative caregiving teams are prone to conflicts due to their close interaction. Collaborative caregiving teams with division of labor or labor outsourcing, because the content of each other does not overlap, there will be no feeling of competition. The alternative supportive collaborative caregiving team is mainly led by one member, and the other members support the substitute work, with less interaction and less chance of conflict. (6) Ways to resolve conflicts among members include: communication and discussion, listening to others' opinions, tolerance, non-interference, habituation, positive thinking. (7) The impact of care work is not always negative, and it may also enable the caregiver to gain valuable experience and important life thoughts. (8) The cognitive function status of disabled seniors does not have a significant impact on family care, but in families with disabled cognitive impairment, there is a conflict between members due to excessive protection.

Conclusions

This study conducted a family-based study and found that family members' willingness and manner of care are influenced by gender and culture, daughters are more likely to be taken care of as caregivers. Children and family members who are unmarried or living together mainly provide direct physical care. The tasks of their own children are mainly "companion" rather than "care".

Poster Presentation Abstracts

ID: 872

Abstract Topic: Attitudes, awareness and stigma

Keywords: dementia awareness, elder financial abuse

A survey about dementia awareness on banking staff in Taiwan

Li-Jung Elizabeth Ku, Yi-Chin Huang, Yi-Han Liao, Yu-Ling Huang

National Cheng Kung University, Taiwan

Abstract:

Introduction: In order to prevent persons with dementia (PWD) from financial scams and safeguard their assets, there has been an initiative to promote dementia friendly banks in response to the 2nd strand of the WHO Global Action Plan on Dementia.

Methods: We conducted a survey about dementia awareness on banking staff in collaboration with the Post Office, the largest financial institution in Taiwan with 1,298 branches over the country. The Post Office recruited frontline staff (tellers) from 2 local branches in each city in Taiwan to respond to the survey about the staff's experience serving a customer whom they think may be a PWD.

Results: The number of survey respondents was 97, and among them 57% were female, and 67% of the staff had college-level education. 46% of the bank staff had more than ten years of experience working as a teller, and when asked about the frequency of their encounter with a customer whom they think might have dementia, 31% reported every six month, followed by 30% of every year, and 30% of every month. Less than 8% of the sample reported having an encounter with PWD more than every week. When asked about how they identified that a customer may have dementia, the top three responses were: repeated questioning of the same issue, could not answer the questions being asked, and customers could not articulate their requests. In terms of what problems the teller had experienced at the counter, they listed that the PWD would forget and make repeated withdrawal as the most common problem, followed by PWD forgetting about account passwords. Moreover, when asked about how they handled the above situations, 56% of the responses were to contact the PWD's family members, followed by 21% to contact the police, and 13% would decline the PWD's request.

Conclusions: This is one of the first few studies about dementia awareness among banking staff, and our findings showed that when faced with a customer that may have dementia, banking tellers usually turned to other family members to resolve the issue. But in cases of a PWD customer living alone, other dementia friendly banks measures may also be needed to safeguard the individual's assets.

Poster Presentation Abstracts

ID: 876

Abstract Topic: Formal carers education and training

Keywords: short course, education, capacity building, neurogeriatrics, dementia

Summer school of neurogeriatrics & dementia: a multidisciplinary short course to empower healthcare practitioners and community members to address dementia in Indonesia

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School of Medicine and Health Sciences, Atma Jaya Catholic University of Indonesia, Indonesia

Abstract:

Background/Introduction:

Indonesia is heading towards an ageing population. In 2010, the population census found that the number of people aged 60 years and above was 18.1 million (7.6% of the total population). This number is projected to increase to 48.2 million (15%) by 2035. As a commitment to contribute in addressing the global ageing issue, Atma Jaya designed the 1st Summer School of Neurogeriatrics and Dementia to facilitate knowledge exchange and discussion in the integrative multidiscipline management of geriatrics problems, especially dementia, through a person-centred care approach.

Materials and Methods:

This short course consisted of 3 modules: Nature of Dementia (week 1), Fundamentals of Dementia Care Planning (week 2), and Living Well with dementia (week 3). Learning methods used including classroom-based lectures, online/recorded lectures, Problem-based Learning (PBL) group discussions, Skills Lab (SL), and optional field trips. At the end of the programme, two focus group discussions were done to gain feedback from the participants. Participants were accepted based on their CV and motivation letters. Issues discussed in the

Results:

A total of 21 people joined the programme. The backgrounds of the participants vary, which include: medical doctor, clinical psychologist, demographic researcher, medical students, communication students, social workers, and carers. The participants reported that the diverse background of the class allowed them to explore ageing and dementia issues from new perspectives. The medical students and clinician participants reported enhanced learning through experiences shared by the non-medical classmates, especially the carers. They became more aware of the multi-faceted complexity of dementia. The non-medical participants also reported their enthusiasm of the basic medical knowledge gained from this course, which they believed has better equipped them in developing strategies to support people with dementia. The medical student participants suggested that this short course be incorporated into a compulsory or elective module for medical education.

Conclusion:

This 3-week programme on dementia was the first short course on dementia available in Indonesia offered to a very diverse participants, including medical and non-medical. The course had been accepted well by participants. The curriculum for this short course can be incorporated into the formal medical education to better prepare future doctors in addressing the issue of ageing population.

Poster Presentation Abstracts

ID: 877

Abstract Topic: Education and training in hospitals – NEW

Keywords: Dementia, Delirium, Training Programme, Dementia Education

Promoting care for the elderly with dementia and delirium in an acute hospital

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Abstract:

Introduction

With an ageing population, dementia has increasingly been recognized as an important and urgent issue, posing major challenges for the care systems. The elderly patients with dementia are more likely to develop incident of delirium during hospitalization, fall and more likely to be restrained to manage their behavioral symptoms. Many a time, nurses are easily bewildered between dementia and delirium as both conditions cause cognitive impairments and often co-exist. The main objectives of this training programme are to improve care staff's knowledge, skills and attitude in caring for patients with dementia and/or delirium, and to support the implementation of evidence based practice or initiatives in dementia and delirium care.

Methods

A three-tier (Essential, Enhanced and Expert Level) training programme was designed and developed to equip nurses hospital wide at different clinical proficiency levels with appropriate competencies in caring for patients with dementia and delirium. It adopts a competency-based curriculum development approach, a relatively novel method for the workplace based learning to promote learner-centeredness and to improve patient outcomes ultimately. The programme utilizes various instructional strategies and workplace-based assessment methods to facilitate learning and evaluation.

Results

The programme has achieved a high learner-reported satisfaction rate of 90%. Over 60% the nurse who have undergone the training demonstrated improvement in their knowledge and confidence level in dementia and delirium care. Significant improvement in nurses' ability in recognizing delirium, performing person centered assessment and management of challenging behavior have been demonstrated.

Conclusion

This training programme has demonstrated its benefit to cultivate a care environment for patients with dementia and/or delirium. It has also highlighted a transformation of nursing practice to produce a noticeable impact on patient outcome.

Poster Presentation Abstracts

ID: 878

Abstract Topic: Dementia and equitable society – NEW

Keywords: equity, dementia, collaboration, qualitative, fieldwork

Lessons Learned Preparing for Qualitative Fieldwork with Unpaid Family Carers in Jamaica – A Middle Income Country

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¹Caribbean Institute for Health Research, The University of the West Indies (UWI), Mona, Jamaica;

²Care Policy and Evaluation Centre, London School of Economics and Political Science (LSE), UK

Abstract:

Background/Introduction:

The challenges of dementia care are likely to add considerable strain to Jamaica's already overburdened health system leading to inequity in both formal and informal dementia care. Research into the costs and consequences (economic, social, emotional, health) of providing unpaid care for people living with dementia is therefore necessary. This paper will consider some of the methodological issues we have encountered in ensuring that evidence about dementia care is equitably produced. Preparation for fieldwork has been extensive and has revealed strengths and areas for growth when conducting health research that is based on partnerships between developed and developing countries.

Methods:

The paper presents our analytical reflections on the planning of highly iterative fieldwork involving in-depth unstructured and semi-structured interviews with unpaid carers of people living with dementia across multiple socioeconomic strata in Jamaica. We focus on lessons learned about our methods of preparation. These include regular meetings of the local team and the work package lead, setting up the data protection and security systems, identifying and training research assistants and developing standard operating procedures for each aspect of fieldwork.

Results (lessons learned preparing for fieldwork):

To date we have learnt several lessons that may be of use to other researchers in planning similar dementia-related research. These include: involving local researchers alongside investigative team members during project planning to ensure realistic timelines and to accommodate unexpected delays or logistical issues; investing in relationship building over time through in-person and online meetings/webinars to enhance communication and the ability to problem solve as a team; building relationships with "gatekeepers", relevant persons from the community or other sectors, to develop informed and customised recruitment strategies and sustainable knowledge translation approaches; involving research assistants in initial data collection and analysis to benefit from their intimate knowledge of the local context and to build research capacity; ensuring close collaboration between both research partners in planning analyses to discuss emerging ideas and clarify meanings within the country contexts; scheduling regular field team debriefings and e-meetings with the field team and the work package team will help to ensure the sustainability of long term collaboration.

Conclusions/Perspectives:

The process of preparing for dementia-related research that involves partnerships between developed and developing countries is complex. Our experiences emphasise the importance of building equitable partnerships between institutions and of recognising the value of 'local knowledge' in helping to interpret data. These lessons are relevant to partners in both settings when planning similar research.

Poster Presentation Abstracts

ID: 879

Abstract Topic: Diagnostic tools

Keywords: translation, neuropsychological tests, cognitive tests, dementia

Translation and adaptation process of cognitive testing instruments into Indonesian context

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Abstract:

Background:

Language and culture are some of the factors influencing the results of data collection using a standardized instrument, including that of cognitive function. As a part of the STRIDE project, a study on prevalence and dementia cost of care in Indonesia will be conducted in two provinces in 2020: Jakarta and North Sumatra. In order to assure the instruments can detect cognitive impairment accurately, a translation and adaptation into Indonesian language and context is done in 2019.

Methods:

All the instruments are translated from English into Bahasa Indonesia/Indonesian language following the WHO recommendation on the process of translation and adaptation of instruments, which comprises of: separate double forward translations into Indonesian – reconciliation – separate double backward translations into English – backward translation review – harmonisation. Translators' academic backgrounds are from medicine and psychology field. The test battery resulting from the translation process will be pre-tested to 30 participants.

Results:

The instruments can be categorised into 3 groups: those intended to be answered by 1) the older adult participants about themselves (older adult-self), 2) the carers about the person they are looking after (informant-proxy), and 3) the carers about themselves (informant-self). Challenges found in forward translations include: 1) questions about emotions and mood, in which the choice of words used in English do not always have a word that describe it accurately in Indonesian, 2) phrases without any culturally relevant translation in Indonesian (e.g: "No ifs and or buts"), 3) prepositions (e.g: in Indonesian, 'above' and 'on' are both translated into 'di atas'), and 4) single words translated into multiple words in verbal memory tests. We have discussion with experts on neuropsychological tests and review the adaptation to other languages to decide the best approach in overcoming these challenges.

Conclusion:

Cognitive testing instruments developed in English-speaking countries might have some cultural barrier to be used in Indonesia and therefore need a careful consideration in the translation and adaptation, involving native speakers familiar with the Indonesian culture and social situations.

Poster Presentation Abstracts

ID: 883

Abstract Topic: Education and training in hospitals – NEW

Keywords: Discharging Planning, Cognitive Impairment, Family Caregivers

Discharge planning for persons with cognitive impairment and their family caregivers: from hospital to home: a pilot study

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Abstract:

Background: Cognitive Impairment (CI) is associated with an increased risk of hospitalization in older people. Persons with cognitive impairment (PWCIs) in acute hospitals were reported to suffer more from dysfunctional syndromes and malnutrition. Their behavioral problems were reported to interrupt formal care routine and increased formal caregiver burdens. Due to patients' compromised cognition, involving family caregivers (FCGs) of PWCIs in acute hospitals becomes particularly essential. Effective discharge planning for older patients in acute hospitals has positive outcomes. However, a conclusion is yet to reach about how to conduct a discharge planning for PWCIs and their FCGs and which components of discharge planning are most beneficial for the dyads. Therefore, the purpose of this study was to pilot test a multidisciplinary discharge planning intervention for PWCIs and their FCGs.

Method: Using the RCT design, we pilot tested the intervention protocol on 10 PWCIs and their FCGs to exam the effectiveness of our discharge planning intervention in a teaching hospital in northern Taiwan. The sample was recruited from the internal wards such as infection, metabolic and heart disease wards. The components of discharge program included: 1. timely discharge need assessment for PWCIs and their FCGs within 48 hours admission; 2. second visit by the trained research nurse to provide individualized educational interventions for prioritizing the discharge needs of PWCIs and their FCGs and prepare FCGs for discharge; 3. a written discharge plan for patients and FCGs; 4. a follow-up home visit by the trained research nurse and 5. actively involving PWCIs and their FCGs. The control group received the usual care.

Results: When using the paired *t* test to compare the outcomes of patients and FCG between T1-T0, T2-T0, and T2-T1, we found that FCG rated patient readiness (physical condition and resources) were significantly improved. Patient satisfaction was improved in the following areas: health promotion education, teaching material, evaluation of nursing care, evaluation of intervention and nursing relationship with patients. FCG had improved their depressive symptoms through our intervention.

Conclusion: From the RCT results, we found the PWCIs in the experimental group manifested improvement in patient readiness for discharge and their satisfaction to our intervention. The FCGs also benefited from participating in the discharge planning intervention because they manifested lower levels of depressive symptoms as comparing with the baseline. Therefore, in the near future, we would like to seek for funding resources to replicate this intervention with a bigger sample and longer observational time frame.

Poster Presentation Abstracts

ID: 884

Abstract Topic: Dementia and dignity

Keywords: Dementia, Dignity, individual, counselling

Enhancing dignity in dementia: a single case analysis

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National Institute of Mental Health and Neuro Sciences, India

Abstract:

- Introduction

Various studies have demonstrated that Dementia and its manifestations can bring about dramatic changes in a person's life. A perceived loss of identity is one of the most deeply felt changes that accompany the cognitive deterioration. The present paper aims to present a single case analysis that employs an intervention to enhance the dignity of persons with early stage dementia.

- Methods

A pretest-post-test single case design was used. The client was a 53 year old lady, working full time as a teacher, who experienced increasing memory disturbances and difficulty in navigating familiar spaces. She was evaluated for her difficulties using standard diagnostic instruments and was diagnosed with Early stage of Dementia. She received multi-disciplinary team care and was referred for counselling. Dignity Therapy is a short psychotherapeutic intervention in which the therapist works with the person with dementia through a guided interview process, producing a 'generativity' document. Through this process, the therapist works with the client to identify and find ways to ensure the sense of identity that she has. The process results in a lasting, written legacy during a time when they are still able to communicate well. The interviews at the baseline and post-test were thematically analysed for observable changes and gains.

- Results / Positive impact

Initiating conversation on ensuring dignity of the individual from the early stages of cognitive impairment was found to help in alleviating the anxiety. The fear of being dependent, being seen as not in control and seeing life in perspective emerged as major themes at baseline. Socio-cultural factors and role functioning was an important influencing theme throughout the interviews. Through the process of generating legacy, the client felt that she could maintain some degree of control over the loss of identity that she found most distressing. The limitations of the study and its implications for practice, training and research will be discussed.

- Conclusions / Perspectives

Incorporating dignity oriented techniques in working with individuals who are in early stages of cognitive dysfunction will contribute towards enhancing the quality of life of the individual and family.

Poster Presentation Abstracts

ID: 886

Abstract Topic: Community partnerships / Public-Private-People partnerships – NEW

Keywords: dementia, integration network, GerIND, capability building

Geriatric integrated network for dementia (gerind): a collaboration between an Asian restructured hospital and community partners in dementia care

Ma. Eloisa Luz Cabarlo Marasigan, Ying Ting Goh, Ying Ying Yeo, Xue Qing Lam, Philomena Anthony, Win Khin Khin, Esther Peiyong Ho, Yin Cheng Yeoh, Noorhazlina Ali

Tan Tock Seng Hospital, Singapore

Abstract:

Background :

Geriatric Integrated Network for Dementia (GerIND) is a collaboration between cognition specialists in tertiary care and community partners who are involved in dementia care. It aims to integrate key partners in the medical and social sectors into the network to provide good holistic dementia care across the cognition spectrum from healthy cognitive ageing to good dementia care and end-of-life care. GerIND adopts the 'many helping hands' approach with diverse partners, to provide person-centered care for persons with dementia and up skill healthcare providers across different care settings within the National Healthcare Group Central Regional Health system. We aim to describe the implementation and evolution of GerIND till its current state.

Method:

From 2012 to 2015, efforts in dementia capability building began with the establishment of a Primary Care Memory Clinic (PCMC) in Ang Mo Kio Polyclinic (AMKP), funded by the Ministry of Health. The clinic represented a new model of shared care, where it was Family Physician (FP)-led, multi-disciplinary (medical, nursing, allied health services), and supported by Dementia Shared Care Team (SCT) from Tan Tock Seng Hospital (TTSH). GerIND was developed in 2016 to enhance collaboration between community partners and restructured hospital. Collaborations were extended to social services, senior care centres, community intervention teams, home care services and long term care facilities such as nursing homes. Various dementia training pedagogies and platforms (zonal case discussions, dementia case conferences, dementia workshops) were developed according to different care settings.

Results:

12 core team members from AMKP had been trained by Shared Care Team (SCT) through a train-the-trainer approach to triage, assess and manage new, straightforward cases of dementia. An additional memory clinic session was started in 2015 for diagnosis of new cases in AMKP. Similar models of care were started in Toa Payoh Polyclinic and will begin in Geylang Polyclinic. Since the inception of PCMC in AMKP till 2018, the clinic had seen a total of 569 patients (46.2 % discharged cases from TTSH, 53.8 % new case referrals). Due to the increased capacity in the primary care setting, TTSH Memory Clinic was able to see more new and complex cases (647 in 2018 vs 607 in 2017). 305 participants had attended GerIND workshops conducted since 2016, averaging 30 attendees per workshop. Overall, GerIND has about 23 agencies or partners with at least one staff trained by TTSH SCT. Satisfaction survey showed 100% satisfaction from agencies supported by SCT.

Conclusion:

GerIND will continue to develop its training structure and scope, to further expand and create more potential for collaboration opportunities, in particular with General Practitioners in primary care. Future

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Poster Presentation Abstracts

work will be targeted at strengthening ties with community partners and rapid access to restructured hospital's cognition specialists.

Poster Presentation Abstracts

ID: 888

Abstract Topic: Diagnostic tools

Keywords: ROCFT, neuropsychology, elders

Greek norms for the rey-osterrieth complex figure in elderly population

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¹Greek Alzheimer Association; ²The University of Sheffield International Faculty, City College; ³1st Department of Neurology, Medical school, Aristotle University of Thessaloniki, Greece

Abstract:

Introduction The Rey-Osterrieth Complex Figure Test (ROCFT) is widely used to measure visual memory, visuospatial and visuoconstational ability and perception (Lezak, 1995) in both adult and elderly populations. However, there are no previous studies extracting norms for Greek elderly population.

Methods In the current cross sectional study, the ROCFT test, specifically the following conditions Copy, Immediate recall, Delayed recall and Recognition trial, was administered in two hundred twenty eight elders from 50 to 87 years ($M=64.12$, $SD=8.69$) with education range from 2 to 18 years ($M=11.5$, $SD=4.45$).

Results According to the multiple regression analyses, age and education affect the four ROCFT tests, whereas the effect of gender was trivial. Greek Normative data adjusted for age and education level are presented for the ROCFT test, as well as the specificity and sensitivity values for the cut-off scores of its four tasks.

Conclusions Future studies could calculate the Greek norms for adult population, in order to expand its use both in research and clinical practice.

Poster Presentation Abstracts

ID: 890

Abstract Topic: Attitudes, awareness and stigma

Keywords: survey, awareness, DKAS, stakeholders' involvement

Development of a dementia awareness online survey through local stakeholders' involvement

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Abstract:

Background and objectives of the study

Dementia awareness and understanding is one of the seven key action areas of the WHO global action plan on the public health response to dementia, and the first goal of the Swiss National Dementia Strategy. In their 2012 report on dementia, ADI and WHO recommend that initiatives to improve the awareness and understanding of dementia across all levels of society actively involve patients, families, caregivers, healthcare providers and the general population. A key step in the development of effective initiatives to raise dementia awareness is collecting evidence on the local context, the target groups, and any barriers to the initiative's uptake. The goal of this study was to develop a locally appropriate, culture-sensitive survey to formally assess public awareness and knowledge of dementia in the Canton of Ticino, Switzerland.

Methods

We collaborated with the local Alzheimer's Association (AT) to develop, pilot, and test an online survey to investigate the dementia knowledge, attitudes, and beliefs in the general population of Ticino (Southern Switzerland). The collaboration (which involved patients, caregivers, and volunteers) was grounded on a participatory approach ensured by regular contacts for consultation and approval. In addition, we also included a previously validated scale (the Dementia Knowledge Assessment Scale, DKAS).

Results

Beyond the DKAS, the final version of the survey included questions on the perceived importance of three main dementia research domains (prevention, diagnosis, and treatment/care), attitudes towards research participation, and a question used to explore the so-called "knowledge illusion bias", that is the perceived knowledge of dementia *before and after* responding to the survey. Agreement on the final version the survey was reached through online and in-person discussions and meetings, and the questionnaire implemented in REDCap to ease data collection and management.

Conclusions

We have successfully developed a culture- and context-sensitive questionnaire to explore public awareness, understanding, and acceptance of dementia, and willingness to participate in dementia research in older adults in Southern Switzerland.

Poster Presentation Abstracts

ID: 894

Abstract Topic: Epidemiology

Keywords: 10/66 dementia, concurrent validity, validity, nursing homes, Italian

The 10/66 short dementia diagnostic schedule in nursing homes: a validation study

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Abstract:

Introduction: The latest estimated number of people suffering from dementia in Italy is 1.272.317, which represents 2.09% of the total population. More than 50% of those living with dementia are residing in nursing homes. However, the majority of them are underdiagnosed and do not receive the proper treatment and care. This prompts further research to provide updated prevalence data on dementia in such settings. The short version of the 10/66 dementia diagnostic schedule has been used in community settings. Evidence on its validity in institutional care facilities is lacking.

Background and objectives: The aim of this study was to test the criterion and concurrent validity of the short version of the 10/66 dementia diagnostic schedule in an older adult population residing in nursing homes in Northern Italy.

Methods: Data was collected from all older adults (65+) residing in nursing homes in Asti, Italy. The criterion validity of the short version of the 10/66 dementia diagnostic criteria, derived from the Community Screening Instrument for Dementia, the modified Consortium to Establish a Registry of Alzheimer's Disease 10-word list delayed recall and the EURO-D Depression Scale were examined against local clinical diagnosis as a gold standard. Concurrent validity was tested by examining the relationships between the short version 10/66 dementia diagnosis and disability measured with the WHO disability assessment schedule 12-items version.

Results: A total of 103 respondents who had completed data on the short version diagnostic schedule were included in this study. The short version of the diagnostic schedule had substantial agreement with clinical diagnosis (77.27% specificity, 92.50% sensitivity, Kappa = 0.69, AUC = 0.85). We also found that those with the short version 10/66 dementia were significantly associated with higher disability.

Conclusions & Scalability of the project: We found empirical evidence that the short version 10/66 dementia diagnosis is a valid case ascertainment tool to diagnose dementia in nursing homes in the Italian population. Using the short version of the 10/66 diagnostic schedule can help in providing regular, consistent and systematic assessment of cognitive functions of older residents in nursing homes across the country and beyond.

Poster Presentation Abstracts

ID: 895

Abstract Topic: Economics of dementia

Keywords: economic impact- Alzheimer disease-

The economic impact of Alzheimer's Dementias through a hospital cohort In Tunisia

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CIC Razi University Hospital, LR FMT UTM Tunisia

Abstract:

Background

IN Tunisia Alzheimer's Dementias have become a public health concern because of their frequency, impact on the quality of life of patients and their families, high cost of care, and the mobilization of multidisciplinary health professionals. Alzheimer's dementia was estimated to affect 3.2% of people aged 65 years and over in 2012. However there is no published data estimating the cost of these diseases.

Objective

This study aimed to assess total, direct and indirect costs of Alzheimer's dementias in Alzheimer unit at Razi hospital.

Methods

Community –dwelling patients attending Alzheimer unit of the RAZI Hospital's Neurology Department and their primary informal caregivers were enrolled in an observational study carried out during the period spanning from Mai to July 2018.

To collect health and non health resources consumption, we used the Arabic version of RUD3.2 questionnaire (Resource Use in Dementia).

The societal total costs were calculated by summing Direct and Indirect costs. The opportunity cost approach was used to estimate indirect costs.

Results:

A total of 92 patients were recruited, 54% of whom were women with an average age of 76 years. The average time spent (h/day) was 6.67 (2-15) for each patient with Alzheimer's dementia. The average direct cost was 182TND (\$63) per month. The indirect cost was 742 TND (\$168). The average total monthly cost was 990 TND (\$345).

Comments

This is the first study on Alzheimer's dementias in Tunisia, in the study design phase we referred to international popular survey method.

Nevertheless, some limitations should be highlighted. The sample size is low and the sample design used was not representative with selected population coming from poor area. Information bias is possible since retrospective data was used.

Conclusion

The high cost of informal care for Alzheimer's dementia suggests the need for special attention by all healthcare decision-makers and more publicly-funded long term care services to assist family caregivers.

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Actually a study with a larger sample size, for a longer period of time is recommended in order to better estimate the cost of Alzheimer's dementias in Tunisia.

Poster Presentation Abstracts

ID: 897

Abstract Topic: Dementia and equitable society – NEW

Keywords: CAREGIVER RESENTMENT DEMENTIA

Primary caregiver resentment of patients with dementia

Raul Fernando Gutierrez, Maria de Lourdes Cristina Mondragon, Celina Gomez, Hector Riquelme, Eduardo Mendez, Felix Martinez

Facultad de Medicina de la Universidad Autonoma de Nuevo Leon, Mexico

Abstract:

INTRODUCTION

Dementia is a chronic neurodegenerative and progressive condition characterized by alterations in cognitive processes, behavior and mood; generator of disability and dependence.

In the world it affects approximately 10% of people over 65 and half of those over 85, with a total of 47.5 million people affected and 7.7 million new cases per year.

Mexican National Survey 2012 a prevalence of 7.9% was found.

Alzheimer's disease represents 60 to 70% of dementias..

The term primary caregiver refers to the person who assumes responsibility for patient care and usually has a family relationship: spouse, children, siblings, among others.

The reactions of caring for a persona with dementia affect mental health due to burden, stress, depression and anxiety.

Anger and resentment are emotions that caregivers often feel, sometimes leading to violence.

Studies reveal that resentment was the only statistical predictor of anxiety or depression symptoms.

Associated with a poor interpersonal relationship, col-residence and behavioral alterations and behaviors classified as controlling or manipulative.

Anger and resentment can impact the caregiver's overall situation and decrease the quality of care.

There are no studies in our country about resentment.

OBJECTIVE

General:

To demonstrate the presence of resentment in caregivers of patients with dementia..

Specific:

1. To measure the prevalence of resentment in caregivers.
2. To describe the profile of the caregivers associated with the presence of resentment.

MATERIAL Y METHODS

Design: Descriptive observational study, through questionnaire application. Conducted in 147 primary caregivers of a family member with a diagnosis of dementia who attend to Family Medicine Department of the University Hospital. Non-probabilistic convenience sampling to caregivers and who agreed to participate in 2017.

Approved by Ethics and Research Committees of the Institution..

A questionnaire with sociodemographic data of both the caregiver and the patient, characteristics of the disease and care was applied. The Resentment Scale of Thompson et al., con alfa de Cronbach .92 was applied.

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Data analysis: It was done in SPSS version 20 for Windows. Frequencies and percentages and the cut-off score of the Resentment Scale were obtained according to the median of 30. Chi square was used for categorical variables with a value of $p < 0.05$.

RESULTS

Profile of the caregiver

They are women, 53 years of age average, married, with college education, housewives, who reside in Monterrey, Mexico of medium socioeconomic level, Catholics, who take care mainly of their mother, 7 days a week, average of 15 hours per day, without receiving any remuneration.

About two third receive help mainly from siblings and children. More than a third are lonely caregivers.

They have hypertension, diabetes and depression, mainly.

They have presented economic and personal health crisis. They consider their health between good and not so good.

Most of them do not attend to support groups

Profile of the elderly

They are women, 81 years of age average, widows, with elementary school, housewives, living in Monterrey, Mexico, medium socioeconomic level, Catholics, who live mainly with their children and spouse.

They have a diagnosis of dementia of 3 years, with a mild to moderate degree, with institutional medical insurance.

They mainly suffer from hypertension and diabetes mellitus.

They present difficulties in motor skills and hearing.

Of the behavioral, they present disorientation, anxiety and isolation.

They have not been hospitalized.

DISCUSSION

Dementia is a disorder that presents cognitive, functional and behavioral impairment that conditions the presence of resentment in the caregiver due to all the activities that must be performed. The degree of dementia was mild to moderate in 64.8% and care activities vary from 59.5% to 86.5%, which implies a burden for the caregiver.

In addition, when they feel too much responsibility associated with care, in 43.2% the caregivers expect to be treated as if they were the only person they depended on, 44.0%. Not having time for him/herself, in 40.5% were the most significant.

In relation to resentment in the international literature, mainly in USA, a prevalence was found between 41.2% and 62.3% compared to our result, which we found 45.6%. This indicates that resentment is a very frequent feeling in the caregiver, classified as a negative feeling.

Resentment has been highly correlated with the presence of depression in the caregiver and with potentially harmful behavior towards the patient with dementia, gathering the risk profile for abuse.

Another US study reveals that there is a correlation between depression and resentment.

In co-residence, a predictive factor for resentment we found that 57.8% live with children and 8.1% with spouses, which shows that children take care of one of their parents, perhaps as a form of compensation.

The lack of communication by the health professional was related to the presence of resentment, perhaps due to ignorance of the disease and uncertainty.

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CONCLUSIONS

About half of the caregivers show resentment.

There are factors related to the presence of resentment such as the occupation, as student and merchant. Activities related to care such as dressing the patient, transferring and accompanying him/her to the toilet, not living in the same city and others factors that act against of the presence of resentment such as attending supports groups and practicing a religion.

Caregivers who were not informed by the health professional of the degree of patient's dementia presented greater resentment, as well as ignoring the degree of dementia.

The profile of the caregiver coincides with international literature.

Resentment is a negative feeling that should be valued in caregivers.

RECOMENDATIONS

To plan strategies to prevent and treat resentment in caregivers by knowing their profile and thus avoid its consequences.

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Poster Presentation Abstracts

ID: 899

Abstract Topic: Dementia and equitable society – NEW

Keywords: CAREGIVER GUILT DEMENTIA

Primary caregiver guilt of patient with dementia

Hector Riquelme, Maria Jose Cavazos, Eduardo Mendez, Celina Gomez, Raul Fernando Gutierrez, Felix Martinez

Facultad de Medicina de la Universidad Autonoma de Nuevo Leon, Mexico

Abstract:

INTRODUCTION

The world today lives an unprecedented demographic transformation causing changes in the structure by age of the population, leading to an aging process, which mostly includes situations of dependence and/or disability, among which are some type of cognitive impairment with a tendency to dementia.

The care of a patient with dementia is demanding in different areas; one of them, time, which is monopolized by the various activities required by the patient, causing emotional discomfort, in which, the guilt lies with the predominant feelings in the caregiver.

Guilt is described as a negative emotion that involves remorse of both the thought, feeling or actions of the person, which is conscious and implies the feeling of responsibility.

Guilt is influenced and conditioned by culture, whose presence produces mostly negative effects and is a tool for the control of society. It is perceived as phenomenon whose presence causes discomfort and that can be replaced by the reasoning of actions.

High scores of feelings of guilt have been linked to depression, anxiety, burden and stress.

There are not previous investigations about the feelings of guilt in the caregiver of patient with dementia, so there is a need to perform it.

OBJECTIVE

General:

To determine the prevalence of feelings of guilt in primary Caregivers of patients with dementia.

Specifics:

1. To define the profile of the primary caregiver of patients with dementia..
2. To define the profile of the patient with dementia..
1. To correlate the time of care with the score of the caregiver guilt questionnaire

MATERIAL Y METHODS

Design: Descriptive, cross-sectional observational study, through questionnaire application. Carried out in 124 primary caregivers of a family member with diagnosis of dementia who attend to Family Medicine Department of the University Hospital. Non-probabilist convenience sampling to caregivers and who agreed to participate in 2017.

Approved by the Ethics and Research Committees of the Institution.

Poster Presentation Abstracts

A questionnaire with sociodemographic data of both the caregiver and the patient, characteristics of the disease and care was Applied. The Guilt Questionnaire of the Caregivers of Losada et al. Alpha de Cronbach alpha of 0.88.

Data analysis: It was done in SPSS versión 20 for Windows. Frequencies and percentages were obtained. Cut-off score of the Guilt Questionnaire was 22. The instrument score consists of the sum of all items; a higher score reflects greater guilt. Chi² was used for categorical variables with a value of $p < 0.05$.

RESULTS

Profile of the caregiver

They are women, 53 years of age average, married, with college education, housewives, who reside in Monterrey, Mexico of medium socioeconomic level, Catholics, who take care mainly of their mother, 7 days a week, average of 15 hours per day, without receiving any remuneration.

About two third receive help mainly from siblings and children. More than a third are lonely caregivers.

They have hypertension, diabetes and depression, mainly.

They have presented economic and personal health crisis. They consider their health between good and not so good.

Most of them do not attend to support groups

Profile of the elderly

They are women, 81 years of age average, widows, with elementary school, housewives, living in Monterrey, Mexico, medium socioeconomic level, Catholics, who live mainly with their children and spouse.

They have a diagnoses of dementia of 3 years, with a mild to moderate degree, with institutional medical insurance.

They mainly suffer from hypertension and diabetes mellitus.

They present difficulties in motor skills and hearing.

Of the behavioral, they present disorientation, anxiety and isolation.

They have not been hospitalized.

DISCUSSION

Dementia is a disorder that presents cognitive, functional and behavioral impairment that conditions the presence of guilt in the caregiver due to all the activities that must be performed. Also, when the caregivers feel too much responsibility associated with the care,

The degree of dementia was mild to moderate in 60,6%.

The prevalence of guilt in our study is higher than was found in the Spanish population of 17.9% and in the British population of 27.6% compared to ours, which was 53.2%, perhaps due to sociocultural factors.

Calzada, et al (2015) mentioned that as longer the evolution of the suffering and care of the person with dementia, there is less guilty feelings; in our study it was not significant,

CONCLUSIONS

More than half of the caregivers have feelings of guilt.

Caregivers feel guilty when thinking about their lack of information and preparation to take better care of their family member.

Caregivers feel guilty about having negative emotions and feelings regarding care; for having ever scolding the person they are taking care; for doing some pleasant activity and not being caring and because of the way they have behaved with their relative.

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RECOMENDATIONS

To plan strategies preventing and deal with guilt in caregivers by knowing their profile and thus avoid its consequences.

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Poster Presentation Abstracts

ID: 900

Abstract Topic: Dementia and equitable society – NEW

Keywords: STIGMA BURDEN ALZHEIMER'S DISEASE

Stigma and family burden in Alzheimer's disease

Celina Gomez, Ileana Aranda, Raul Fernando Gutierrez

Facultad de Medicina de la Universidad Autonoma de Nuevo Leon, Mexico

Abstract:

BACKGROUND

Many factors influence the perceived burden of caring for a relative with Alzheimer's Disease (AD).

Family, public and structural stigma had been described in caregivers of people with dementia.

Research in the area of stigma and AD is scarce.

Family physicians should be aware of the impact of stigma on caregivers so that they can provide more effective support.

OBJECTIVE

To correlate the family stigma with caregiver burden of family member with Alzheimer's disease.

MATERIAL AND METHODS

Design. Descriptive, correlational study with structured face to face interviews by convenience sample.

Setting. Monterrey Mexico Alzheimer Association. **Participants.** 60 primary caregivers, over 18 years of age and who volunteered to participate, in 2014. The study was approved by the Institution Ethics and Research Committees with FM14-005 code. **Main outcome measures.** The AD FS-validated scale on family stigma in Alzheimer disease and Zarit burden scale were used. Spearman correlation was performed between the score of Zarit, which assesses burden and different types of stigma. The χ^2 for categorical variables with a P value <0.05 was used.

RESULTS

Caregivers profile

Mostly women, of 53 years on average, married, housewives, with college education, Catholics, with medical insurance and medium income. Caring usually of her mother for 5 years or less, 78 years on average, 7 days a week, 24 hours. Third part of caregivers receive help of 2 persons, usually siblings. Half of them are healthy, and those who have a disease are hypertension and diabetes.

DISCUSSION

The most notable finding is the impact of family stigma on burden (moderate to severe), it suggest the caregiver's perception of being stigmatized by their association with the sick relative. More than a third of Caregivers refer limited distancing and social interactions with the person with Alzheimer, not with the same severity found by Liu, et al, 2008 perhaps due to the lack of knowledge about the disease and the reactions of others with the behavioral problems. In the emotional attributions in both the caregiver and the public, the desire to be useful, provide support and help prevails. Positive emotions, like sympathy were high both in the caregiver and in the dimensions of the public. Contrary to what was reported by Werner, Mittelman, Goldstein and Heinik (2012), in which the shame was high. shame represented 16.7%.

Mac Rae, 1999; Werner & Davison (2004) found that people with Alzheimer cause more positive than negative reactions. In half of the cases, compassion, grief and misfortune were presented. In a third part there was annoyance, embarrassment and terror of caring for his relative.

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CONCLUSIONS

Family stigma is more related to caregivers burden. Public stigma is associated with moderate caregiver burden. Structural stigma is not related to caregiver burden.

Effects of stigma are harmful to caregiver burden.

Effectiveness of evidence based clinical interventions may be significantly increased if we evaluate and address caregiver stigma. ++

RECOMENDATIONS

Effectiveness of evidence-based clinical interventions can be significantly increase if the caregiver's stigma is evaluated and addressed. Conduct future research on the impact of stigma on formal caregivers and different socioeconomic status.

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Poster Presentation Abstracts

ID: 902

Abstract Topic: Dementia and dignity

Keywords: dementia, philosophy, personal identity, dignity

Clinician reflecting on patients with dementia: can philosophy help?

Zvezdan Pirtosek, Milica Kramberger

University Medical Centre Ljubljana, Dpt of Neurology, Slovenia & Chair of Neurology, Faculty of Medicine, University of Ljubljana

Abstract:

Reasonable thinking (*Lógos* or *Word*) has remained one of the great issues of philosophy from the times of Heraclitus. The Delphic maxim "Know thyself" (γνῶθι σεαυτόν, transliterated *gnōthi seauton*) echoed in philosophical systems of Socrates, Plato, Kirkegaard and existential philosophers. Neurological dimension started to shape modern philosophy of mind with the emergence of cognitive science and the new field of neurophilosophy

Dementia - as the final act in the drama of progressive decline of *Lógos* – has been rarely addressed by philosophers, mainly with the questions of the nature of mind, nature of normality and of ageing, nature of personal identity, personhood and selfhood and nature of human (patient's and carer's) suffering.

In this presentation, the philosophical question of personal identity will be addressed.

Two main accounts of the personal identity can be traced through the history of philosophy: (i) a 'commonsense' *memory* based understanding of the identity represented particularly by Locke, Descartes and others, (ii) in the tradition of continental philosophy rooted *embedded-in-the world* identity (Heidegger, Merleau-Ponty).

The former defines Selfhood as an ability to order personal memories and it largely represents a default way in dementia discourse and in dementia management (keeping the brain as fit as possible, relying on external supports: from *Do-it* notes to implants). It is powerful, deeply rooted in clinician's mind setting, but also dangerously partial (dispersed circuitries of selfhood & memories), often leading to a silent denial of patient's Selfhood.

The latter defines Selfhood not only as an autobiographical string of memories, but rather as an interlace of relationships with others, as 'beings-in-the-world'. This view explains why the sense of loss that comes with dementia is inevitably shared (suffering of the carer) and rather than pin hopes on memory implants, it emphasizes the role of adaptive attitudes and environments. Also, detailed observation of the life of many demented patients reveals that fundamental moral principles & dignity might remain unaffected even when the social being, based on experience & education vanishes.

Therefore, not only our intuitions and wishes, much of philosophy also supports the view that patient with dementia is still a person with interior life, who should be treated with respect and dignity.

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Poster Presentation Abstracts

ID: 904

Abstract Topic: Dementia and spirituality

Keywords: dementia, paradoxical lucidity, communication

Paradoxical lucidity in dementia: new questions, new interpretations

Zvezdan Pirtosek

University Medical Centre Ljubljana, Slovenia

Abstract:

A case of an unexpected, dramatic, meaningful, and relevant verbal communication and social connectedness in a 72-year man who was, for the last two years, assumed to have utterly and permanently lost the capacity for meaningful verbal, motor, emotional or cognitive interaction due to advanced dementia with Lewy bodies, is described.

The presentation will address this phenomenon, called paradoxical lucidity and unveil important questions and ethical issues that it raises, but also demonstrate how paradoxical lucidity is offering new interpretations of mechanisms and pathophysiology in neurodegenerative dementias.

Poster Presentation Abstracts

ID: 912

Abstract Topic: Well being and quality of life

Keywords: Acute confusional state, prevention, management, guideline, Hospitalized older patients

Evaluation of guideline implementation for prevention and management acute confusional state in hospitalized older patients

Tipanetr Ngamkala, Porntip Malathum, Orapitchaya Krairit

Mahidol University, Thailand

Abstract:

Acute confusional state is a common phenomenon associated with acute illness in hospitalized older patients, especially, ones with dementia. This symptom usually decreases cognitive function abilities, on the other hand, increases costs of care, hospitalization period, mortality, and institutionalized rate. The purpose of the study was 1) to develop guideline for prevention and management acute confusional state 2) to evaluation this guideline after implemented in Ramathibodi Hospital, Thailand. This one group pretest-posttest design and prospective study had been conducted between June and September 2018 in 60 years old or above patients who were admitted to a general medicine ward. The Confusion Assessment Method (CAM) was selected to measure outcome collaborated with specialize evaluation. The average age of the sample ranged from 64 to 89 years (M=79). The patients were assessed by nurse and advanced practice nurse, then were evaluated by a geriatric consultant to managed a care plan for them. Non-pharmacological was the main nursing care and antipsychotics drug might be prescribed.

The study found that after implemented guideline protocol, the incidence of acute confusional state was 3.87% decreased from 12.85% in the preliminary survey. The symptom usually showed up with in the third day of the admission and took 2 to 17 days to recovery. Common risk factors were multifactorial, including infection (69.20%), electrolyte imbalance (61.50%), dehydration (38.50%), hypoxemia (15.40%), and hypoglycemia (7.70%), respectively. All of the sample had more than two risk factors. The highest type of acute confusional state was Hyperactive which was at 61.50% and were restrained at 69.20%, no complication such as fall, injury and pressure ulcer reported during admission.

Poster Presentation Abstracts

ID: 915

Abstract Topic: Dementia and spirituality

Keywords: Stream Café; Alzheimer café; Spiritual care

Stream café: the use of gospel activities for both people with dementia and their caregivers

Wen-Chuin Hsu^{1,2,4}, Li-Yu Tang^{1,2}, Mei Mei Niou¹, Hsiu-Hsia Pan^{2,3}, Chen-Chen Chang²

¹Taiwan Alzheimer's Disease Association; ²Foundation of Wisdom; ³Bread of Life Christian Church;

⁴Dementia Centre Chang Gung Memorial Hospital

Abstract:

In Stream Café, a model of Alzheimer café, we gathered both people with dementia and their caregivers.

For caregivers, a talk of one of experts, in various fields which are interesting to them, was to catch their attention and to enrich their knowledge and life. Following it, a carer support group was conducted by a facilitator. In addition to the supportive atmosphere, the participants could be comforted by spiritual materials given *impromptu*. We pray for people with dementia and carers, we enjoy the hymn sign together.

We arrange activities for people with dementia in a separated room while family carers participate support group. The activity leaders brought spiritual music, songs and handcraft activities to people with dementia. People with dementia read and copy the scriptures. We made Gospel into activities. It became the bread of their mind. Both people with dementia and carers felt love and peace in the activities.

The work power was consisted with, in majority, the volunteers from different churches. They were recruited while we toured around different churches for educational purposes. They were committed to learn how to communicate with people with dementia and to support caregivers of people with dementia. We conducted volunteer trainings for them and involved them in the Stream Café. When these volunteers are well trained they became the trainers of dementia service in their own churches. We will share more about the achievement and challenge.

Poster Presentation Abstracts

ID: 916

Abstract Topic: Informal carers training

Keywords: Informal carers, family functioning, persons with dementia, Training and education

Family dynamics of informal carers among persons with dementia- rural Thiruvananthapuram, Kerala, India.

Sam Sangeeth, Daniel Solomon

Bishop Heber College, India

Abstract:

Dementia is a progressive, chronic, non-communicable disease where family mediation is highly required. The aim of the study is to investigate the family functioning of cares of persons with dementia. The following objectives were framed in order to achieve the overall aim of the study which is as follows. To describe the socio-demographic characteristics of the respondents, to measure the family functioning of respondents and to understand strength and weakness of the family functioning of the respondents and to suggest measures to develop smoother family functioning. The hypotheses were framed for the study. The researcher has adopted sequential exploratory research design. 135 samples were selected in rural Trivandrum by adopting survey method. McMaster's family assessment device was developed by McMaster in year 1983 was administered. The scale consists of 7 domains, 53 items and it is 4 point likert scale. The instrument has both positive and negative items. In-home interviews were adopted to collect data from the selected respondents and the collected data was analyzed using Statistical Package for Social Science

It was found that the respondents were experiencing moderate family functioning from qualitative results. Furthermore results in specific will be discussed in the conference. So geriatric care and social gerontology studies has to boom to fulfill the unmet needs of family carers with persons with dementia. This scenario highlights that there is urgent need for family mediation, administration of therapies and intervention globally for maintain the families in hemostatic in spite of a presence of a person with chronic illness. Families have to be sensitized on timely and early identification and intervention. Training needs are enormous for families for persons with dementia.

Poster Presentation Abstracts

ID: 920

Abstract Topic: Dementia and the Convention on Human Rights of Persons with Disabilities (CPRD) – NEW

Keywords: UNCRPD, MentalCapacityAct, Dementia, WillandPreference, AdvanceStatement

The 'will and preference' paradigm and what it means to a person with dementia - is this realised by the mental capacity act in Singapore?

Yue-En Chong

Bethel Chambers LLC, Singapore

Abstract:

The Singapore Mental Capacity Act is modelled after the England and Wales Mental Capacity Act. A hallmark of the MCA is that it introduces a support decision making regime where a person (called 'a patient') with fluctuating or deteriorating mental capacity is to be supported and assisted in their decision-making process where they are encouraged to make their own decisions. In situations where the patient is assessed and found to not possess the necessary mental capacity to make their own decisions, a donee or a deputy, adopts a 'best interest' framework and then makes decisions in the 'best interest' of the patient. One of the factors in the 'best interest' framework is the Patient's 'past and present wishes and feelings and in particular, any relevant written statement made by him when he had capacity.' This is pertinent to persons with dementia where it is reasonable for the person with dementia would have expected his will and preferences to be primarily guide for his donees and deputies when he is unable to articulate decisions.

Yet, this 'best interest' framework in the Mental Capacity Act has been criticised Committee on the Rights of Persons with Disabilities in General Comment No. 1 (in 2014) to not to be compliant with Article 12 of the UN CRPD with demands that the 'best interest' framework must be replaced with a 'will and preferences' paradigm.

This presentation would firstly summaries the current analysis and interpretations of this 'will and preferences' paradigm by legal scholars and then examine in the practice of mental capacity law in Singapore is aligned with Article 12 and Article 13 of the UN CRPD. Thereafter, the author would examine the current legal documentations in order to preserve a person's will and preferences before finally proposing possible avenues to reform and the corresponding challenges such that this could perhaps be more aligned 'will and preferences' paradigm as wanted by the CRPD Committee.

Poster Presentation Abstracts

ID: 921

Abstract Topic: COVID-19 and dementia - NEW

Keywords: dementia, Admiral Nurses, experiences in practice, COVID

Evaluating the experiences of admiral nurses during the COVID-19 pandemic

Gayle Madden¹, Karen Harrison Dening¹, Kay De Vries²

¹Dementia UK, United Kingdom; ²De Montfort University, Leicester

Abstract:

COVID-19 has meant that people, organisations and governments have had to make huge changes to lives and ways of working. This study explores its impact on Admiral Nurse (AN) practice (specialists in dementia care who support families affected by dementia) [1]. They use a case management approach to provide psychological support, advice and information to help families adapt to their changing situation. During the pandemic families living with dementia have felt less supported than during normal times [2]. ANs have proved to be an adaptable and flexible workforce in these challenging times. It is important to examine how a workforce adapts its practice, but also how they feel about this; what their lived experience is; how prepared they felt and what existing clinical skills they have drawn upon and whether they have identified new skills required. Such knowledge is of value in ensuring they are equipped in future pandemic situations and ensure their resilience in supporting families affected by dementia. This evidence is important for the Dementia UK AN Practice Development Team to continue to target education and resources in support of ANs post COVID-19. It is anticipated that the learning from this study will be applicable to other roles and models of dementia care and support.

The research used qualitative, semi-structured interviews following a topic guide and aimed for a sample of 20 ANs from various care settings, such as, community, acute hospital, hospice and care homes. All ANs were informed of the study during their monthly practice development sessions and invited to participate. Purposive sampling was carried out of those that expressed interest. The aim was to ensure that the final sample was represented by ANs from all settings which involved a process of accepting the first four nurses from each of the identified settings. Interviews were audio recorded using the Microsoft Teams platform, transcribed verbatim and anonymised by assigning a participant code.

A total of 19 ANs were interviewed during August 2020. Interviews were analysed using a theoretically flexible thematic approach that follows 6 phases [3], 1: gaining familiarity with data; 2: generating initial codes; 3: searching for themes; 4: reviewing themes; 5: defining and naming themes; 6: producing the report.

Currently the researchers are analysing the data and expect to be able to present early findings to the ADI 2020 conference.

Aldridge Z, Burns A & Harrison-Dening K (2019) ABC Model: A tiered, integrated pathway approach to peri and post diagnostic support for families living with dementia. *Dementia*. <https://journals.sagepub.com/doi/10.1177/1471301219838086>

Wang H, Li T, Barbarino P, Gauthier S, et al. (2020) Dementia care during COVID-19. *Lancet*. 2020 Apr 11;395(10231):1190-1191. doi: 10.1016/S0140-6736(20)30755-8

Braun, V., Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3:2, 77-101.

Poster Presentation Abstracts

ID: 922

Abstract Topic: COVID-19 and dementia - NEW

Keywords: social care, COVID-19, mental health

Impact of COVID-19 related social support service closures on people with dementia and carers

Clarissa Giebel^{1,2}, Jacqueline Cannon³, Kerry Hanna¹, Sarah Butchard^{1,2}, Ruth Eley⁴, Anna Gaughan⁴, Aravind Komuravelli⁵, Justine Shenton⁶, Steve Callaghan⁷, Hilary Tetlow⁸, Stan Limbert², Rosie Whittington⁹, Carol Rogers¹⁰, Manoj Rajagopal¹¹, Kym Ward¹², Lisa Shaw¹, Rhiannon Corcoran¹, Kate Bennett¹, Mark Gabbay^{1,2}

¹University of Liverpool, UK; ²NIHR ARC NWC, UK; ³Lewy Body Society, UK; ⁴Life Story Network, UK; ⁵North West Boroughs NHS Trust, UK; ⁶Sefton Older People's Forum, UK; ⁷EQE Health, UK; ⁸SURF Liverpool, UK; ⁹Me2UCare, UK; ¹⁰National Museums Liverpool, UK; ¹¹Lancashire & South Cumbria NHS Trust; ¹²The Brain Charity, UK"

Abstract:

Accessing social support services, such as day care centres, support groups, or paid home care, are important to live well and independently in the community after a dementia diagnosis. With sudden public health measures imposed in March 2020, including a nationwide lockdown, accessing these services is likely to be affected. The aim of this qualitative study was to explore the experiences of people living with dementia and carers in accessing social support services since the pandemic. For this purpose, we interviewed 50 carers and people living with dementia in the UK in April 2020, and asked them about their experiences of accessing care and whether services were providing any form of remote support. Interviews were conducted over the phone and transcripts were analysed using thematic analysis. Looking at the overall experiences, we identified three overarching themes: (1) Loss of control; (2) Uncertainty; and (3) Adapting and having to adapt to the new normal. Carers noted faster deterioration of the dementia since the pandemic, and were worried about whether their relative with dementia would be able to go back to social support services once these would re-open. There was also a great deal of concern as to when and how services would re-open. Where remote services were provided, which was very limited, the support was not adequate, and not suitable to everyone based on their dementia symptomatology and limited internet access issues. These are some of the first findings on how people with dementia and carers have been affected early on during the pandemic, and findings highlight the importance of better supporting these groups during the second wave of the pandemic, which we are currently facing.

Poster Presentation Abstracts

ID: 924

Abstract Topic: COVID-19 and dementia - NEW

Keywords: dementia, peer support, virtual groups, COVID-19

Exploring the experiences of families affected by dementia during the COVID-19 pandemic

Karen Harrison Dening^{1,2}, Emily Cousins², Ghazal Mazloumi³, Kay De Vries²

¹Dementia UK, United Kingdom; ²De Montfort University, Leicester; ³University of Nottingham

Abstract:

Coronaviruses cause illness in animals or humans. In humans, several coronaviruses are known to cause respiratory infections ranging from the common cold to Severe Acute Respiratory Syndrome. The most recently discovered coronavirus is COVID-19. The World Health Organisation declared the outbreak as a global health emergency in January 2020 [1]. The pandemic has led to huge changes to our ways of working and living. As part of the UK government's response to containing the infection a 'lockdown' was enforced and people were asked to stay at home and physically distance from March 2020. Living with dementia at any time brings everyday challenges for the person and those around them, in particular carers of people living with dementia (PLWD) often experience greater mental and physical strain than those supporting people with other long-term conditions [2]. The UK's National Dementia Strategy recognises that peer support can be a helpful way of addressing some of these challenges. Peer support is a system of giving and receiving help to fellow members of a group founded on the key principles of commonality of experience, reciprocity of support and shared learning [3]. However, peer support groups were suspended to maintain the principles of social distancing and to avoid unnecessary contact with others. Trent Dementia is a small charity in the East Midlands of the UK who facilitate several peer support groups. They responded to the enforced closure of face-to-face groups by streaming them all on-line. It is important to understand how the changes brought about by the pandemic have impacted on individual experiences of PLWD and their family carers. It is important to understand how the temporary measures employed by facilitating such groups remotely was of use to participants. The aim of this research was to explore the experiences of families affected by dementia attending a peer support group before and during the COVID-19 pandemic.

Objectives: i) to gain an understanding of the experiences of people with a diagnosis of dementia and their family carers during the COVID-19 pandemic; ii) explore the impact and implications of lockdown on PLWD and their family carers

Using semi-structured interviews, participants were recruited from three peer support groups operating virtually in Nottinghamshire, UK. Up to 20 participants were sought (10 PLWD; 10 family carers). Currently the researchers are analysing the data and expect to be able to present early findings to the ADI 2020 conference.

WHO (2020) <https://www.who.int/emergencies/diseases/novel-coronavirus-2019/question-and-answers-hub/q-a-detail/q-a-coronaviruses>.

Smith et al. (2018) The impact of befriending and peer support on family carers of people living with dementia: A mixed methods study. *Archives of Gerontology and Geriatrics*. 76: 188 – 195.

Keyes et al. (2016) We're all thrown in the same boat: A qualitative analysis of peer support in dementia care. *Dementia*. 15(4): 560 – 577."

Poster Presentation Abstracts

ID: 926

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Dementia; COVID-19; care homes; ethical care; ethical values

Delivering ethical care during the COVID-19 pandemic: considerations relating to care home residents living with dementia in the UK

Emily Cousins¹, Kay de Vries¹, Karen Harrison Denning²

¹De Montfort University, United Kingdom; ²Dementia UK, United Kingdom

Abstract:

Introduction

The COVID-19 pandemic has had a devastating impact on care homes, particularly for those residents living with dementia. The authors conducted a media analysis review of news and academic articles, to understand the initial and emerging impact of COVID-19 on care home residents living with dementia during the early months of the pandemic. That review identified ethical care as a key theme warranting further investigation within the context of the COVID-19 crisis in care homes.

Consequently, this paper has two aims. First, to discuss the experience of ethical care for care home residents living with dementia during the pandemic. Second, to offer suggestions for how the dementia research community active in care homes can respond to the COVID-19 pandemic with ethical integrity.

Methods

To explore ethical care further, a set of salient ethical values for delivering care to care home residents living with dementia during the pandemic were derived from a synthesis of relevant ethical standards, codes and philosophical approaches. These professional standards and codes were specific to the UK. The ethical values identified were: caring, non-maleficence, beneficence, procedural justice, dignity in death and dying, wellbeing, safety and personhood.

These ethical values were used to analyse real life experiences of care home residents living with dementia, which were reported in media and academic articles during the initial phase of the COVID-19 pandemic, and the extent to which they received ethical care.

Results

The analysis identifies positive examples of ethical values displayed by care home staff, care sector organisations, healthcare professionals and third sector advocacy organisations. However, concerns relating to the death rates, dignity, safety, wellbeing and personhood – of residents and care home staff – are also evident. Based on the analysis, implications for ethical care practice and research during the COVID-19 pandemic are also discussed

Conclusions

Exceptional sacrifices have been made by health and care staff displaying strong ethical values and behaviours during the pandemic. However, care home residents living with dementia, and health and care professionals, have been let down by a system unable to cope with these unprecedented circumstances. Shortcomings in the delivery of ethical care during the COVID-19 pandemic are attributable to negligent government strategy, which resulted in delayed guidance, lack of resources and PPE, unclear data and inconsistent testing. Consequently, this paper champions the work of care homes during the pandemic, and draws attention to the ways in which they are underfunded, under resourced and undervalued.

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Poster Presentation Abstracts

ID: 927

Abstract Topic: Economics of dementia

Keywords: economic costs, caregiver costs, agitation

THE COSTS OF AGITATION: A LITERATURE REVIEW

Mary Michael

Otsuka America Pharmaceutical, United States of America

Abstract:

OBJECTIVE: To evaluate the extent to which the cost of both treated and untreated agitation in Alzheimer's disease has been studied in order to inform future research and development of predictive models

Poster Presentation Abstracts

ID: 928

Abstract Topic: Economics of dementia

Keywords: economic costs, caregiver costs, agitation

The costs of agitation: a literature review

Mary Michael

Otsuka America Pharmaceutical, United States of America

Abstract:

OBJECTIVE: To evaluate the extent to which the cost of both treated and untreated agitation in Alzheimer's disease has been studied in order to inform future research and development of predictive models of the cost of untreated agitation in Alzheimer's disease.

BACKGROUND: There is inadequate understanding of the costs of agitation in Alzheimer's disease in the scientific and academic literature. Agitation in Alzheimer's disease contributes to negative social and financial outcomes for people with the condition, their care partners, and health systems. When left untreated, the impact of these outcomes is exacerbated, yet the scale of this impact is unknown. This gap in the literature both reflects and perpetuates the broader under-recognition of agitation as a serious unmet need in the Alzheimer's community. Conversely, a better understanding of the costs can help elevate agitation within the global Alzheimer's dialogue.

METHODS: We used MEDLINE, PubMed, PsychINFO the Cochrane Library and Google Scholar databases to identify relevant articles published between 2000 until May 2020. We also reviewed reliable literature published outside of these databases. Keywords utilized in the search include agitation in Alzheimer's, neuropsychiatric symptoms of Alzheimer's, cost of informal and formal care, Medicare and Medicaid costs, economic costs associated to delirium, among others. Only articles in English were included. Inclusion and exclusion criteria were determined by study design, data source and population studied, number of cases included in analysis, source of health service use or cost data, statistical methods and agitation in Alzheimer's attributable and/or incremental costs.

RESULTS: Results will describe the breadth and depth to which costs of treated and untreated agitation in Alzheimer's have been examined, indicating data and statistical methodology used.
CONCLUSIONS: This literature review serves as the basis for understanding global costs of agitation in Alzheimer's disease. From our analysis, we recommend that further cost modeling activities be conducted. We also urge the greater community to use these findings to elevate agitation to the top of the Alzheimer's agenda.

Poster Presentation Abstracts

ID: 929

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Multi-Stakeholder Groups, Citizen Activities, Advocate

The hopes of people with dementia and their families in Japan during the COVID-19 pandemic

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¹Liaison Committee among Dementia Stakeholders and Supporters Groups in Japan; ²Alzheimer's Association Japan, Japan; ³National Family Association of Early-Onset Dementia and Supporters Liaison, Japan; ⁴The National Network of Male Carers and Supporters, Japan; ⁵Dementia With Lewy Body Support Network, Japan

Abstract:

Purpose: The purpose of this study is to investigate the effects of the prolonged coronavirus pandemic on people's lives, identify various voiced concerns, troubles, and requests and use the results to address their problems. The aim was to produce material that could be shared and worked on as a proposal to the national and local governments.

Data Collection Period: 7th to 30th September, 2020

Method: Web-based questionnaire survey. We made announcements on the websites of each associated organization and through public media, and obtained the cooperation of suitable people with dementia and their families, irrespective of any affiliation with each associated organizations.

Survey items: 1) Respondent's position, 2) Respondent's place of residence, 3) "Concerns" and "Troubles" due to the impact of the COVID-19 pandemic on life, 4) Requests to national and local governments, 5) Regarding changes in symptoms of dementia due to COVID-19, 9) Status of people with dementia and their families meetings such as dementia cafes and gatherings, 10) Others (free comments)

Ethical consideration: The survey was disseminated through public relations media of associated organizations on the web, and the response was voluntary, and consideration was given to privacy by not collecting personal information.

Result: We analyzed 274 valid responses. Respondents are 3 people with dementia, 152 current family carers, 7 former family carers, 101 supporters such as volunteers and health care welfare personnel, and 11 other / unanswered. Respondents lived in 42 prefectures.

From the results of the 253 responses received regarding, 131 people in total, about half of the respondents, answered that refraining from going out due to the COVID-19 pandemic had an effect on dementia (progression of dementia, worsening of dementia symptoms, etc.).

205 responses were received regarding the status of holding meetings or gatherings, the most common answer (76 responses) was that meetings or gatherings "could not be held at all".

Approximately 40% of the respondents indicated that some gatherings were not held. 39 people responded "held meetings online" and 37 people indicated that "meetings were held with countermeasures such as limiting the number of times and the number of participants, changing the venue, etc.", with family meetings being held online, or with countermeasures in place for face-to-face family meetings. By contrast, 14 people responded that they, "couldn't hold regular family meetings, but the family members could interact with a small number of people." Only four people indicated that meetings "could be held in the same way as before".

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Responses indicate that due to the new lifestyle caused by the spread of the novel coronavirus, people with dementia suffer effects on their mind and body: "I feel like I am isolated due to restricted contact with people." "Communication with my family is lessened as is my willingness to live. I felt that my activity was restricted through refraining from going out, and that I was infected, and that I was anxious about getting infected. There is anxiety that "the future cannot be seen" due to the coronavirus situation, but "excessive fear of the virus feels like fear of dementia in the world", so prejudice needs to be eliminated. A desire for activities to continue as much as possible and for the creation of opportunities for interaction with society as much as possible was evident.

Comments on the following topics were received from 163 respondents including long-term families: <Response to infection> <Response to visits> <Impact on people with dementia> <Impact on long-term care family> <Requests to national and local governments> <Response in medical care > <Community activities> <Institutional care>

Based on the results of the survey, we recommend the following to the national and local governments.

- 1) Create national standards for coronavirus measures for people with dementia
- 2) Allow family caregivers to undergo a PCR test if they wish, and after taking sufficient measures against infection, support them so that they can visit hospitals and facilities and resume the long-term care services they have been using.

Poster Presentation Abstracts

ID: 930

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Digital Tea Party Pandemic

Digital tea parties

Fusun Kocaman

Turkish Alzheimer Association, Turkey

Abstract:

Wednesdays had been the "ACTION" days, since the first Day Care Centre in Turkey was initiated in 2011. On the first Wednesday of every month, a health worker or a caregiver presented information about the disease and the related care issues; while on the third Wednesdays an expert psychologist offered a group therapy session to caregivers. Second and fourth Wednesdays were "Fun Days" and people with dementia and their caregivers, get together for a party with live music and they enjoyed singing and dancing all together, regardless whether they are members of the Centre or not. These activities were called "Tea Parties", because after each one the attendants were served tea, cakes, cookies, etc.

Since the break of the pandemic, the first measure taken by the Association was to shut down the Centres and start help-line and publishing printed text and videos on web page and social media immediately. For the first weeks, this worked very well because all people needed was information and comfort. However, after the first month was over it was realized that both caregivers and people with dementia started longing for their Tea Parties, where they enjoyed socializing. Consequently, "Digital Tea Parties" were started that are performed every Thursday afternoon, to which "anybody" can participate unconditionally.

Now on Thursdays, a meeting is organized on Zoom that is announced on all digital channels and for each meeting a "guest speaker/performer" is invited based on the theme of the week. Examples to the guest participants are a nurse, a social worker, a music therapist accompanied by all participants singing and dancing, a psychologist presenting a therapy session on caregivers' selfcare, a neurologist, a physical trainer guiding a live exercise, a chef cooking desserts live, a story-telling therapist, a psychiatrist, a nutrition expert, etc. One week, psychodrama is exercised with people with dementia and their caregivers, the following Thursday "Art Therapy at Home" is planned. In order to amplify participation, information on how to participate in Zoom/Telco/Skype meetings are accommodated by colourful posters prepared and published frequently on social media.

The feedback and experience indicate that this type of functions need to be continued no matter what follows the extraordinary circumstances of the time being. First of all, distances are conquered because one doesn't need to be in the same building, city or country to join. Additionally, time limitations are overcome since the links to the video recordings of the meetings are disseminated instantly. Last but not the least, the meetings become public property and anyone can participate anonymously.

Poster Presentation Abstracts

ID: 931

Abstract Topic: COVID-19 and dementia - NEW

Keywords: Dementia, Italy, COVID-19, elderly people

The COVID-19 health crisis and elderly people with dementia in Italy

Luca Croci

iSenior SpA, Italy

Abstract:

The Istat report of 4th June 2020 on mortality due to COVID-19 infection in the first four months of 2020 shows that in the provinces with high infection rates the age groups with the most significant excess deaths are 70-79 and 80-89 years for men, and 90 years and more for women. The latter is the age group with the greatest difference in mortality when compared with the period prior to the pandemic, regardless of gender, and even in areas with medium and low infection rates. For both men and women, the greatest number of deaths from COVID-19 in the general population are concentrated in the 80-89 age. Of the deceased patients, 16.1% were affected by dementia (23.3% for women and 12.6% for men): a not surprising figure if we consider that according to the ISS's Dementia Observatory more 20% of those over 80 are affected, equal to about 1 million Italians.

There is no data to suggest that people with dementia suffer more severe symptoms of SARS-CoV-2 disease than people of the same age and health condition. However, the WHO, a few days after declaring a pandemic, highlighted the repercussions of the disease on mental health, and identified as particularly fragile elderly people with dementia and cognitive impairment, in whom confinement can induce increased levels of anxiety, anger, stress and agitation.

The difficulty that people with dementia may experience in accessing accurate information and applying containment health measures makes them particularly vulnerable and consequently much more exposed to the risk of contagion. The limitations lie not only in their capacity to understand health and hygiene precautions, such as wearing a mask or regular hand washing, but also in the lack of memory resources necessary for remembering them. Furthermore, quarantine can be very complicated to implement, whether following contact with a sick person or one at risk, or in the case that the patient with dementia demonstrates symptoms of respiratory disease. This increased exposure to contagion may explain why dementia represents an observed comorbidity of SARS-CoV-2 disease.

Confinement and isolation, whether at home or in medical assistance facilities, also seems to constitute a decisive factor in aggravating the symptoms of dementia. The patient undergoes a sudden change in daily routine with a consequent increase in stress and agitation. Dementia is also a critical factor to take into account when deciding as to whether hospitalization is the appropriate course of action. The ban on access to family members in COVID-19 wards puts the dementia sufferer in a situation of anxiety, confusion and delirium: s/he is in an unknown environment, unable to communicate with health professionals and unable to make decisions independently.

For the elderly patient in medical assistance structures, the imbalance undoubtedly derives from the temporary cessation of visits by family members and from the regulation or reduction of human contact and activities within the centre itself. Moreover, isolation and containment measures are difficult to apply, increasing the risk of accidents, patient agitation and the need for complementary pharmacological treatments. To these problems we can add a shortage of personnel and a specific need for protective material that combine to make managing this situation complex and expensive. In a context in which telematic communication channels have often proved to be the only resource that can meet the needs arising as a result of confinement, including for the elderly with dementia and their caregivers, these tools can constitute a useful and sometimes life-changing support both in terms of maintaining social contact remotely and to provide a new form of assistance. In a completely unprecedented health emergency, the evolution of which is uncertain and unpredictable, it is important to seek long-term solutions to protect the elderly with dementia.

Poster Presentation Abstracts

ID: 932

Abstract Topic: COVID-19 and dementia - NEW

Keywords: social policy, economics, COVID-19, health outcomes

Social, health, and economic impacts of COVID-19 on dementia care: interviews from Washington state

Carolyn M. Parsey¹, Clara Berridge², Maggie Ramirez³, Callie Freitag⁴, Ian Johnson²

¹University of Washington School of Medicine, USA; ²University of Washington School of Social Work, USA; ³University of Washington School of Public Health, USA; ⁴University of Washington, Evans School of Public Policy & Governance, USA

Abstract:

Background: The COVID-19 pandemic presents significant and costly disruptions to the social services and healthcare systems in the US. Eight in every ten deaths from the COVID-19 virus in the U.S. have been in people 65 and older (CDC, 2020), and Washington was the first state to identify a case in January 2020. On top of the mortality risk, the pandemic presents grave health and economic risks by disrupting services to older adults that prevent institutionalization, emergency room visits, and other negative health outcomes. We explored how the pandemic has affected operation of the social service and healthcare organizations that support Washington state's 1.7 million older adults, including 107,000 people with Alzheimer's disease.

Methods: We conducted semi-structured interviews with 45 social service and healthcare organizations serving older adults and people living with dementia in Washington state, USA. 37 participants also completed surveys about their clients/patients and the services that they provide.

Results: Providers for people living with dementia reported exacerbations of behavioral symptoms, and in some cases, symptoms that led to preventable hospitalizations. With social and physical constraints due to COVID-19, there are fewer options for treatment and providers are relying more on pharmacological approaches. Social isolation was a highlighted issue, and the relationship between social contact and routine with behavioral changes in dementia. Issues of reduced staffing and financial difficulties were also reported. Although telemedicine and other virtual approaches were lauded, they also are not a perfect solution, such as in the case of palliative or hospice care, or reaching people in rural communities without adequate internet. Several organizations offered creative adaptation, as well as areas where they still need support to promote social, emotional, and physical well-being for people with dementia.

Conclusions/Perspectives: Organizations are reporting that the state's most vulnerable older residents are falling through cracks. Social isolation among older adults and people with dementia was a growing public health problem made urgent by the pandemic. While it has been in its emergency response, the state's aging social and healthcare services sectors are struggling to reach some of the most vulnerable and isolated older adults. Addressing the digital divide is an important component, but to equitably serve older adults in our state, it must be paired with resources to strengthen services that reach those who are digitally disconnected. The intensifying need for aging services, particularly those that reach the most marginalized older adults and people with dementia, mean that going back to normal quickly isn't necessarily the best thing for these communities or organizations - were it possible. Our study offers insights, considerations, and recommendations for other US states and international communities in their pursuits of supporting people with dementia during the pandemic.

Poster Presentation Abstracts

ID: 934

Abstract Topic: COVID-19 and dementia - NEW

Keywords: COVID-19, dementia, low- and middle income countries (LMICs), health and demographic surveillance systems (HDSSs)

Health and demographic surveillance systems (HDSS): potential COVID-19 dementia registries for low-and middle-income countries (LMIC)

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¹Health System and Population Studies Division, icddr,b, Bangladesh; ²Global Dementia Prevention Program (GloDePP), University of Edinburgh, United Kingdom; ³Global Public Health, Jeffrey Cheah School of Medicine and Health Sciences, Monash University Malaysia; ⁴South East Asia Community Observatory, Monash University Malaysia, Malaysia; ⁵School of Social Sciences, Monash University; ⁶Centre for Global Health, Usher Institute, University of Edinburgh, United Kingdom

Abstract:

Recent articles and commentaries have discussed the relationship between COVID-19 and various neurological conditions. We believe that one major neurological impact from the pandemic will reveal itself over time: increased rates of global dementia.

Dementia is associated with risk factors including age, smoking, depression, physical inactivity, and social isolation, as well as cerebral microinfarcts, stroke, and a systemic inflammatory response linked to various chronic conditions, including rheumatoid arthritis, heart disease, hypertension, obesity, and diabetes.

There are indicators that SARS-CoV-2 may increase the risk of future dementia in people who developed COVID-19. COVID-19 is associated with a massive inflammatory response and subsequent coagulopathy including the formation of microclots throughout the body (although brain autopsies were not included). There are also early indications and clinical case reports of associated significant neurological sequelae. Thus, the peripheral inflammation from COVID-19 can lead to neurological sequelae, and potentially increase the rate of deterioration in pre-existing neurological conditions. Furthermore, population-wide, public health measures for managing COVID-19 (social distancing and quarantine restrictions) exacerbate the risk factors for dementia in multiple ways.

European and North American researchers are, in virtue of ongoing registries and cohort studies, well placed to study the COVID-19-related risk factors of, and detect early trends in, dementia incidence as well as incident events of other neurological conditions. Indeed, there have already been calls by high-income country researchers for an international/global register. Unfortunately, in most LMICs, registries remain relatively rare and these calls miss obvious structural barriers that could prevent their timely establishment. However, one proven mechanism for understanding the impact of COVID-19 on dementia remains in about 50 LMICs: ongoing health and demographic surveillance systems (HDSSs). Originally established to obtain insights into basic demographic trends around fertility, mortality, child survival, marriage and divorce, in settings lacking good vital registration, HDSSs are community-based, geographically-located, dynamic cohorts ideally placed to follow recovered COVID-19 patients over time. In keeping with previous HDSS studies, COVID-19 follow-up could include regular testing to capture incident dementia supplemented by various biological sampling regimes.

Such an undertaking would contribute to a much-needed understanding of the long-term impacts of COVID-19. Given that the global dementia burden will fall mainly on LMICs, these cohorts can improve the structures and capacities for community-based dementia research in these countries for generating the necessary data to improve prevention, early detection and clinical management of dementia.

Poster Presentation Abstracts

ID: 935

Abstract Topic: COVID-19 and dementia - NEWS

Keywords: dementia, BPSD, caregiver burden, pandemic

Impact of COVID-19 pandemic control measures on persons with dementia and their caregivers: an audit study

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¹Woodlands Health Campus, Singapore; ²Tan Tock Seng Hospital, Singapore

Abstract:

Background/ Objectives

The ongoing COVID-19 pandemic has disproportionately affected persons with dementia (PWD). In Singapore, restrictive public health measures were implemented during the “circuit breaker (CB)” period (from 7th April to 1st June 2020) to contain the spread of COVID-19. There is emerging evidence that the duration of home confinement during COVID-19 pandemic correlates with both severity of behavioural and psychological symptoms of dementia (BPSD) as well as distress experienced by caregivers. Thus, it is important to ascertain the impact of stringent public health measures during CB period on PWD and their caregivers due to disruption of community services and social support networks. This audit aims to evaluate the impact of pandemic control measures on exacerbation of BPSD and caregiver stress.

Methods

Electronic medical records of community-dwelling PWD who attended clinic consults in a Geriatric Medicine clinic in Singapore between 23 January and 1 June 2020 were audited. Data collected include severity of dementia, presence of baseline BPSD, and use of home- or community-based services. We compared trends before and after CB period for the following: presence of recent behavior change and whether this was related to COVID-19; presence of caregiver stress; and adjustment of psychotropic medications.

Results

Our study comprised 444 (70%) and 190 (30%) PWD who attended clinic consults before and during CB period respectively. During the CB period, 48 out of 50 (96%) PWD had to stop attending DDC. The proportion of PWD with BPSD exacerbation increased significantly during compared to before CB period (37% vs 23%, $p < 0.001$), mainly in agitation, sleep disturbance and irritability. Of these, 44.4% with BPSD exacerbation during CB were attributable to COVID-19, compared to 8% before CB ($p < 0.001$). Before CB, a significant number of moderate to severe stage PWD had behavior change compared to those with mild dementia (27.8% vs 12.8%, $p < 0.001$). However, during CB there was no significant difference between the two groups (43.4% vs 32.9%, $p = 0.159$). There was also a significant increase in reported caregiver stress (22% vs 9%, $p < 0.001$) and need for adjustment of psychotropic medication (38% vs 27%, $p < 0.001$) during the CB period. In addition, clients of DDC were more likely to exhibit BPSD exacerbation (39.1% vs 24.3%, $p = 0.002$).

Conclusions

Audit studies provide a responsive and systematic way to evaluate current practice during a pandemic situation compared with established good practice. Our audit study clearly reveals the association of more stringent public health measures implemented during CB period with BPSD exacerbation, increased caregiver stress and adjustment of psychotropic medications. As caregiver burnout is a known and eminently modifiable risk factor for negative outcomes in PWD, it is paramount to help caregivers cope with the increased caregiving demands as well as their own social isolation in the form of emotional support, informational support and peer support from other caregivers. Given the severe impact of pandemic measures on PWD and their caregivers, it is imperative to plan for such vulnerable populations in future public health emergencies. Notwithstanding, this COVID 19 pandemic had provided an excellent opportunity for the use of technology home-based interventions to deliver holistic dementia care and development of innovative strategies to support PWD and their caregivers.

Poster Presentation Abstracts

ID: 937

Abstract Topic: Well being and quality of life

Keywords: Design, Day Care, Carer respite

Day care - but not as we know it

Babs Harris, Stephany Bardzil

Alzheimer's Support, United Kingdom

Abstract:

Old Silk Works, a purpose-designed day club for 13 members each day, opened in May 2018. The former factory building is now a vibrant, welcoming space for people with dementia.

The design provides a modern light, airy and comfortable space with an emphasis on normality. Members are of differing ages and varying stages/types of dementia, a retro design from a specified time period could have comforted some but alienated others.

Renovating the space was a remarkable collaboration between the charity and community. Local organisations and individuals contributed in many ways and hold a sense of ownership.

The first-floor club is accessed via a gentle ramp and wheelchair lift. Members arrive into a light, uncluttered reception and proceed into the single-level club through opaque-glazed doors.

The big main room is arranged into three areas: a circle of armchairs of various heights and fabrics, small tables and chairs for dining and small group activities and an open-plan kitchen. Screened to one side are an indoor garden, quiet lounge and office.

The layout is designed to be flexible. Tables and chairs are easily moved to accommodate activities. A table tennis/snooker table is permanently available. At lunch, everyone sits down together at small tables, each with a vase of fresh flowers and homely crockery.

Members' artwork and photographs decorate the walls. A map of the world surrounded by postcards creates a subliminally positive effect and gives members a further sense of ownership. Music, chosen by members and ranging across the decades, is played at an ambient level on four-way speakers.

The open-plan kitchen encourages members to help prepare the freshly cooked lunch. Fitted cream cabinets and domestic-sized appliances are similar to those of a residential kitchen. Our super-long breakfast bar is designed to fit chairs and knees under, providing a wonderful space for cooking. Vintage kitchen equipment and food packets at the end of the bar are a talking point and spark reminiscences.

Behind an ivy-strewn trellis is an indoor garden complete with plants, wooden bench and water feature. It serves as a chill-out area and intimate space for meetings with carers and potential members who can see club activities through the trellis, but not feel pressured to take part.

Next door is a retro lounge containing a juke box, vintage newspapers, dansette record player and Singer sewing machine, all donated by the community. This part of the club is carpeted to make it look like a living room. With vintage armchairs, an ancient cabinet TV set and gramophone, members know it's a period piece.

Glazed double doors to the staff office are kept open, as members' needs take precedence over paperwork. All spaces are easy to maintain and clean and all levels of mobility are catered for. Light, non-slip wood effect flooring is level throughout. A keypad lock is discretely positioned on the wall so no-one feels locked in.

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A life-size poster of the Beatles crossing Abbey Road directs members towards the toilets which have easily identifiable yellow doors. Personal items are kept in a shut closet opposite to minimise confusion.

The club is flooded with natural daylight due to large windows along both sides of the original Victorian structure. Harsh tube lighting has been replaced with daylight bulbs which diffuse and enhance the interior light.

Regular club attendance helps keep members in their own homes for longer as it supports them to retain skills (e.g. making their own toast) and provides essential respite for families.

The club was full to capacity after three months and now has a waiting list. The space quickly calms anyone who arrives distressed or confused and helps assuage concerns or guilt carers have at leaving their loved one. Families tell us repeatedly about the positive changes in their relative's mood and abilities. The welcoming environment encourages the wider community in. Visitors always remark it is not what they expected!

Poster Presentation Abstracts

ID: 938

Abstract Topic: COVID-19 and dementia - NEW

Keywords: COVID-19, Dementia, Quality of Life, Offline and Online Programs, Acknowledgement

Offline and online (virtual) activities during world's Alzheimer month 2020 in the pandemic COVID-19 era

Michael Dirk Roelof Maitimoe

Alzheimer Indonesia, Indonesia

Abstract:

Background

The COVID-19 pandemic outbreak has affected us in the world, including Indonesia, all of our plans and activities have been repurposed and adjusted from offline to online (virtual). Our challenge is to continue to improve the quality of life the People with Dementia and their Caregivers and communities in the pandemic era. How to support them through these challenging times?

Objective

To continue providing services and empower families and people with dementia, family caregivers and our communities in Indonesia and overseas through offline and online activities in Pandemic COVID-19 era (isolation, anxiety, mental health avoided).

Activities

The session during World Alzheimer's Month consist of 88 activities in 21 chapters ALZI (16 in Indonesia, 5 overseas) with platforms including: Zoom, Webex, Youtube Live, Facebook Live, Google Meet, Instagram Live, Television, Radio, Articles and also offline programs.

- Online Session Series in Zoom, Webex, Google Meet, Facebook, Youtube
The online session brings the specific topic to the communities and public.
- Instagram Live, Television, Radio
The platform brings the person/communities's voice to the public through intimated direct approach
- Media Coverage (Articles)
ALZI's provided information, resource person and content for the journalists. There are more than 50 articles that have been published in media online and offline including newspaper and radio, TV talkshow and insertion.
- The 1 Minute Risk-Reduction #JMDPChallenge
This Do Not Underestimate Video (Jangan Maklum Dengan Pikun) challenge has been promoted since May 2020 and followed by inter-generations from 5 to 91 years old from Indonesia and also overseas including Indonesians living in The Netherlands, US, UK, Switzerland, Italy, Qatar and Australia.
- Video Production
ALZI video production produced 89 short testimonials and inspiring videos on dementia care tips and tricks, inspiring people, meaningful engagements with people with dementia, the elderly, all video production's launched and published in the ALZI's Social Media Platform including Youtube Channel (Alzheimer Indonesia), Facebook and Instagram (@alzi_indonesia)
- Short Movie Launch
ALZI collaborated with youth communities group and individuals (champions) and created the short movie. The aim is to reach out a thousand of youth generation to be engaged and be aware with dementia and how to reduce the risk.
- Staple Package Distribution (Offline)
ALZI's supported by several private sectors to contribute and distribute 1000 food staple package for people with dementia, the elderly and caregivers communities in Indonesia

Result

In September 2020 alone (1 month) ALZI has engaged 300.000 people and viewers during September

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2020 through online activities. The President of Indonesia assigned Minister of Health to give welcome remarks and acknowledged ALZI's work and attended in one of the webinar in September World's Alzheimer Month. The numbers are expected to be increased to 500.000 people in the end of 2020 and 1 million in the 2021. The 1000 food staple packages were successfully distributed to 56% elderly, 16% People with Dementia, 21% The Family Caregivers, and 8% others (volunteers, media and partnership). An impactful initiative. We are committed to continue to explore new ideas on how to reach our goals aligning with the 7 action areas of dementia global and national plan including putting dementia as national priority, dementia awareness and friendliness, risk reduction, dementia diagnosis, treatment & care, support for caregivers, established information system for dementia, dementia research and innovation. Through our online events in September, we have proven that physical distancing did not mean socially disconnected.

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Poster Presentation Abstracts

ID: 940

Abstract Topic: Attitudes, awareness and stigma

Keywords: attitudes, rights, public spaces, awareness, dementia-friendly

Attitudes and assumptions about people living with dementia and their carers, and their influence on rights to participation, inclusion and access to public spaces.

Carmela Leone, Rachel Winterton, Irene Blackberry

La Trobe University, Australia

Abstract:

People living with dementia and their carers experience stigma and social exclusion. While dementia-friendly communities go some way to addressing these issues, there is still a lack of focus on access to outdoor environments and public spaces. Public spaces are important for creating and practising social connections – which in turn play an important role in the use of health and social care services. While public awareness about dementia has increased, misconceptions have led to a lack of policy prioritisation and the embedding of attitudinal barriers in institutional practices relating to the design, planning and use of public space. This study explores the attitudes and assumptions of the news media and community stakeholders, in relation to the rights of people living with dementia and their carers to participation, inclusion and access to public spaces. It also explores the experiences of people living with dementia and carers in public spaces. It uses a rights-based conceptual framework, and a discourse analysis method to examine how knowledge about dementia, people living with dementia, carers and their rights to public space are constituted. This study is being conducted in the rural and regional catchment area of the City of Greater Bendigo, Australia. Findings will be shared with community stakeholders and will inform dementia awareness-raising and education programs, towards the development of a rights-based dementia-friendly community.

Poster Presentation Abstracts

ID: 941

Abstract Topic: Well being and quality of life

Keywords: Staff Perspectives, Supportive Physical Environment, Person-centered care, Dementia Care Facility

Exploring staff perspectives of the impact of physical environment in dementia units

Sook-Young Lee¹, Lillian Hung², Habib Chaudhury³

¹Yonsei University, Korea, Republic of (South Korea); ²University of British Columbia, Vancouver, Canada; ³Simon Fraser University, Vancouver, Canada"

Abstract:

Background and Objectives

Person-centered care is a philosophy that recognizes that each person has equal right to dignity, respect and to participated in their environment (Alzheimer Society of Canada, 2011; Brooker & Surr, 2005). With the spread of the person-centered care philosophy, the physical environment of a nursing home has been increasingly acknowledged as important in influencing quality of life for older people with dementia living in nursing homes. The term "environment" is a broad concept, which consists of physical, social and organizational aspects. Cohen and Weisman (1991) established a conceptual framework to understand dementia care setting as a holistic environment with dimensions of the physical (e.g. building, interior space and furnishings), social (e.g. relationships between residents-staff, family-staff) and organizational (e.g. facility policies, care philosophy, staffing structure) contexts. According to this conceptual framework, the physical environment of a care setting affects both its social and organizational domains.

The purpose of this study was to examine staff perceptions on the affect of physical environmental features on residents' behaviors and their care practices in two care facilities in Vancouver, Canada.

Methods

We used focus group method to elicit staff's shared perceptions on the impact of the physical environment on residents' behaviors and on their own care practice.

Settings

Two dementia care facilities were selected as study sites based on purposive sampling in order to obtain rich data from a breadth of perspectives. The primary selection criterion was to have contrasting physical environmental features between the two care facilities, i.e., one was selected for its traditionally designed large institutional physical setting and the other was selected for its purpose-built small-scale setting.

Rosegarden Home was a purpose-built dementia care facility, with multiple small units (12 residents on each unit), with relatively short corridors (about 14m) and all single bedrooms.

Maple Manor was a traditional care setting, with 30 residents on each unit, long corridors (about 41m) and mixed single/semiprivate bedrooms.

Participants

At Rosegarden Home, six staff members participated in the focus group discussion: one administrator, one nurse, one recreation assistant and three care aides. Nine members participated at Maple Manor: one administrator, two nurses, five care aides and one family member. All participants were women. Participants in Rosegarden Home had been working at the facility from 12 to 30 years with an average of 23.3 years and in Maple Manor from 2 to 34 years with an average of 14.4 years.

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Results

Two substantive themes emerged: (i) a supportive physical environment contributes positively to both quality of staff care practice and residents' quality of life (ii) an unsupportive physical environment contributes negatively to resident's quality of life and thereby makes the work of staff more challenging. A supportive environment was identified as one that has comfort, familiarity and an organized space. An unsupportive physical environment contributed to "challenging" behaviors in residents and negatively to staff care practice. These include: stimulation overload, safety risks, wayfinding challenges for the residents and staff providing rushed care.

Conclusion

Findings of this study suggest that a well-designed physical environment can lead to higher morale, closer social interaction between staff and residents and work-effectiveness in staff, potentially resulting in better care in enhanced well-being of residents.

This study adds to the current body of literature by providing evidence that demonstrates the interactive relationship among the physical environment, staff work practice and residents' quality of life outcomes in dementia care settings.

Poster Presentation Abstracts

ID: 942

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, pandemic, program, online

Stichting Alzheimer Indonesia nederland: online activities during COVID-19 pandemic

Tania M. Setiadi, Manik Kharismayekti, Amalia Fonk-Utomo

Stichting Alzheimer Indonesia Nederland

Abstract:

Background

Since the corona virus disease (COVID-19) pandemic started in early 2020, the world has suffered from the devastating effects of this contagious virus. The pandemic has brought great challenges, especially for older persons, people with dementia (PwD), and caregivers, who are forced to remain self-isolating within their own homes or institutional cares. Participation and social interaction that has played an essential role in improving the quality of life of these particular groups are limited due to restricted physical gathering. Therefore, during the COVID-19 pandemic, a new method to enable participation and social interaction without physical contact is needed.

Objective

Stichting Alzheimer Indonesia Nederland (ALZINed) aimed to organize a series of activities to reach and support the elderly, PwD and caregivers during the pandemic using a virtual platform.

Methods

A series of online sessions was organised by ALZINed since April 2020. All sessions comprised of various activities that cover three main cores of our programs: meaningful engagement (e.g. intergenerational sing-along karaoke, dementia care colouring session, Indonesian cooking class); education (e.g. music and the brain, medication compliance, dental health for elderly, elderly migrants, best practice for dementia care in Indonesia and The Netherlands); and risk reduction (e.g. yoga, pilates, brain gym, low impact exercise). All sessions were done using the Zoom platform and streamed through a YouTube channel. Small surveys were conducted in May and September to gain feedback about the activities and ideas for future events.

Results

From April to September 2020, ALZINed has organized 27 various online sessions. The average number of participants for each session were 25 people. Participants (age between 25-63 years old) were varied in background (i.e. older persons, people with dementia, caregivers, students, and volunteers) and origin (i.e. The Netherlands, Switzerland, Brunei, Singapore, Qatar, Japan, Taiwan, Austria, and Indonesia). Participants shared that these regular online sessions gave positive impacts on improving their quality of life and activating engagement between PwD and caregivers, even when they had to stay at home during the pandemic. Moreover, the best practice for dementia care session which involved experts from Indonesia and The Netherlands provided knowledge transfer between these two countries. Other activities have also been suggested for future events, such as small group (a 3-persons) meetings or walks with a friend (as an offline activity).

Conclusion

ALZINed online sessions showed to be beneficial for participants, especially the older persons, PwD, and caregivers on different aspects. These activities have enabled participation and increased social interaction among participants, increased the knowledge of dementia/ Alzheimer through webinars and strengthened the cooperation of dementia care between Indonesia and The Netherlands.

Poster Presentation Abstracts

ID: 943

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, music, singing, technology, wellbeing

Optimising online singing groups for people with dementia: guidelines based on current practice

Becky Dowson, Justine Schneider

University of Nottingham, United Kingdom

Abstract:

Background: People with dementia face a dual challenge to their wellbeing from COVID-19; the risk of severe illness coupled with disruption to usual activities and support. Fortunately, many of these activities, including group singing, have been able to continue by moving online. Prior research has demonstrated that the benefits of group singing include cognitive stimulation, social support and meaningful activity. However, since online singing has arisen as a very spontaneous response to recent events, there is little existing research or guidelines about implementing online singing groups. This paper aimed to develop recommendations for online singing and dementia based on current practice.

Methods: Online searches were conducted in order to document and describe current music making opportunities, including the platforms used to deliver them, the approach of the facilitator, and the content of the sessions. Technological challenges and solutions were also considered, and a set of recommendations were developed. A draft of this work was circulated to practitioners and others involved in music provision who commented on the draft and their own experiences, and this feedback was integrated into the final recommendations. A suggested structure and format for an online singing session was also produced.

Results: Several different types of sessions were identified, most commonly including live interactive videoconferencing sessions, live broadcasts, and pre-recorded videos. Conducting live music sessions online comes with technological challenges relating to latency, sound quality and accessibility and it will be necessary to adapt the sessions to address these challenges. Practitioners commented that uptake of digital sessions varied depending on the context, and that online sessions would not be suitable for everyone. Involvement of professional care staff and/or family carers was crucial to the success of the sessions. The resulting recommendations contain suggestions for maximising accessibility, maintaining participant and practitioner safety and wellbeing, optimising the musical quality of the experience, and helping musicians to work sustainably.

Conclusions: Disruption cause by the SARS-CoV-2 pandemic has resulted in innovation from music practitioners, coupled with resilience and adaptation by people with dementia and their carers. Continuing music sessions online offers continuity in an uncertain time. There may also be a demand for digital sessions in a post-COVID world, as they offer flexibility for those who find attending a session in person difficult. We should be mindful, however, of the dangers of digitally excluding those who cannot access online sessions, and provide alternatives where possible. We hope that these recommendations will be helpful for practitioners during and beyond the pandemic.

Poster Presentation Abstracts

ID: 952

Abstract Topic: Models of care

Keywords: Core Team Member

Bringing dementia care at doorsteps – together we aspire

IRSHAD BADARUDEEN, Dr Hanadi Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth

Dr Haroon Saleh, Dr Shafi Khan

HAMAD MEDICAL CORPORATION, Doha, Qatar

Abstract:

Dementia remains the biggest Health and Social Care Crisis of the 21st Century and is an important cause of disability and dependence. With an increase in ageing population and the absence of a cure, the focus is on risk reduction, early diagnosis and intervention across the globe.

In Qatar, population estimates project elderly population (65+) to grow significantly to 30% over the next three decades. This could contribute to a growth in dementia prevalence which will have a significant impact on the Health and Social care sectors. Qatar National Dementia Plan (QNDP) which sets out the vision for future services for dementia patients and their carers promotes the need for early diagnosis of dementia but stigma and reduced awareness has posed a significant barrier to achieving this. With a well-established Primary Health Care model in Qatar which provides easy accessibility of service in a less stigmatizing environment, it was decided to establish an Integrated Memory Clinic in the Primary Health Care Corporation (PHCC) with input from Specialist Geriatric Services from the Tertiary Health Care sector to serve the complex needs of the elderly population presenting with memory concerns.

Aim

To establish an integrated memory assessment clinic in the PHCC with Specialist input from Tertiary Health Care Sector.

Method

Establishment of Memory clinics with specialist input from Geriatric Psychiatrist, Geriatrician and multidisciplinary team from the Tertiary Health Care Sector in the three major PHCC across the 3 Zones of the country -North, Central and West

Results

Since the establishment of 3 memory clinics 18 months ago, there has been a significant increase in the number of patients accessing our memory care services. Author will present further details about this innovative service and the future expansion plans.

Poster Presentation Abstracts

ID: 953

Abstract Topic: Attitudes, awareness and stigma

Keywords: Core Team Member

Dementia – breaking barriers and building bridges

IRSHAD BADARUDEEN, Dr Hanadi Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, Dr Haroon Saleh, Dr Sameer Valappil

Hamad Medical Corporation, Qatar

Abstract:

Introduction -

Dementia is the 21st century health and social care crises.

It is one of the major causes of disability and dependency among older people worldwide that significantly impacts not only the individuals, but also carer's, families, communities and societies. Dementia diagnosis is surrounded by stigma leading to delayed help seeking, which impacts the quality of life both of patients and carer's

Problem -

Evidence suggest stigma associated with dementia is a pivotal factor in delaying diagnosis and seeking help. Raising awareness and education across all sectors helps in minimizing stigma enables better acceptance of care and enhances the quality of life.

Aim – Launch of National Dementia Awareness Project to Raise awareness of dementia across healthcare settings and community in the state of Qatar

Methods -

We identified the following three groups as they play a pivotal role in supporting and enhancing dementia care in Qatar.

Healthcare Professionals

Community

Carer's Group

As part of Project we designed and developed Specific Tailored Dementia awareness and education programmes for the above three groups over the Year

Results -

With 17 healthcare events targeting a population of 748 professionals.

23 community events targeting 2782 community members

6 Carer events focused for 110 Carers Over the Year ,The National Awareness Project achieved following Key Outcome

1. Dementia made as a Public Health Priority
2. Formed national dementia carer's group
3. Qatar National dementia plan launched On 27th November 2018

Conclusion -

National Dementia Awareness Project -Cutting across Boundaries Across Health Care ,Social settings and Community Raised the Profile of Dementia to be the Public Health Priority and It Being Everybody's Business and all systems to work Together in Care For Person with Dementia and support the Carers.

Poster Presentation Abstracts

ID: 956

Abstract Topic: Attitudes, awareness and stigma

Keywords: Core Team Member

“One country 77 events reaching to 9000 plus population in 18 months -is it time to close down dementia awareness campaigns?”- reflections from our memory clinic nurse

IRSHAD BADARUDEEN, Dr Hanadi Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, Dr Haroon Saleh, Marwa EL Orrabi
HAMAD MEDICAL CORPORATION, Qatar

Abstract:

"Dementia is the 21st century health and social care crises.

It is one of the major causes of disability and dependency among older people worldwide that significantly impacts not only the individuals, but also carer's, families, communities and societies.

Dementia diagnosis is surrounded by stigma leading to delayed help seeking, which impacts the quality of life both of patients and carer's

Evidence suggest stigma associated with dementia is a pivotal factor in delaying diagnosis and seeking help .. Raising awareness and education across all sectors helps in minimizing stigma enables better awareness better acceptance of care and enhances the quality of life.

Qatar -What We Did so far over last 2 year

With 77 healthcare and Community Events targeting a population of 9340

Our National Awareness Project achieved following Key Outcome over the Years

1. Dementia made as a Public Health Priority
2. Formed national dementia carer's group
3. Qatar National dementia plan launched On 27th November 2018

The questions asked is ? Do we still Need Dementia Awareness Campaigns in our Country

Our Memory Clinic Nurse will share a Firsthand Personal Experience she had in one of our Recently Held Community Dementia Awareness Project which will help us answer this question Not from Evidence based Research report -But Human Evidence of a Powerful Emotive Account from Our Community Highlighting the Fact that Our Job has just Begun in terms of Patient and carer Engagement with reference to Dementia

Poster Presentation Abstracts

ID: 958

Abstract Topic: COVID-19 and dementia - NEW

Keywords: informal carers, dementia, coronavirus, social services, residential care

Experiences of informal carers during the COVID-19 pandemic restrictions in Australia – preliminary results from a qualitative study.

Katarzyna Małgorzata Lion¹, Wendy Moyle^{1,2}, Monica Cations³, Pu Lihui^{1,2}, Day Sally³, Jenny Murfield^{1,2}, Clarissa Giebel^{4,5}

¹Menzies Health Institute Queensland, Griffith University, Brisbane, Australia; ²School of Nursing and Midwifery, Griffith University, Brisbane, Australia; ³College of Education, Psychology and Social Work, Flinders University, Adelaide, Australia; ⁴Department of Primary Care and Mental Health, University of Liverpool, Liverpool, UK; ⁵NIHR ARC NWC, Liverpool, UK

Abstract:

Introduction: Australian Federal and State governments introduced public health measures and social distancing restrictions early in 2020 due to increasing numbers of novel coronavirus infections. This resulted in changes and restrictions in social service access for people living with dementia and informal carers as well as visitor access in residential care across the country. This study aimed to explore the experiences of informal carers for people living with dementia regarding the use of social services and their access to visit and contact their relatives with dementia in residential care during the time of COVID-19 restrictions in Australia.

Methods: Informal carers of people living with dementia in Australia were eligible to take part in this qualitative study. Semi-structured interviews, conducted over the telephone or via Zoom, explored individual experiences with a) social care services access for people with dementia and carers at home, b) being able to contact or visit people with dementia living in residential care as well as c) well-being of interviewees.

Results: We will present the preliminary results of the thematic analysis of the 15 interviews with carers providing informal care for people with dementia living at home or using residential care in Australia. The results will be focused on day care service availability due to implemented restrictions and its impact on emotional and physical well-being of carers and people with dementia. Additionally, we will report on experiences with contacting/visiting people with dementia in long-term care facilities.

Conclusions: The COVID-19 pandemic has highlighted and strengthened concerns about the quality of aged care services provision in Australia. This is the first scientific, qualitative study to report on individual experiences of informal carers of people with dementia during Australia government public health restrictions. The study results will explore and describe the impact of the pandemic on carers and people with dementia living in Australia. We will propose new recommendations to be implemented in the Australian aged care sector in the course of the COVID-19 pandemic and the foreseen future.

Poster Presentation Abstracts

ID: 962

Abstract Topic: Non-pharmacological interventions

Keywords: BPSD, rocking chair, sensory integration, service evaluation

Effectiveness of the wellness nordic relax chair on behavioural and psychological symptoms of dementia

Fan Jun Samantha Tan, Guek Hon Maria Kung, Wei Ting Jiang, Hwan Jing Koh, P'ing-Ping Joy Lim

Alzheimer's Disease Association, Singapore

Abstract:

Introduction/Background of study

Pharmacological interventions have typically been used to manage behavioural and psychological symptoms of dementia (BPSD) with limited benefit. Research on platform-styled rocking chairs have shown reduction in BPSD with observations of the users being less depressed and anxious. Pilot studies conducted using the Wellness Nordic Relax Chair have shown that it may result in people with dementia becoming calmer, and agitation and pain scores were decreased in those acutely ill. Sensory processing theories have suggested that adequate sensory stimulation may result in increased arousal and attention, while a lack of it may cause irritability and disorientation.

Objectives/Rationale of the study

The main aim of this study is to explore the Wellness Nordic Relax Chair as a non-pharmacological tool for use with people with dementia with sensory integration deficits, and as a continual effort for service evaluation in our daycare centre.

Methods

Eleven clients from the centre were recruited for the study. Inclusion criteria are the presence of BPSD and sensory processing deficits. Clients choose their preferred mode of rocking motion for the planned twelve session(s) of twenty-minute duration.

Results

Four out of eleven clients attended all twelve sessions. There were subjective reports of positive mood and relaxation, and observations of positive affect, increased verbal expression and engagement in self-directed activities. Although not statistically significant, there was an improvement of scores on the Cohen-Mansfield Agitation Inventory at the end of twelve sessions. No significant changes were observed for ratings on the Cornell Depression Scale. Attrition from the study was mainly due to clients not willing to sit on the chair.

Conclusions/Perspectives

These findings suggest that the Wellness Nordic Relax Chair may have the potential to support the needs of persons with dementia exhibiting BPSD, but given the small sample size in this study, the results are inconclusive. Single subject experimental design may be more suited for future studies.

Poster Presentation Abstracts

ID: 964

Abstract Topic: COVID-19 and dementia – NEW

Keywords: community awareness, COVID-19, infection control, older people

Community awareness programme for elderly care during COVID-19 pandemic in Brunei Darussalam

Ahmad Iqbal Hafiyuddin Sofian¹, Siti Amirah Nabilah Md Jappar¹, Amirah Fakhriah Amzizulfadzillah¹, Mohd Syahmi Hazmi Hj Mat Sarudin¹, Nur Hilmiyah Husaini¹, Shyh Poh Teo², Fazean Irdayati Idris¹, Mohd Ayub Sadiq¹

¹PAPRSB Institute of Health Science, University Brunei Darussalam; ²Geriatrics and Palliative Unit, Department of Internal Medicine, RIPAS Hospital, Brunei Darussalam

Abstract:

Background: COVID-19 significantly impacts older people with associated higher mortality rates, risk of neglect, and worsening mental health, social and economic well-being. This pandemic poses a greater challenge for people with dementia; as social distancing adds to loneliness, depression and social isolation, with possible worsening of dementia symptoms. Thus, caregivers should be aware of how to care for older people to maintain their physical and psychological health. According to Alzheimer's Disease International, there is an estimated 1,200 people with Alzheimer's dementia living in Brunei, the majority of whom are undiagnosed. A community awareness project was organized with the following objectives: (1) to raise awareness among older people on the importance of self-care during COVID-19 pandemic (2) to provide educational resources and materials regarding the COVID-19 pandemic to older people at a local Senior Citizens Activity Centre and (3) to distribute COVID-19 infection prevention and control kits to these centres to reduce transmission.

Methods: Exhibitions and information sessions were held during the month of September throughout various locations in Brunei Darussalam to educate the public regarding information related to COVID-19, particularly older people and their caregivers. These included informative posters regarding approaches to care and mental health considerations for an older person during the pandemic. A public webinar entitled "Older People and COVID-19 in Brunei Darussalam" was also held. Community outreach programmes were organised at the Senior Citizens Activity Centres in two districts, namely Brunei-Muara and Tutong. This aimed to educate older people about safety measures, particularly infection prevention and control during the COVID-19 pandemic. Care packages were then distributed to attendees of the Senior Citizens Activity Centre which included information leaflets, face masks, hand sanitizers, wet wipes and hand soaps.

Results: For the Senior Citizens Activity Centres (Brunei-Muara and Tutong), there were 57 and 63 attendees respectively. Participants from the Senior Citizens Activity Centres found the programme helpful and content easy to understand. All the participants agreed or strongly agreed that they understood more about the importance of care during COVID-19 than prior to the session, and majority agreed they would likely participate in similar sessions in the future. Participants also perceived the COVID-19 safety measures and practice of healthy living as relevant especially during the COVID-19 pandemic.

Conclusions: This programme imparted relevant knowledge to older people and their caregivers regarding important practices during the COVID-19 pandemic. Similar programmes should be considered to mitigate the spread and risk of infection among this high-risk group.

Poster Presentation Abstracts

ID: 965

Abstract Topic: Environment and architecture for dementia

Keywords: dementia, alzheimer, healthy aging, long-term care, palliative care, dementia friendly society, age-friendly environments, new housing needs, health care system, social care system

Person living with dementia in existing housing system and requirements of modern time

Osman Kučuk, Emina Kučuk

Alzheimer Association A&R / Alzheimer Udruzenje AiR, Bosnia and Herzegovina

Abstract:

Background: The current societies of SEE are adjusted for normal functioning of population age between 15 and 55, endure a big challenges. That societies will in short time until 2030.: will have population decline more than 15%, median age of native population will be over 47 and the percentage of population over 60 years of age is already twice as big as the average world percentage (UN DESA; World Population Prospects: 2015). It will have a strong impact on life of older adults and people living with dementia, changing their requests and adjusting themselves to newest facts. The real questions are: how to protect these population from future pandemic, how to organize palliative care and long-term care and how to optimize that costs which will growth on 2,7% GDP until 2070., who and how will provide health and social care.

Method: The research will compare today's way of life elderly and possibilities by the system with recommendations by WHO (Aging and Health Global strategy) and to necessity of system adjusting in the new one, self-sustainable system in accordance with needs of elderly.

Results: older adults and people living with dementia into that group practice traditional way of life which is inappropriate and offer of social and health care services which will compensate shortcomings these system are insufficient.

Conclusion: The answer can lay in Aging and Health Global Strategy by WHO which has 5 objectives:

1. Fostering healthy ageing,
2. Creating Dementia friendly societies,
3. Aligning health systems to the needs of older populations,
4. Developing long-term care systems (home, communities and institutions),
5. Improving measurement, monitoring and research on healthy ageing

„Dementia, a different cognitive disabilities, mental illness named non-visible diseases requires knowledge, skills, post-diagnostic support, person centred care, coordinated health care services and support of social care system on the way that people affected by non-visible diseases have a full protection and inclusion to their commune in accordance to their possibilities and wishes.

Poster Presentation Abstracts

ID: 968

Abstract Topic: COVID-19 and dementia – NEW

Keywords: Core Team Member

“Raha”-rises amidst Covid 19 pandemic in Qatar

IRSHAD BADARUDEEN, Dr Hanadi Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, Dr Shafi Khan

HAMAD MEDICAL CORPORATION, Qatar

Abstract:

Introduction:

Dementia with its wider impact straining through the fabric of Individuals ,families ,society ,Country and Global Community at large during regular times ,undoubtedly during this unprecedented time of COVID Pandemic carries the risk of breaking the carer support systems .Surveys across the globe has highlighted the increased level of stress and isolation among people with Dementia and their caregivers during this pandemic.

At no time before has support for Dementia care givers been so paramount in the living times of this century than ever before ,taking this into context the rise of Pandemic enabled us to rise to the occasion for our Dementia carers in Qatar ,Qatar National Dementia Plan Taskforce Team unveiled the unique carer support service –“ RAHA” (Comfort -in Arabic) -The National Alzheimer’s and Memory Services Helpline .

Objectives:

To establish a Helpline which is

Easily accessible to all the sections of the society across the State of Qatar

Provide confidential support to people with dementia and the care givers

Has input from highly skilled Multispecialty Team including Geriatricians and Geriatric Psychiatrist.

Direct access to Memory Assessment services for a prompt and comprehensive assessment.

Easy accessibility to appropriate services for evaluation of physical and mental health needs including community outreach services where indicated for people with dementia.

Methods:

“RAHA “The National Alzheimer’s and Memory Services Helpline remains unique in its structure as it is manned by a multidisciplinary team comprising of Geriatricians, Geriatric Psychiatrists, Psychologist and Specialized Nurses with multi-lingual skills assigned to support callers who contact the helpline. This Helpline service also has access to other essential services which makes it a unique helpline ever in Dementia Care.

“ RAHA “ works in collaboration not only with the Geriatric Memory Clinic which provides prompt , comprehensive memory assessment either through virtual clinics or face to face assessment but also to the dedicated National Geriatric Helpline which provides immediate telephonic consultation from a Geriatrician for physical health issues and Geriatric Medical Day Units which is open 15 hours a day , seven days of the week with access to Geriatricians, Neurologist and other team members including Occupational Therapists and Physiotherapists, Speech Therapists ,Geriatric Telepharmacy services .

Results: Since the launch of this Helpline on June 15th, 2020, It has received over 1200 calls from service users from all sectors including Government and Independent sector healthcare. Easy accessibility of the service during this challenging pandemic period has given that sense of inherent support to people with dementia and their families and equally the popularity of the service has enabled to raise awareness about dementia and break the stigma to an extent in the State of Qatar.

Poster Presentation Abstracts

ID: 969

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, public policy, Gulf region, Arab, dementia, older population, services

A scoping review of support structures and policies for older persons with ADRD since COVID-19: spotlight on the GCC region

Suzanne H. Hammad¹, Sanaa Alharahsheh²

¹Independent Sociologist and Research consultant; ²Senior Research Associate, World Innovation Summit for Health, Qatar Foundation

Abstract:

Dementia has emerged as a pandemic in an ageing society that has rendered persons living with or at risk of dementia among the most vulnerable population groups. Mitigating the impact of COVID-19 on persons with dementia has become a public health priority, and many countries have begun to take special measures towards their protection. With rapidly growing older populations and improved health services in the Gulf Cooperation Council (GCC) region, and in the context of increasing prioritization of healthy ageing within public policy and health and social care sectors, this contribution aims at taking stock of how countries of the GCC region have responded to protect and enhance the care and wellbeing of older persons with dementia. It will map out the range of policies and interventions that have sought to empower, protect, and sustain the care of this population group and their caregivers as part of the national response. It will compare and contrast key initiatives and services and national guidelines in place in each country, with attention to modes of cooperation across governmental and non-governmental sectors, drawing out lessons, best practices, and shortcomings. Considering the strict social distancing measures and greater restrictions for people over the age of 60, this review will also examine whether practical support structures have been put in place to enable family caregivers to continue to care at home in a safe and life-enhancing way. The methodology used will be a thorough desk-based review of academic and grey literature, together with a content analysis of key national policies and guidelines pertaining to this population group and dementia care specifically. We see this contribution as an important foundation that will synthesize disparate efforts in this region and identify best practices that can be adopted to enhance existing systems. It also fills a knowledge gap about countries in the Arab region, opening channels for greater exchanges and collaborations across regions in the service and care of persons with dementia during the global COVID-19 pandemic.

Poster Presentation Abstracts

ID: 970

Abstract Topic: COVID-19 and dementia - NEW

Keywords: creative narratives, well-being, quality of life, tele-psychosocial programmes

The power of creativity in quarantine: the challenges and triumphs of online creative narrative programmes in Medellín, Colombia

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¹Aston University, United Kingdom; ²Antioquia Neuroscience Group, University of Antioquia, Colombia;

³Corporación Universitaria Remington, Colombia

Abstract:

Our Creative Narratives and Dementia in Colombia project began pre-COVID-19. The project investigates the potential impact of creative narrative programmes on quantitative indicators of quality of life and psychological wellbeing and on qualitative measures associated with personhood amongst people with dementia, people with mild to moderate cognitive decline, and amongst care partners in Medellín, Colombia.

Our international and interdisciplinary team of neurologists, psychologists, language therapists and health humanists designed a 10-week series of creative narrative workshops to be held at the headquarters of the Antioquia Neuroscience Group (GNA) in Medellín.

The incidence of dementia in Colombia, as in many other low and middle-income countries is set to increase by over 200% in the next 30 years. In addition, the Antioquia region of Colombia is home to 250 extended families affected by the world's highest incidence of hereditary early-onset Alzheimer's disease (caused by a rare genetic mutation known locally as the *mutación paisa*).

The GNA is a vanguard Latin American research centre that has been working with local communities for more than 35 years and is now leading a major international study into the effectiveness of the Crenezumab drug on the build-up of amyloid plaques in the brain. Ours is the first health humanities project the GNA has been involved in.

The project uses two distinct creative narrative methods:

TimeSlips (Basting, 2001) is an oral storytelling method that was designed especially for people with dementia as it calls on participants' creativity rather than their memory and validates all contributions to the collective storytelling process.

MicroCuentos is a written narrative technique designed by the project's principal investigator on the basis of several years of research and teaching on the micro-fiction literary genre.

Our project recruited 32 participants to four study groups:

Group A: 8 people with the *mutación paisa*;

Group B: 8 people with sporadic/late-onset dementia.

Both groups would use the TimeSlips method.

Group C: 8 people with mild to moderate cognitive impairment;

Group D: 8 carepartners (of participants in the other groups).

Both groups would use the MicroCuentos method.

Our workshops began on 19 February 2020. Although there was no formal evaluation of the potential impact on participant wellbeing and mood at that stage, their enthusiasm was somewhat self-evident: group A's first TimeSlips story included an impromptu and rather raucous song!

Just after our 4th workshop, the GNA (following Colombian government guidelines) halted all research that involved face-to-face contact with participants. In response, we began to urgently adapt our methods for online delivery.

In our presentation to the ADI Virtual Conference we would:

Hope In The Age Of Dementia.

NEW SCIENCE. NEW KNOWLEDGE. NEW SOLUTIONS.

10-12 December 2020



Poster Presentation Abstracts

Discuss the different strategies we devised for our study groups:

Group A: coaching and mentoring of participants' family members in order to facilitate at-home TimeSlips sessions.

Group B: online group TimeSlips sessions facilitated by members of the study team.

Groups C & D: WhatsApp-based interaction and YouTube-based instructions for independent written narrative activities to be carried out at home.

2. Discuss the practical and technical challenges faced by both the study team and the participants (particularly those in remote rural areas).
3. Talk about the ongoing adaptations we have made to maximise participation, communication and socialization with and between our participants.
4. Talk about some of the remarkable narrative results obtained with both the oral and written methodologies.
5. Discuss the potential our research offers for the extension of online psychosocial services for people with cognitive decline and their families as a cost-effective, flexible and sustainable alternative to face-to-face service provision in Colombia, and beyond.

Poster Presentation Abstracts

ID: 971

Abstract Topic: Non-pharmacological interventions

Keywords: non-pharmacological interventions; arts therapies; dance movement therapy; mindfulness; person-centred care

Challenging the biomedical model in dementia: is there a role for arts and mindfulness-based interventions?

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¹Department of Psychology, National University of Ireland Maynooth, Ireland; ²Faculty of Arts and Sciences and Faculty of Health and Social Care, Edge Hill University, UK

Abstract:

Background: Numerous guidelines and medical organisations recommend non-pharmacological interventions (NPIs) as a first line treatment in dementia care (WHO, 2015; Kales, Gitlin, & Lyketsos, 2015). At the same time, there is a growing interest in interventions based on arts/arts therapies and mindfulness for people with dementia (PwD) and their caregivers, although little is known about their implementation and effectiveness.

Methods: The present study aims to develop an innovative, non-pharmacological intervention for people with dementia (PwD) and their caregivers, based on a unique combination of dance movement therapy (DMT) and mindfulness techniques. A series of interviews and formal consultations with international experts and practitioners (n=30) were conducted in order to explore their views and experiences as well as any challenges and difficulties they may have encountered in the implementation/use of arts/ arts therapies and mindfulness with PwD and/or their caregivers. Informal consultations with members of the Dementia Research Advisory Team (DRAT) of the Alzheimer Society of Ireland (ASI) were also conducted to inform and enhance the study findings.

Results: Preliminary findings indicate a strong consensus on the need for more non-pharmacological interventions with a focus on arts/arts therapies and mindfulness, delivered using person-centred approaches. These should capitalise on the remaining skills and capabilities of PwD and provide creative opportunities for their socialisation/meaningful engagement whilst also improving their health, mood, well-being and quality of life. Furthermore, there was a high level of perceived need for personalised and multicomponent interventions for PwD and their caregivers, the impact of which, should be assessed on a personal (PwD/caregiver), dyadic (PwD- caregiver), family and community level. DRAT members confirmed the need for more non-pharmacological interventions for PwD and their caregivers in Ireland and especially to reduce loneliness and isolation and promote engagement through creative arts, thereby cultivating enjoyment and purpose in life/life satisfaction.

Conclusions: These early findings build on the most recent INTERDEM manifesto which recommends that dementia researchers should consider more integrated biopsychosocial approaches (Vernooij-Dassen et al., 2019). Our ongoing analysis explores barriers to, and facilitators of, the implementation of arts and mindfulness-based interventions for dementia. Perhaps now more than ever, as we live through COVID-19 pandemic, there is an even greater need for innovative approaches to promote positive experiences in people living with dementia, their families and carers.

Poster Presentation Abstracts

ID: 972

Abstract Topic: New and future treatments

Keywords: Blood brain barrier, Brain drug delivery, Oral and Maxillofacial device, Immunotherapy, Alzheimer's

A novel device to deliver drugs across the blood brain barrier

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¹UR Anoop Research Group, India; ²Central Inter-Disciplinary Research Facility, Sri Balaji Vidyapeeth (Deemed To be University), SBV-Mahatma Gandhi Medical College And Research Institute Campus;

³Pondicherry Central University

Abstract:

Background:

Delivering drugs into the brain has been a challenge for the past 100 years because of the blood brain barrier. The existing non-invasive techniques do not provide controlled and continuous drug delivery into the brain. Invasive techniques, like placement of catheters into the brain make the brain prone to infection from external agents.

In Alzheimer's disease, the blood brain barrier allows only 0.1% to 0.2% of peripherally administered antibodies to enter the brain .

Hence a new technique which can provide controlled and continuous drug delivery across the blood brain barrier without the need for any surgical intervention in the brain holds immense potential.

Objective:

The objective of this proof of concept study was to deliver drugs into the brain by using a patented oral and maxillofacial technique and device.

Method:

The device was placed in the maxillofacial region of an in vivo animal model and the drug was delivered into the brain from the oral and maxillofacial region .

Results:

Drug was detected in the brain.

Conclusion:

It may be useful for delivering drugs into the brain in neurodegenerative diseases like Alzheimer's disease.

Poster Presentation Abstracts

ID: 973

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, Memory loss, Nucleus Tractus Solitarius, blood brain barrier, Preventive interventions

COVID-19 and the brain - a neural hypothesis

ANOOP U R, KAVITA VERMA

UR Anoop Research Group, India

Abstract:

Background:

Many people who get infected with the corona virus are developing neurological symptoms even without any serious infection. Patients are presenting with strokes, haemorrhage, memory loss etc. Though the virus has been reported to have a neurogenic potential, the exact mechanism by which it affects the brain has not yet been found.

Therefore, we are presenting a new neural hypothesis to explain the involvement of the brain. The role of nucleus tractus solitarius in the manifestations of COVID-19 is discussed. We are presenting interventions that can be used to avoid the targeting of the brain by the virus. We are also proposing alternate routes for delivering drugs for COVID-19 based on our hypothesis, so that the drugs can cross the blood brain barrier.

Poster Presentation Abstracts

ID: 974

Abstract Topic: Informal carers training

Keywords: caregiver, carer, dementia, educational intervention, online

Moving forward during COVID-19 pandemic: online educational intervention for carers of people living with dementia

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¹Department of Mental Health and Community Nursing, Faculty of Medicine, Public Health, and Nursing, Universitas Gadjah Mada, Indonesia; ²Department of Neurology, School of Medicine and Health Sciences, Atma Jaya Catholic University of Indonesia, Indonesia; ³Alzheimer's Indonesia

Abstract:

Introduction: The COVID-19 pandemic strikes every part of the world, regardless of geographical area, country development and socioeconomic status, putting people with dementia and their carers in a more vulnerable state. On top of existing challenges due to the disease progression and behavioural changes experienced by people living with dementia, carers might encounter new challenges. Physical distancing limits other aspects in life, such as travelling to shop for necessities or accessing health services, contributing to an increase in carer burden. It is essential to equip carers with dementia care skills to help them cope with these challenges. This study aims to evaluate the development of a compact and a feasible online training module with an experiential approach for carers, based on an existing face-to-face module.

Methods:

A Mixed-method approach will be used to evaluate the implementation of this online educational intervention. An intervention consisting of a 6-hours online training on dementia care skills will be given to carers. The module is developed based on an existing educational intervention for carers of people living with dementia, the Bahasa Indonesia version of the ADI's Dementia Care Skills training module for Asia-Pacific. Alzheimer's Indonesia's Research and Education Division have started the development of the online version since March 2020 in response to the pandemic. The intervention developed include adjustment of the modules to online format, and updating trainers' list, guideline of training, and evaluation process. The first implementation of this online training will take place in October 2020 to be attended by representatives of Alzheimer's Indonesia chapters, 21 chapters in total.

Positive impacts:

With restrictions of face-to-face learning, government and non-government organisations are racing to deliver information through online platforms, resulting in the vast quantity of online events happening in Indonesia which might overload carers with pieces of information. This study addresses this problem by providing carers with feasible online training that specifically tailored to carers' needs.

Perspectives:

The development of this online training will bridge the gap between carers' needs and availability of online resources to better support people with dementia.

Poster Presentation Abstracts

ID: 976

Abstract Topic: COVID-19 and dementia – NEW

Keywords: Carers, COVID-19, pandemic, concerns, interviews

Concerns of family carers during COVID-19

N Aker, E West, N Davies, K Moore, E Sampson, P Nair, N Kupeli

UCL, United Kingdom

Abstract:

The COVID19 pandemic has had an impact on the decisions that family carers of people living with dementia are needing to make, and it has also brought new challenges and concerns with it. More people are now providing support to friends and family members than before the pandemic, with many carers feeling overwhelmed. It has taken health and social care services time to adjust to new ways of working, with some facilities still inaccessible due to COVID19 measures, and carers less willing to make use of some services due to infection risk. This has resulted in many carers taking on additional or increased responsibilities. This study aimed to identify key areas of concern for carers during each stage of the first-wave pandemic in England, and the decisions they were having to make throughout.

Eight helpline support workers from Dementia UK and Marie Curie in England, took part in semi-structured qualitative interviews about the nature and content of calls received from carers. Interviews were conducted via Microsoft Teams and were recorded with participants' consent. Interviews were transcribed and checked via the Microsoft Stream automated system. The data was analysed using thematic analysis. Interview data was coded according to the point of time in the pandemic; early (beginnings of lockdown), later (a few months into lockdown), or more generally across these timepoints.

Themes that emerged during the early stages of the pandemic focussed on carers continuing to provide care and keep their relatives safe. Themes in the later stage of the pandemic mainly focussed on difficulties with people living with dementia using face masks, and carers returning to work and being less available to provide care. Concerns that were reported more generally included accessing health and social care services; particularly seeing GPs, getting a diagnosis, and contacting community nurses. Rapidly changing governmental guidelines was another key concern which impacted on whether carers should continue to visit relative or if they were able to visit if the person resided in a care home. In hospitals, lack of carer involvement and lack of communication from staff was a concern.

In conclusion, carer concerns changed over the course of the pandemic. While there have been many issues that existed at the early stages of the pandemic and have remained throughout, there are others that have been more specific to the early or later stages. Some concerns, such as visiting and self-isolation, were present generally but were more prevalent in the early stages. It is possible however that this may become an issue again as COVID19 cases increase. COVID19 has also had a huge emotional impact on carers and people living with dementia, though the nature of the pandemic has meant that carers are less likely to seek outside help. In light of the pandemic, delivery of services needs to be flexible to remain accessible to people living with dementia and their carers.

Poster Presentation Abstracts

ID: 979

Abstract Topic: COVID-19 and dementia – NEW

Keywords: Rapid Review, COVID-19, Decision-making, Older Adults, Place of Care/Death

Decision-making for place of care and death in older people: a rapid review of current evidence, and implications for COVID-19

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¹Marie Curie Palliative Care Research Department, University College London; ²Department of Primary Care and Population Health, University College London

Abstract:

Introduction

COVID-19 has disproportionately affected older adults, including those living with dementia. There have also been significant effects on the functioning of healthcare systems. In this context, decision-making surrounding place of care and place of death involves significant new challenges. This paper aimed to review current evidence concerning key factors that influence place of care and place of death decisions in older adults, including factors that influence the process and outcome of these decisions. Findings from current evidence was then considered in the context of COVID-19.

Methods

A rapid review of reviews, undertaken using guidance from the WHO. Ten papers published between 2005-2020 were included for data extraction. Data extracted was synthesised using narrative synthesis, with thematic analysis and tabulation.

Results

Results were divided into papers that explored the process of decision-making and outcomes of decision-making. Papers included discussed both actual and preferred place of death. Themes including caregiver capacity, the availability of multidisciplinary teams, cultural appropriateness of care packages and advanced care planning were found to be important.

Conclusions

The process of making decisions and outcomes of decision-making for older people are affected by many factors that influence both patients and caregivers experience of illness and dying. Within the context of COVID-19, such decisions may have to be made rapidly and be reflexive to changing needs of systems and of families and patients. This evidence base will provide a foundation for decision-making in the context of the pandemic.

Poster Presentation Abstracts

ID: 982

Abstract Topic: COVID-19 and dementia – NEW

Keywords: dementia, long term care, nurse practitioner

Nurse practitioners in long term care homes in the time of COVID-19: a qualitative study

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¹University of Toronto, Canada; ²Toronto Rehabilitation Institute, Canada; ³Ryerson University, Canada; ⁴Research Institute of Aging, Canada; ⁵Nurse Practitioners' Association of Ontario, Canada; ⁶Ministry of Health Ontario, Canada

Abstract:

Background: Most residents living in long term care homes (LTCHs) are older adults with dementia. COVID-19 laid bare long-standing structural deficiencies affecting the LTC sector, resident deaths in LTC represent almost 80% of all COVID-19 deaths in Canada. Staffing has the most significant impact on both the quality of care provided to residents and on the resident-centered outcomes. Evidence indicates that Nurse Practitioners (NPs), highly skilled healthcare providers with extended scope of practice to diagnose and treat patients, are associated with better resident outcomes, such as timely access to care and reductions in hospital transfers. During the pandemic, NPs were present in LTCHs providing direct care to residents and supporting staff. It is important to understand the NPs' roles, responsibilities, and factors influencing their capacity in order to develop guidance to better prepare LTCHs for the future. The main objective of the study was to examine NPs' practices in promoting quality care for residents and supporting LTC staff prior to and during the pandemic.

Methods: The study is exploratory, involving semi-structured qualitative interviews with NPs who worked in LTCHs that had reported positive COVID-19 cases. A diverse purposive sample of 13 NPs was recruited to allow for the examination of differences and similarities in their experiences.

Results: Our sample represents approximately 12% of all NPs in Ontario and were geographically dispersed. Our preliminary findings reveal that social isolation, due to a lack of family and care partner visits, was a major challenge to residents. Social isolation led to worsening of residents' cognitive and physical states, depression, suicidal ideation, and hypoactive delirium. Residents with dementia who purposively walked and/or had behavioural and psychological symptoms (BPSD) were a focus for NPs. Furthermore, inadequate staffing and lack of staff's training on infection control and isolation techniques were identified as challenges. NPs were primarily involved in resident care (end of life care, communication with care partners) and team support (staff education, emotional support). NPs also served as liaison for staff and residents in providing essential services through external partners, such as hospital staff and specialty clinicians.

Conclusion: There is preliminary evidence that NPs are essential in LTCHs and contribute to beneficial resident outcomes through better management of BPSD and end of life pain, symptom management, care partners' satisfaction with care, and communication between acute care and LTCHs. By exploring their practices, we have gained a better understanding of NPs key contributions to the coordination and provision of care. This could help develop and implement guidance for LTCHs to prepare for future crisis situations. Advocating for creating more NP positions in LTC to improve outcomes for persons with dementia and their care partners is an essential next step.

Poster Presentation Abstracts

ID: 983

Abstract Topic: COVID-19 and dementia - NEW

Keywords: COVID-19, Care Partners, Dementia, Assessments

Charting through new normal: adapting outpatient services to meet the needs of patients and care partners in the COVID-19 era.

Tolulola Taiwo, Charlene Lawrence

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Abstract:

INTRODUCTION: The Specialized Geriatric Services provides care to older adults across the Central Zone/Region of Alberta, Canada. Patients are referred by primary care and specialist physicians and by community nurses.

We provide patient care in various settings including our outpatient clinic, homes and in the different level of residential care (facilities) in various communities in the Central Zone.

At the outset of the COVID-19 pandemic and prior to the restrictions being placed on direct patient assessments, we sought to develop strategies to preserve continuity of care. We contacted the residential care facilities informing them that no physical visits would be undertaken and assuring them of our availability for phone consults. We have been in touch regularly (weekly and sometimes multiple times a week) with some of the residential care facilities. The restrictions on movement and absence of visits from family members has had some negative effects with reports of disruptive behaviors and emotional distress from care partners.

METHODS: We also developed a framework (attached) which we have used for our assessments. We have been seeing both existing and new patients using Tele-medicine.

FINDINGS: The feedback from patients and care partners was very positive.

Most patients and care partners understood why they are unable to have direct clinic appointments. Some family members who had been unable to attend previous clinic appointments are now able to be involved because of the access to Tele-medicine. Tele-medicine has also afforded our team with some flexibility. We are able to see more patients sooner than can be accommodated at a clinic appointment. It saves on travel time – for patients, care partners and the team. It has cut back considerably on delays in providing geriatric assessments and in meeting patients' needs.

Some of the challenges faced by patients and care partners include:

1. Lack of social stimulation
2. Delays in investigations – lab tests, brain imaging scans etc.
3. Rehabilitation and Recreational Therapy services (Tele-Rehabilitation would be an asset)

From our standpoint, some of the potential and actual challenges are:

1. Inability to provide a definite new diagnosis
2. Inability to conduct Capacity assessments/ decision making assessments – need direct patient assessment.
3. Ensuring confidentiality – Guidelines are used to ensure that patient confidentiality, autonomy and other ethical principles are recognized and maintained as much as possible.

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CONCLUSION: The framework adopted and flexibility to adapt to changes have brought about an increase in the number of cases seen since the outset of the COVID-19 pandemic. We have also been able to reduce delays in providing geriatric care. We have adopted our services by identifying the potential challenges and mitigating their impact through various strategies including the involvement of local and remote interdisciplinary teams in geriatric assessments.

Poster Presentation Abstracts

ID: 984

Abstract Topic: COVID-19 and dementia – NEW

Keywords: COVID-19, Dementia Care, Formal and Informal Care

The impact of covid-19 on formal and informal dementia care in Hong Kong

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Abstract:

Introduction: It has been well-established that older adults, especially those with underlying chronic conditions such as dementia, are at an increased risk for COVID-19. Besides contracting the virus, COVID-19 has also posed other threats to people with dementia (PwD). Within a global-scale lockdown, formal dementia services may be suspended as they are usually considered 'non-essential.' In addition, the way informal caregivers, such as family members, take care of the PwDs may also have changed to cope with the COVID-19 pandemic.

The present study aims to (1) explore the impact of COVID-19 on both formal and informal care for PwDs in Hong Kong; (2) investigate the types of coping strategies used by both service providers and family carers; (3) identify the challenges for the carers in the COVID-19 global crisis.

Methods: We developed an online survey and collected responses from 250 formal (service providers) and 250 informal (family members or friends) dementia carers in Hong Kong. Formal carers answered questions on (1) the impact of COVID on regular dementia services; (2) coping strategies used at the organizational level; and (3) challenges faced to provide services during the pandemic. Informal carers answered questions on (1) the impact of COVID on PwD's life routine and health condition; (2) changes in the dementia services received from the providers; (3) coping strategies used at the individual level; and (4) challenges faced and external support needed.

Results. We found that COVID has significantly impacted both formal and informal dementia care in Hong Kong. Results also suggested that both service providers and family care-takers have, flexibly and effectively, adopted new approaches to take care of the PwDs at the time of COVID-19.

Conclusion. The present study explored the influence of COVID on dementia care and services, the coping strategies used, and challenges faced, from the perspectives of both the service providers and the family carers in Hong Kong. Our findings provide insights into ways to better support both PwDs and their carers in public emergencies and get prepared for future challenges beyond the current COVID-19 pandemic.

Poster Presentation Abstracts

ID: 985

Abstract Topic: Dementia policies and public policy

Keywords: Collaborative, stakeholder engagement, policy, innovation, HTA, registries, cost-effectiveness

Project Alzheimer's value Europe | pave

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Abstract:

Alzheimer's disease has been called the greatest health challenge of the 21st century. Adding urgency to an already critical situation, the incidence of Alzheimer's disease is projected to quadruple by midcentury as populations age. Today, there are causes for hope. New therapeutic and diagnostic innovations are poised to enter the market and we know more about the brain than ever before.

However, serious challenges remain that will need to be addressed if these future innovations are to result in real-world patient access and outcomes. New treatments and diagnostics for Alzheimer's disease will challenge today's models for health technology value assessment and funding approaches. Providing access to and funding for future innovations in Alzheimer's diagnosis and treatment will require new models for measuring and assessing value that include the holistic and societal benefits of Alzheimer's disease treatments and diagnostics.

Project Alzheimer's Value Europe (PAVE) has been established as a collaborative, multi-stakeholder forum focused on the value assessment of and funding for emerging therapeutic and diagnostic innovations in Alzheimer's disease in Europe.

PAVE's goals are twofold: to educate policymakers, payers, and other Alzheimer's disease stakeholders in European countries on the current challenges related to assessing value in Alzheimer's disease; and, to work together with European payers and policymakers to develop solutions related to the value assessment of, and funding/financing for future Alzheimer's disease therapies and diagnostics.

Along these goals, PAVE aims at achieving the following outcomes in 2020:

1. Improve Understanding of Epidemiology & Impact by generating a high-level review of epidemiological literature to clarify what currently defines and quantifies dementia and Alzheimer's disease with the end goal of pinpointing eligible populations for treatment. Based on the outcomes of the epidemiological review of specified regions, the report would aim to help outline industry-wide budget and resource impacts of diagnosing and treating Alzheimer's disease while providing common reference points for stakeholders beyond the general epidemiology of Alzheimer's disease.
2. Delineate how Alzheimer's Registries can be used to support a holistic value assessment using guiding questions such as: how can registry data be used to inform value assessments that discern the full health and societal benefits of emerging therapies and treatments; how can this information be leveraged to secure payer support that will result in patient access; and what are the current barriers to using registry data, including any "data gaps," in the creation of new drug value assessments.
3. Identify & Catalogue Countries with Core Elements for Measurement for approaches to health technology assessment (HTA) that take a broad view of the direct and indirect impact when evaluating innovative treatments and diagnostics for Alzheimer's disease. Currently, HTA/cost effectiveness plans are assessing cost-benefits within healthcare systems and not fully addressing Alzheimer's significant impacts on delayed institutionalization, caregiving homes, caregiver costs, etc. Therefore, there is a need to demonstrate larger societal influence that innovative diagnostic tools and treatments will have.

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To accomplish these goals, PAVE enlists the help of an informal, voluntary, network of expert advisors that understand clinical, value and access processes and decisions for Alzheimer's disease innovations as well as leaders that have developed evidence that address the concerns of policymakers and relevant stakeholders. PAVE members work collaboratively to define objectives for the work of PAVE, provide a community perspective on key considerations, and are a sounding board for PAVE's workplan and deliverables.

For more information please visit: www.PAVEurope.com

Poster Presentation Abstracts

ID: 986

Abstract Topic: Economics of dementia

Keywords: Alzheimer's disease, cost

Moving towards a holistic value assessment of innovative Alzheimer's therapies

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Abstract:

OBJECTIVE: To better understand how good practices in value assessment may need to be modified to make a holistic appraisal of the distinct needs and challenges presented by Alzheimer's

BACKGROUND:

The Alzheimer's community is facing a defining moment. For the past 17 years, no new Alzheimer's treatments have been approved by the Food & Drug Administration, and a 2014 study found that disease treatment candidates had a failure rate of 99.6%.^[i] This lack of progress deprioritized questions about how to value innovative therapies, and value frameworks have not kept pace with the pipeline. Yet such questions now take new urgency. Currently, there are 29 candidates in Phase 3 of clinical development – a notable increase over previous times – and 80.2% of all candidates are disease-modifying therapies, ^[ii] some of which may slow progression of the disease and preserve independence and function, while reducing caregiver burden. From 2002-2012, only 83 trials reached Phase III in total, and there were never more than 14 Phase III trials in a single year.^[iii]

This scientific momentum is prompting renewed attention to both the burden of AD and current approaches to value assessment of these potential innovations. Current direct medical cost estimates show that AD costs \$948 billion annually, with projected increases of nearly 16% each year as prevalence increases.^[iv] Yet most of these costs fall outside the narrow healthcare payer perspective and are passed on to families and societies. Current approaches to value assessments need to be reconsidered and broadened if the full benefits of new therapies in AD are to be demonstrated.

METHODOLOGY: We apply two value frameworks – the Value Flower framework (Fig. 1) and the “tip of the iceberg” cost assessment model (Fig. 2) – to Alzheimer's, and we ask how these frameworks can inform a holistic assessment of value of innovative Alzheimer's therapies. .

Conclusions:

Established value frameworks – e.g., the Value Flower (Fig. 1) – should be examined and potentially modified to meet the specific needs of Alzheimer's (as illustrated in Fig. 2)

Across many disease areas, there are three elements of cost: direct costs, indirect costs, and intangible costs. These three elements should be applied to Alzheimer's and fuse them to create a holistic value assessment.

Decisionmakers must assess the value of “scientific spillovers” of innovation, particularly in a moment when the Ph3 pipeline has 29 candidates.

It is important to evaluate what Alzheimer's patients, caregivers, and families (“family spillovers”) want most out of a potential innovative therapy. These desires should be integrated into holistic value assessments.

Figure 1: The Value Flower^[v]

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Elements that warrant consideration in value assessments:

The progression into mild dementia marks a uptick in costs for all stakeholders

Patients and caregivers experience high costs at moderate stages of the disease

Figure 2: The Escalation of Costs:[vi]

As Alzheimer's progresses, it raises direct, indirect, and intangible costs for all stakeholders.

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[iv] Anders Gustavsson, Peter Pemberton-Ross, Melissa Gomez Montero, Mahmoud Hashim & Robin Thompson (2020) Challenges in demonstrating the value of disease-modifying therapies for Alzheimer's disease, *Expert Review of Pharmacoeconomics & Outcomes Research*, DOI: 10.1080/14737167.2020.1822738

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[vi] El-Hayek YH, Wiley RE, Khoury CP, et al. Tip of the Iceberg: Assessing the Global Socioeconomic Costs of Alzheimer's Disease and Related Dementias and Strategic Implications for Stakeholders. *Journal of Alzheimer's Disease : JAD.* 2019 ;70(2):323-341. DOI: 10.3233/jad-190426.

Poster Presentation Abstracts

ID: 987

Abstract Topic: Environment and architecture for dementia

Keywords: Design, principles, culture, context, built environment, architecture, living well with dementia

Goals, principles, approaches and responses: designing in a way that enables people living with dementia to live well

Kirsty Bennett¹, Richard Fleming², John Zeisel³

¹University of Wollongong, Australia; ²Richard Fleming & Associates; ³Hearthstone Alzheimer Care Ltd

Abstract:

Introduction

People living with dementia are often unable to live as they wish. The built environment acts as a barrier, unnecessarily limiting people's participation in society and reinforcing the stigma associated with dementia. However, a well-designed environment can play a positive part in people's lives. Whether at home or in the community, in residential aged care or at work, the environment can enable people living with dementia to do what they wish to do by creating opportunities for them to live the life they choose.

Methods

How do we design well? There is broad agreement about what makes a well-designed environment for people living with dementia. The terms that are used and the way concepts and ideas are framed, however, can vary widely. This means that conversations can be at cross purposes and the applicability of design knowledge compromised.

This paper presents a schema which identifies and organises key aspects of designing for people living with dementia across four key domains: overarching goals, design principles, design approaches, and design responses. Each domain has an increasing level of specificity and detail and relates to the other domains which precede and follow it. The use of a schema offers a way for people living with dementia to influence and inform design at many levels, rather than on a design by design basis.

Incorporating the voices of people living with dementia in a design process is essential if a design is to be meaningful for the people who will use it.

Examples of environments are used to illustrate each domain and show how the domains are interrelated. There is a focus on the Fleming-Bennett design principles and the Zeisel approaches. The importance of culture and context when formulating design approaches and responses is emphasized, as is the way the application of the same principle can lead to environments that are very different.

Positive Impact

Using a schema to describe the different domains of environmental design will assist people across the world to take part in the conversation about designing well for people living with dementia.

It will support a conversation which starts with goals and principles rather than solutions (which are not transferable and are not relevant or affordable).

It will highlight how culture and context can be considered in any design response, while still applying key design principles and responding to goals.

The use of the schema will assist the knowledge that has been gained in well-resourced countries to be applied in a meaningful way in less resourced settings.

Conclusions

A well designed environment is essential if people living with dementia are to live well.

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The use of a four part schema to distinguish between overarching goals, principles, responses and approaches allows knowledge gained over many years to be embraced and provides a framework for current and future conversations.

It recognises the place of culture and context in design and encourages the voices of people living with dementia to be included in design.

Poster Presentation Abstracts

ID: 988

Abstract Topic: Environment and architecture for dementia

Keywords: Environment, Architecture for dementia

Designing for the homes of community dwelling people with dementia

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Abstract:

Background: Environmental design and modification has emerged as an important intervention to enhance the social health of people living with dementia. Therapeutic design has been used to minimise the difficulties and risks that people with dementia may encounter within different care settings, and to facilitate and support engagement in meaningful activities to promote quality of life. Valid and reliable tools exist to supporting auditing and application of dementia design principles within care environments and more recently within public buildings and neighbourhood precincts. However, a gap exists in understanding how to usefully assess the heterogeneous and dynamic home environments of community dwelling people with dementia.

Objectives: This paper documents the three stage methodology used by an interdisciplinary research team (including a co-researcher with dementia) to map underpinning evidence for assessment of home environments. A systematic review of dementia home environmental design literature was conducted to identify existing guidelines, principles and tools. Environmental features identified within these papers were coded against Fleming's ten established dementia design principles.

Results: A new taxonomy which embraced the dynamism of the person-environment relationship was developed. The taxonomy highlights that it is essential to both assess and consider strategies at the building, furniture, object, assistive technologies and the personal-behavioural supports level to more effectively promote home environments which are enabling to people with dementia.

Discussion/Conclusion: Future research should seek to test the usefulness of this taxonomy mapped against dementia design principles to inform the auditing and modification of the home environments of community dwelling people with dementia.

Poster Presentation Abstracts

ID: 989

Abstract Topic: Diagnostic tools

Keywords: Machine Learning, Early Diagnosis, Digital Biomarkers, Language

Langaware: extensive evaluation of a robust ml based language agnostic approach for the early detection of neurodegenerative diseases

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Abstract:

Background:

Although Alzheimer's disease (AD) is associated with changes in spoken language, these have not been exhaustively subjected to systematic analysis on a large scale. We evaluated the effectiveness of LANGaware's language agnostic approach to detect the language indicators that are coupled with MCI and early AD, thus assisting with their diagnosis. We evaluated LANGaware using recordings of speech samples obtained from AD patients and matched healthy controls (NC) derived from various elicitation tasks across languages. Within the current context we also evaluated the efficacy of a LANGaware's digital verbal memory test to detect MCI and early AD.

Method:

Multilingual audio recordings were analyzed employing various feature configurations to choose the most prominent multi-level linguistic analysis features differentiating the AD from the NC group across languages. The platform's diagnostic performance was evaluated on its ability to classify "unseen" audio recordings employing these salient features. Similarly the digital verbal fluency test's diagnostic efficacy was evaluated towards a test cohort of participants.

Results:

Evaluation results indicated that LANGaware achieved equally high classification scores across languages. Most significantly, these scores were achieved by employing a set of LANGaware-developed cross-linguistic markers. Moreover the evaluation of LANGaware's digital verbal memory diagnostic test yielded very interesting insights.

Conclusion:

The overall evaluation verified the robustness of the platform's predictive models using audio datasets across languages. Based on the findings, we conclude that LANGaware provides a time and cost effective language agnostic platform for cognitive screening pertaining to the detection of prodromal and early stages of neurodegenerative diseases in a range of clinical settings.

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