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New horizons in dementia: building on hope



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674

Importance of diagnosis from the perspective of a Person Living with Dementia

Tomofumi Tanno, Dementia Advocate, Japan

Plenary session

Plenary 2: The imperatives of diagnosis and treatment

Abstract

My advocacy works have two pillars: 1. "The Orange Door" provides a one-stop comprehensive help service for people with dementia as a peer, and 2. "The Peer Support" functions as in-clinic peer support offered immediately after diagnosis.

The Orange Door is born out of my own experience. When I was depressed after diagnosis, I met a smiling man actively living with dementia. His presence showed me that we can live well after several years of diagnosis. Thus I created a space for other people with dementia, to bring back their smiles. The Orange Door started just by me, and now in 2022, we are a group of five experts of lived experience.

The Peer Support evolved out of The Orange Door. There were many who could not even make it to the service venue. Thus, I thought of outreaching at a clinic so as not to miss them. We set a day for the support, and the doctors will book an appointment for the patient in mind. We share our conditions and symptoms, and our coping skills in our daily lives. Now we have six peer support members, ranging from their 40s to 88-year-old. The interaction allows us to develop a sense of empathy that helps us live a positive life.

When people with dementia feel better about themselves, their families will be at ease, and the social stigma will be reduced. I believe I can do this work precisely because I have dementia.



668

The imperatives of diagnosis and treatment

Serge Gauthier, McGill University, Canada

Plenary session

Plenary 2: The imperatives of diagnosis and treatment

Abstract

A combination of factors are changing the way we approach diagnosis and treatment of Alzheimer's disease (AD). The COVID-19 pandemic has accelerated the use of remote assessments, and cognitive, functional and mood/behavioral scales validated for online use may speed up referrals to primary care services and to speciality consultations. The biological diagnosis of AD may become possible through blood testing for the ApoE genotype and levels of pTau isoforms and other disease makers, followed if needed by cerebrospinal fluid examination and/or metabolic brain imaging.

New drugs with the potential to delay disease progression are emerging. Their use will require earlier diagnosis into the prodromal or pre-dementia stage of AD. The arrival of this new generation of drugs presents both a challenge and an opportunity to rethink our approach to early and accurate diagnosis of dementing conditions in their early symptomatic stages.

The World Alzheimer Report 2022 on post-diagnostic care of dementia will describe the natural progression of dementia through stages and indicate how to manage symptoms as they emerge over time. This Report will review the current non-pharmacological interventions, new models of care around the world, and emphasizes the need to increase educational opportunities for healthcare professionals, persons living with dementia and their carers. Prevention strategies towards dementia risk reduction will be updated.

Cautious optimism in our field is thus appropriate, if there is a sustained public and governmental support to improve care at all stages of AD, as is currently done for other chronic conditions.





671

Barriers and Enablers for diagnosis and treatment in Lower and Middle Income Countries

Meera Pattabiraman, Alzheimer's and Related Disorders Society of India, India

Plenary session

Plenary 2: The imperatives of diagnosis and treatment

Abstract

Dementia unlike other diseases, affects not only the persons concerned, but impacts the primary caregiver, the family and friends as well. Even though we have over 55 million persons living with dementia worldwide, the majority do not get diagnosed. Over 60% of persons with dementia live in lower and middle income counties, where the cases that are undiagnosed go up to 90%.

Early and timely diagnosis is critical both for the person with dementia and their families. Only this can address the treatment gap and improve the quality of care provided. The barriers to diagnosis, more so in developing economies, are lack of awareness among the general public and health care professionals, paucity of diagnostic facilities and tools, stigma and the costs involved. Unless the governments recognise dementia as a health priority and address these challenges, the situation will not improve significantly.

The enablers for improved diagnosis are more awareness, diagnosis at the primary care level, inclusion of dementia in programmes for elderly and equipping medical professionals with the requisite knowledge.

Timely diagnosis will not only help to delay the progression of the disease, but will aid in optimising treatment and care. The caregivers and families are impacted physically, socially, financially, and emotionally. When there is early diagnosis and greater awareness about the disease, the challenges can be mitigated leading to improvement in the quality of care through better coping strategies.

675

British Virgin Islands Experience- Fighting Stigma Through dementia Campaigns

Enda Williams, Virgin Islands Alzheimer Association, British Virgin Islands

Plenary session

Plenary 3: World Alzheimer's Month and Dementia Friendly Communities: urgent priorities

Abstract

The gap between vision and current reality is a source of energy. If there is not a gap there would be no need to move towards the vision. This gap is called creative tension. This statement is a paraphrase of Peter Senge's quote in the Fifth Principle.

In 2010, the words Alzheimer's and dementia were not heard in any public forum in the British Virgin Islands (BVI). As Warren Bennis says, we have to create a compelling vision, one that takes people to a new place and then translates the vision into a reality. This has been the path of our Alzheimer's/dementia movement in the BVI.

With a vision of a dementia friendly community, the Virgin Islands Alzheimer's Association (VIAA) knew it had to develop strategies that would bring about awareness and educate the community through these strategies and campaigns. That vision had to be compelling enough to get people on board and move the BVI to a new reality.

This session will examine these strategies and campaigns that have been developed to move the British Virgin Islands towards a dementia friendly community and as a consequence decrease the stigma associated of Alzheimer's and other dementias.



676

Building safe spaces and stigma-free communities: The Brazilian experience

Elaine Mateus, Federação Brasileira de Associaçãoes de Alzheimer (FEBRAZ), Brazil

Plenary session

Plenary 3: World Alzheimer's Month and Dementia Friendly Communities: urgent priorities

Abstract

A recent study estimates that 1.8 million Brazilians live with dementia. Nonetheless, lack of awareness and understanding of dementia contributes to fear, stigma, and social isolation. A survey of 70,000 respondents worldwide published at the ADI WAM Report 2019 indicated that 70% of the Brazilian general public believes that people living with dementia (PLWD) are impulsive and unpredictable, and that 26% of the country's healthcare workers would keep the dementia diagnosis a secret in case they developed the condition in the future. A qualitative study conducted in the state of São Paulo indicates that PLWD are often depersonalized, infantilized, underestimated, and expected to obey their care partners. The Alzheimer's Associations in Brazil work towards creating experiences where members are provided with accurate dementia knowledge and motivated to develop positive attitudes towards PLWD. As part of the awareness raising and anti-stigma activities, PLWD and their care partners have been encouraged to be involved as much as possible in a number of initiatives. In this session, we share two of them. One is a national online open access educational program and the other is a local Cognitive Stimulation Therapy (CST) experience. We discuss how those initiatives can help building safe spaces and developing dementia-inclusive communities. Evidence comes from PLWD's own perspectives about what it was like for them to voice their experiences in the educational program and to participate in a series of tailored CST activities.

669

The cost of care: new figures, forecasts and implications

Anders Wimo, Karolinska Institutet, Sweden

Plenary session

Plenary 4: Solutions and challenges in strengthening care support

Abstract

Introduction: As part of WHO's Global Status Report on the public health response to dementia, launched in September 2021, new estimates on the global economic burden of dementia have been released.

Methods: A systematic review.

Results: In 2019, the global societal costs of dementia were estimated at US$ 1.3 trillion for 55.2 million people with dementia (about US$ 24,000 per person). 50% of these costs were associated to informal care. Over 60% of the global dementia population live in low-and-middle-income countries (LMIC) but represent only about 25% of the global costs. Informal care costs accounts for 65% in LMIC and 44% in high-income countries. There is a strong relationship between costs and severity of dementia: about US$ 16,000 per person with mild dementia, US$ 27,000 with moderate dementia and US$ 36,000 with severe dementia. Informal care expressed in terms of global hours corresponds to 133 billion hours, with a clear association to the income level: about 12 hours are spent caring per day in low-income countries and 7.6 hours per day in high-income countries. About 70% of the informal care hours are provided by women.

Conclusions: Given the expected increase in numbers of people with dementia worldwide, countries need an action-plan for dementia care and to support families. There are also great imbalances regarding how resources for dementia care are distributed worldwide. The financing of dementia care is a great challenge for every country, but it is even greater for LMIC due the lack of infrastructure for long-term care.



670

A decade of disruption and transformation

Henry Simmons, Alzheimer's Scotland, United Kingdom

Plenary session

Plenary 4: Solutions and challenges in strengthening care support

Abstract

Scottish Government made dementia a priority in 2007, by 2010 the first National Dementia Strategy was developed, highlighting post diagnostic support as a key priority area. However, it was not until 2013 that this defined model of Post Diagnostic Support combined with a guaranteed minimum of one year's support from a named skilled Link Worker became policy. It complimented the medical model and elevated a bio-psychosocial model of support to an equal policy status. However, implementing this new model and disrupting the core philosophical paradigms around dementia has not been without challenges.

In this presentation, Henry Simmons will discuss these challenges and share the experience of developing and implementing this new model of post diagnostic support in Scotland over the past 10 years. He will explain how the "Five Pillar" Post Diagnostic Support Model, developed by Alzheimer Scotland, moved from the conceptual fringes of policy and dementia practice to become a core foundation of support throughout Scotland, delivered now by some 100 skilled Alzheimer Scotland Post Diagnostic Link Workers. He will explore the philosophy of this approach, the impact on practice and most importantly people. He will describe the ways it utilises individual natural supports, community assets and peer support, to build a person-centred plan that empowers and enables individuals to live well with dementia. He will also describe how this shift has helped create the conditions for change that led to the emergence of Scotland's approach to Brain Health and Dementia Prevention.

667

Advances in risk reduction or prevention of dementia and national public health strategies.

Gill Livingston, University College London, United Kingdom

Plenary session

Plenary 5: Risk reduction and prevention: the latest research and the challenges of bringing new messages to the broader public

Abstract

The Lancet dementia commission on prevention intervention and care in 2020 identified 12 risk factors which had consistent, biologically plausible, longitudinal evidence about potentially modifiable risk factors which might prevent or delay dementia. I will discuss further research since then including adult cognitive stimulation, inflammation, sleep, psychosis and air pollution. The WHO says all nations should have a dementia plan and this should include dementia risk reduction. I will discuss some policy responses including in the United States and the United Kingdom.



672

Prevention: from epidemiological studies to prevention trials

Sandrine Andrieu, Toulouse University Hospital, France

Plenary session

Plenary 5: Risk reduction and prevention: the latest research and the challenges of bringing new messages to the broader public

Abstract

Neurodegenerative diseases, such as Alzheimer's disease, have become public health priorities in many countries in recent years, given their frequency (10 million new cases per year worldwide) and their significant contribution to loss of autonomy.

Thus, research on the determinants of this disease is the subject of intense research and several potential protective factors have been highlighted by large-scale epidemiological studies. However, randomised controlled trials designed to demonstrate the effectiveness of preventive strategies have produced conflicting

Results: Various prevention strategies have been investigated, such as pharmacological, non-pharmacological (diet, physical activity, cognitive training) interventions, with encouraging results from pilot studies but rather disappointing results from large-scale studies designed to demonstrate the actual effectiveness of an intervention. While the more recent trend to test combined interventions seems promising, the emergence of biomarkers for Alzheimer's disease is a new development that could transform current approaches. This presentation will summarise recent data in the field of prevention of cognitive decline and neurodegenerative diseases such as Alzheimer's disease and will address the methodological challenges of this research at the frontier between clinical and public health research.

673

Closing global gaps through technological solutions

Rhoda Au, Boston University, USA

Plenary session

Plenary 6: Data, research, innovation and therapies: New thinking, new directions

Abstract

Worldwide the number of people over the age of 65 is now greater than those under the age of 5. With this major shift in age demographics, dementia and in particular Alzheimer's disease (AD), is rapidly overtaking other chronic diseases as the most prevalent and the most feared. AD research data to date remains both highly biased as well as highly siloed. The net result is scientific knowledge generated that represents some but not all. Recent technological advances in hardware, software and advanced analytics provide opportunity to implement methods of research practice that are highly inclusive. But making equal opportunity science a reality will require re-architecting study designs, re-constructing data collection methods and re-developing data accessibility and data analytic approaches. In essence the foundations of long-accepted peer-reviewed science will need to be completely reshaped to fully capitalize on what research tools are available today and what research opportunities lie in the future. Our precision brain health initiative has spent over a decade developing and implementing its strategic vision. We will provide a brief overview of work being done through the Framingham Heart Study and the Boston University Alzheimer's Disease Research Center and how the Davos Alzheimer's Collaborative Global Development Program is taking these lessons learned and seeking to deploy at a global scale.



4

Peer Support: the importance of tea and cake

Mr Willy Gilder
STAND, Fife, United Kingdom. Deepness Dementia Radio, Lewis, United Kingdom. University of Edinburgh, Edinburgh, United Kingdom. University of Exeter, Exeter, United Kingdom

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

In Fife, Scotland, a peer to peer support group for people with early onset dementia has proved the importance of peer support. People with dementia are now both training others with dementia and members of the wider community. We suggest that people living with dementia need to seize power to help themselves.

5

Genetics and environment – an integrated approach

Dr Gerardo Alfonso Perez, Dr Javier Caballero Villarraso

Universidad de Cordoba, Cordoba, Spain

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Nowadays it is clear that Alzheimer is a multifactor condition caused by a combination of genetic as well as environmental factors. The objective of this paper is to highlight the need for interdisciplinary approaches that combine the analysis of genetic factors as well as environmental factors in order to be able to provide personalized medicine to individuals. Over the last years there has been a very substantial increase in the amount of genetic data available for instance, GWAS or DNA methylation data. There has been also a multitude of research papers related to gene expression in Alzheimer. While these analysis are of obvious importance at the population level they are less relevant when dealing with individual cases. In the case of Alzheimer this is particularly important because of the very heterogeneous timeline evolution of the disease.

It is acknowledged the complexities on a multidisciplinary analysis when tackling Alzheimer but as big data becomes a reality it starts to be possible to combine traditional genetic data to at least some environmental factors such as diet and stress. Traditional genetics or environmental data alone are unlike to be enough to enable researches to get a detailed understanding of the condition. This multidisciplinary approach requires a significant effort from the scientific community bring together experts from different fields as well as substantial investment and policy support for such initiatives.



6

Electroacupuncture could balance the gut microbiota and improve the learning and memory abilities of Alzheimer's disease animal model

Dr Jing Jiang
Beijing University of Chinese Medicine, Beijing, China

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Alzheimer's disease (AD), as one of most common dementia, which mainly affects older people, gains more and more awareness from the worldwide. In this study, we intended to explore the possible mechanism of improving cognitive function and protecting the neuron effect by electroacupuncture.

Method: We applied senescence-accelerated mouse prone 8 (SAMP8) mice as AD animalmodel, used Morris water maze, HE staining,16S rDNA amplicon sequencing of gut microbiota and ELISA to demonstrate our hypothesis.

Results: electroacupuncture improved the learning and memory abilities in SAMP8 mice ($P<0.05$) and could protect the frontal lobe cortex and hippocampus of SAMP8 mice; electroacupuncture significantly decreased the expression of IL-1β ($P<0.01$), IL-6 ($P<0.01$) and TNF-α ($P<0.01$ in hippocampus, $P<0.05$ in serum) in serum and hippocampus; electroacupuncture balanced the quantity and composition of gut microbiome, especially of the relative abundance in *Delta-proteobacteria* ($P<0.05$) and *Epsilon-proteobacteria* ($P<0.05$).

Conclusion: lectroacupuncture treatment could inhibit the peripheral and central nerve system inflammatory response by balancing the gut microbiota.

7

Seeing dementia through my parents' eyes: supporting people to live as well as possible with dementia. A series of ten short films document a year in the life of a couple living at home with Alzheimer's Disease with the aim of supporting informal and formal carers through lived-experience.

Ms Kimberley Sian Littlemore
Assistive Technologies Innovation Centre, University of Wales, Trinity St Davids, Swansea, United Kingdom. Centre for Aging and Dementia Research, Swansea University, Swansea, United Kingdom

Topic

Support for dementia carers: Education and training for informal carers

Abstract

When my parents both developed dementia I wanted to better understand the condition and how to support them. Despite reading and attending courses I was struck by the fact that I couldn't SEE what dementia looked like and felt like.

I have made films with my dad all my life; it's probably why I became a documentary maker at the BBC. 10 years producing films for BBC Comic Relief, showed me the power of sharing the stories of ordinary people, to open our eyes and engage us with unfamiliar and often challenging topics.

As I worked out how to care for my parents, I realised that our family journey could act as a powerful story-telling tool to support other carers, both formal and informal. My parents agreed. During the COVID-19 lockdown, fixed cameras recorded our lives 24/7. I showed the footage to a series of experts from universities, health and social care including Teepa Snow in the US. They shared their advice about the situations I showed them and we began to construct a series of films based around what we saw. They are often funny, warm, sometimes sad, but they offer engaging and memorable practical advice for carers which has been incredibly well received. An innovative user-experience report documents that feedback. Here is a taste www.medic.video/dementia-intro

The films will be used by the National Dementia Carers Training programme in Wales. We are starting our next series in residential care. I would love to share our work with you.



8

Collaborate, co-create, participate? How to conceptualise and use collaborative research approaches in nursing homes and home care services.

Dr Sophie Nadia Gaber[1,2,3], Dr Manuel Guerrero[3,1,4], Dr Lena Rosenberg[1]

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Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Aims: Collaboration, co-creation, participation, and partnerships are frequently discussed in dementia research and innovation. However, there is a knowledge-gap about how these collaborative approaches are conceptualised and used in practice. This presentation aims to:

- increase understanding of how collaborative approaches are conceptualised and used with older adults including those living with dementia, as well as staff, in the context of nursing homes and home care services;
- provide recommendations about ways to facilitate these collaborative approaches.

Method: A meta-ethnography was used to review the knowledge base about collaborative approaches with older adults including those living with dementia, as well as staff, in the context of nursing homes and home care services.

Results: We identified creative and novel collaborative approaches, including visual methods, co-dwelling, and co-construction of research, narrative and imagination. However, the degree to which older adults, especially those living with dementia, desired and felt able to participate varied between studies. The longer-term benefits and consequences of their participation were frequently overlooked.

Conclusion(s): There are opportunities but also tensions and compromises underlying the conceptual, ethical, and methodological assumptions and strategies of collaborative research in nursing homes and home care services.

9

Technology facilitated reminiscence in dementia: The InspireD study

Dr Assumpta Ryan[1], Dr Maurice Mulvenna[2], Dr Claire McCauley[3], Ms Aideen Gibson[1], Dr Finola Ferry[1], Dr Brendan Bunting[3], Dr Kevin Curran[1], Dr Debbie Goode[1], Dr Raymond Bond[2], Dr Kyle Boyd[4]

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Aim: This study investigated the outcomes of a home based; individual specific reminiscence intervention facilitated by an iPad app (InspireD) for people living with dementia and their family carers.

Methods: The study used a quasi-experimental design with three phases. **Phase 1**: A User Development Group comprising apaired sample of 6 people living with dementia and their family carers worked with the research team to design and test the technology. **Phase 2**: The InspireD reminiscence app was then used at home for 12 weeks by 30 people living with dementia and their family carers. Outcome measures examined the impact of reminiscence on mutuality, wellbeing, quality of life and quality of the relationship between participants living with dementia and their family carers.Phase 3: Individual interviews were conducted with a sample of participants (n=31) to explore their experience of the intervention.

Results: People living with dementia used the app independently and more frequently than their carers. Therewere statistically significant increases in mutuality ($p < .0005$), quality of caregiving relationships ($p < .0005$), and emotional well-being ($p < .0005$) from baseline to endpoint for people living with dementia. For carers, there were no significant changes in these outcome measures from baseline to endpoint. Participating dyads perceived the intervention as a positive experience which focused on gains rather than losses in the context of memory retention and learning new skills.

Conclusion: Individual specific reminiscence supported by an iPad app can deliver positive outcomes for people living with dementia and their carers.



11

Post diagnostic services for people with dementia in the Arab world

Dr Hamed Nasser Al Sinawi
Sultan Qaboos University, Muscat, Oman. Oman alzheimers Society, Muscat, Oman

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Dementia is a global public health problem and the middle Arab world has been witnessing an increase in the number of people at risk of developing dementia. Dementia remains an underdetecred and stigma toward people with dementia remains a major factor limiting access to diagnostic services along with lack of trained health care professionals, limited availability of diagnostics tools and treatment options. Post diagnostic services catering for the needs of people with dementia and their Cargiveres are also underdeveloped and when avaliable, only limited to tertiary care hospital located in big cities. This presentation will explore post diagnostic services in the arab world, what is available and what can be adopted and modified from the west to suit the needs of people with dementia and their Cargiveres in the arab world. We wil also discuss attitudes and practices of disclosure of the diagnosis from a cultural perspective.

12

Cultural adaptation and validation of a scale measuring social functioning in patients with dementia in Taiwan

Ms Ruan-Ching Yu, Dr Naaheed Mukadam, Dr Andrew Sommerlad, Dr Gill Livingston

Division of Psychiatry, UCL, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Objectives: The patient- and carer-rated 20-item social functioning in dementia scale (SF-DEM) evaluates social function in people with dementia. It is undergoing translation and validation in Germany, Japan, and Hong Kong. However, it has not been validated in Taiwan. This study therefore aimed to explore acceptability and validation of the SF-DEM in those with dementia in Taiwan and its correlates

Methods: We translated the SF-DEM for Taiwan (T-SF-DEM) according to relevant cross-cultural guidelines and then tested it with people diagnosed with dementia and their carers in Northern Taiwan. We used descriptive and correlation analysis to explore how scores relate to the Clinical Dementia Rating (CDR), Addenbrooke's cognitive examination III (ACE-III) and Quality of Life in Alzheimer's Disease (QoL-AD).

Results: We recruited 12 people aged 45 to 100 with dementia (9 very mild, 3 mild). All patients and 92% of carers completed the SF-DEM. The mean ACE-III score was 64.4. The mean scores on patient- and carer- rated T-SF-DEM were 19.9 and 19.0, including 3.3 and 4.9 on the sub-domain of "spending time with other people (max 21 points)", 5.7 and 5.4 on "communicating with other people (max 18)", 10.9 and 8.7 on "sensitivity to other people (max 12)". The correlation of the carer-rated SF-DEM with patient-ratings was low (r = 0.33), and moderate with ACE-III (r = 0.66) and carer-rated quality of life (r = 0.44).

Conclusions: The T-SF-DEM is an acceptable test for measuring social function in Taiwan. It requires more extensive reliability and validity testing.



13

Guilt, abandonment, tears, and burnout - Impact of UK care home restrictions on the mental well-being of staff, families, and residents

Dr Clarissa Giebel[1,2], Dr Kerry Hanna[1], Mr Paul Marlow[2], Mrs Jacqueline Cannon[3], Ms Hilary Tetlow[2], Mrs Justine Shenton[4], Mr Thomas Faulkner[5], Dr Manoj Rajagopal[6], Dr Stephen Mason[1], Dr Mark Gabbay[1]

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Objectives: The aim of this longitudinal, qualitative study was to explore the impact of the pandemic on the emotional and mental well-being of family carers, care home staff, and residents, in light of changing restrictions, increased testing, and vaccination roll-out in the UK.

Method: Remote semi-structured interviews were conducted with family carers of care home residents with dementia and care home staff from different care homes across the UK. Baseline and follow-up interviews were conducted in October/November 2020 and March 2021, respectively. Data were analysed using inductive thematic analysis involving members of the public with caring experiences.

Results: Forty-two family carers and care home staff participated at baseline, with 20 family carers and staff followed up. We identified four themes: (1) Increasing anger and frustration; (2) Impact on relationships; (3) Stress and burnout; (4) Behavioural impact on residents. The mental health of everyone involved, including family carers, care home staff, and residents has been negatively affected, and relationships between family carers and staff has been severely strained. There was a general lack of adequate mental health support, with little relief.

Conclusions: The pandemic has had a detrimental impact on the lives of those surrounding care homes – from residents and staff to family carers. Consideration should be given on how to best support the mental health needs of all three groups, by providing adequate easily accessible mental health care for all. This should also focus on rebuilding the relationships between family carers and care home staff.

14

Audit of delirium assessment and management in Geriatric Medicine inpatients, RIPAS Hospital

Dr Doreen Jing Wen Lim, **Dr Shyh Poh Teo**

Raja Isteri Pengiran Anak Saleha (RIPAS) Hospital, Bandar Seri Begawan, Brunei Darussalam

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Delirium is an acute confusional state and is common in hospitalised patients. Delirium is a risk factor for dementia and should be recognised and managed. The aims of this audit were to identify whether risk factors for delirium were identified and whether investigations to evaluate for causes were performed.

Methods: All patients admitted under Geriatric Medicine, RIPAS Hospital from 1st to 31st May 2021 were included. Data was obtained via the hospital electronic clinical records. This included patient demographics, documented assessment of risk factors such as cognitive impairment, falls, dehydration and pain, and whether investigations for delirium were performed. Data was entered into Excel and analysed.

Results: There were 34 patients included in the audit. There were 26 (76%) females and 8 (24%) males. Median age was 82 years (Range 71-93 years), while median length of stay was 8 days (Range 1-26 days). There were 15 (44.1%) with known dementia, 3 (8.8%) with depression, while 5 (14.7%) did not have cognitive function documented. There were 12 (35.3%) with previous falls. History of falls was not documented in 15(44.1%). Hydration status was documented in most, except for 2(3%). In terms of investigations, serum vitamin B12 and folate were not done in 17(50%), serum calcium not performed in 4(12%) and thyroid function test not done in 13(35%) patients. Among the 17 (50%) that complained of pain, 15 (88%) were prescribed analgesia.

Conclusion: This audit identified a need to improve identification of risk factors for delirium.



15

Instagram as a medium to raise public awareness in Brunei for World Dementia Month 2021

Ms Ummi Zakiyah Junit[1], Ms Siti Hafizah Lazawardi[1], Ms Nur Afifah Ali Amat[1], Ms Nuryanezza Yakub[1], Ms Izzah Haziqah Chuchu[1], Ms Syafiqah Sairabiatul 'Ain Said[1], Mr Rusydi Saidin[1], Ms Nurul Bazilah Ali[2], Ms Irnawati Mahir[2], **Dr Shyh Poh Teo**[2]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

World Dementia Month (WDM) is celebrated every September and is an opportunity to raise public awareness regarding dementia. Initially, roadshows were planned for all four districts in Brunei during WDM 2021. However, the second wave of COVID-19 affected Brunei on 7th August 2021, necessitating a change to a totally virtual approach. Instagram (IG) was the main medium used by Demensia Brunei (DB) for WDM 2021. There were 180 posts in total on the DB IG account in September 2021, which will be shown. This consisted of 48 IG Posts, 114 IG Stories, 13 IGTV videos and 5 IG Live videos, with 8156, 8567, 2613 and 280 reaches for each post type respectively. The DB IG account reached 1907 accounts during WDM, which was 315% higher than the previous month. Of these, 1410 (74%) were non-followers of DB IG. There were 25,581 impressions, with 1214 profile visits and 1289 content interactions, including 838 Likes, 55 Saves and 28 Shares. IG Posts with the highest reach related to promotions of IG Live talks and DB merchandise (masks). IG Stories with the highest reach were informative posts regarding exercise, pain in dementia, and the role of family and caregivers in dementia. Given the success of the IG-based campaign for WDM, DB has organised further informative talks using the medium. Future IG campaigns will also focus more on IG Posts and IGTV videos, which has more reach per post compared to IG Stories and IG Live Videos.



16

Innovative psychoacoustics neurostimulation technology for the personalized treatment of brain disorders to driving an instant cognitive boost.

Mr Dan Anzyo Anzyo
NeuroAudit, Tel Aviv, Israel

Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

NeuroAudit was founded in 2016 as a multidisciplinary startup focused on developing innovative psychoacoustics neurostimulation technology for the personalized treatment of brain disorders.

NeuroAudit developed daily use neuro stimulation patch, driving an instant cognitive boost.

NeuroAudit tackled the complexity of neurological disorders through continuous monitoring of the brain state and data-driven effective neurostimulation.

Our vision is to develop closed-loop, AI-powered monitoring-stimulation cycles that target the specific user, tracking and adapting to changes throughout the course of treatment.

NeuroAudit is currently conducting a monitoring study under unique stimulation to improve an instant cognitive boost as a first step toward treating Alzheimer diseases.



17

Care Co-ordination for People Living with Dementia and their Carers: The Critical Success Factors

Ms Lynn Flannigan[1], Mrs Jill Carson[2]

[1]Healthcare Improvement Scotland, Glasgow, United Kingdom. [2]Alzheimer Scotland, Glasgow, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Scotland's National Dementia Strategy (2017) committed to deliver a more flexible, co-ordinated, person-centred approach to supporting people with dementia from diagnosis to end of life, building on the existing 1-year guaranteed post diagnostic support (PDS).

Evidence shows effective care co-ordination can lead to improved outcomes for people with dementia and their carers, including fewer hospital admissions and lower medical costs. We conducted a qualitative and quantitative inquiry in one health and social care organisation regarded as an exemplar for delivering care co-ordination for people living with dementia and their carers to better understand their approach and outcomes. Our methodology included qualitative analysis of focus groups and interviews with staff, feedback from service users and quantitative analysis of healthcare costs. We found reduced overall resource costs for people with dementia compared to other local areas; lower levels of unplanned admissions; and lower deaths in hospital. From the analysis we extrapolated 12 Critical Success factors (CSFs) for care co-ordination and developed a self-assessment for services and organisations. We are now using the CSFs as a framework to improve whole pathway, whole system care co-ordination in a second community health and social care organization. We have increased our understanding of effective care co-ordination and now have a framework we can share with others, forming the basis for the enhanced coordinated support.

18

Dementia Awareness for Caregivers: Development of a brief, international educational intervention for carers of people with dementia, and feasibility testing in India

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aims: Knowledge of dementia varies across countries and, in some low and middle-income countries, access to person centred, easily accessible information about dementia can be challenging, especially for family caregivers. This suggests an urgent need for brief, culturally appropriate educational courses that can be used in multiple countries and contexts

Method: A multidisciplinary team from Brazil, India, Tanzania, and the United Kingdom (UK) developed a standardised course entitled 'Dementia Awareness for Caregivers (DAC-International)' and methodology for cross-culturally adapting this for specific countries or regions (DAC-Local). DAC-Locals were created and piloted in Brazil, India and Tanzania. In India, four DAC-Locals were co-developed by psychiatrists and psychologists across four states and further amendments were made for virtual delivery during the COVID19 pandemic. The Chennai version was initially delivered to 17 family caregivers.

Results: The DAC-International consisted of three modules: 'What is dementia?', 'Positive engagement' and 'Caring for someone with dementia'. In Chennai, amendments included replacing Malignant Social Psychology terms with everyday examples of the concepts in action. Feedback from caregivers indicated the course was acceptable and feasible. Case studies were noted as particularly helpful in encouraging positive communication between a carer and a person living with dementia.

Conclusions: The DAC-International is a culturally appropriate and acceptable means of developing country and context specific, brief, educational courses for carers of people living with dementia. Work is ongoing to formally evaluate the efficacy of country specific DACs in Brazil, India and Tanzania in large-scale research studies and a DAC-United Kingdom is in development.



20

Effects and value of Chinese medicine nursing in Alzheimer's disease

Miss Ruxia Yu, Dr Jing Jiang

BEIJING UNIVERSITY OF CHINESE, BEIJING, China

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Alzheimer's disease (AD) is a neurodegenerative disease, accounting for about 80% of all types of dementia, mainly manifested as affective dysfunction, memory dysfunction and cognitive dysfunction. With the aggravation of population aging, dementia is expected to reach about 150 million people worldwide by 2050[1], and the cost of treatment and nursing will reach $9.12 trillion [2], bringing a huge burden to medical staff, caregivers, families and society [3].

Nowadays, Chinese medicine nursing, according to the type of individualized AD patients, take comprehensive nursing of Chinese medicine, such as acupuncture moxibustion, massage, ear acupressure and other nursing techniques. Researchers [5] found that moxibustion therapy with oral medicine could effectively improve the cognitive function of AD patients. What's more, the mental state Scale (MMSE) was used as the main evaluation index for AD patients after electroacupuncture intervention for about 12 weeks, which showed that both the electroacupuncture group and Donepezil hydrochloride group could increase the MMSE score, but electroacupuncture therapy had an advantage in long-term efficacy[6]. In addition, due to the long-term of illness, geography, economy, and other factors, it was difficult for AD patients to adhere to long-term medication. Therefore, Chinese medicine nursing, such as acupoint pressure and ear acupressure were easily suitable for caregivers and AD patients at home. Because of the strong compatibility, high safety, economic benefits, small adverse reactions and good efficacy of Chinese medicine nursing, it is now favored by more and more AD patients and caregivers in China.

21

The vital role of a knowledge broker in the development of a Dementia Enabling Environmental Assessment Tool for Singaporeans - A research collaboration between two countries

Dr Joanna Sun
University of Tasmania, Hobart, Australia. Wicking Dementia Research and Education Centre, Hobart, Australia

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Research in Dementia Enabling Environments is a growing field with literature across the globe spanning more than three decades. However, there is a lack of research about dementia enabling environments in East and Southeast Asia. Without culturally appropriate evidence, the ability to implement necessary changes and improvements in the field can be challenging. Stakeholders involved in the implementation of dementia enabling environmental design recognised that there are fundamental principles that make a home. However, there are also apparent differences in key characteristics that contribute to the environment for different cultures. In addition to the differences in the characteristics of dwellings in different countries, there are varying research capabilities, levels of health literacy, local attitudes, and acceptance of non-culturally specific research in the field of dementia care. This presentation highlights the significance of the use of a knowledge broker (KB) in a project that requires the collaboration of international stakeholders from Singapore and Australia to pave the way for tangible research outcomes. The project adapted the Australian Environmental Assessment Tool High-Care (EAT-HC) for a Singaporean population, resulting in the development of the Singapore Environmental Assessment Tool (SEAT). This commentary offers insight into the workings of a KB whose role in this project enabled the adoption of knowledge by facilitating its transfer across cultures and languages. The presentation provides a personal and in-depth narrative of the functions, activities, tasks, barriers, and facilitators encountered by a KB in research embedded in a global health setting.



22

Discourse and Dementia: Using positioning theory to explore whether an Appreciative Inquiry approach supports people living with dementia to challenge discourse

Dr Ian Davies-Abbott, Dr Jaci Huws, Dr Sion Williams

Bangor University, Bangor, United Kingdom

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: People living with dementia experience discourse, which malignantly positions them within society. An Appreciative Inquiry approach was used by people living with dementia to inform a mechanism of change to positively influence the discourse of family members/carers, healthcare workers and lay people.

Methods: Appreciative Inquiry was adapted as the research methodology to support democratic social research and action when considering positioning theory in the discourse about people living with dementia. A cohort of four people living with young onset dementia worked through three phases of Appreciative Inquiry (Discovery, Dream and Design) and the outcome was presented to three natural discussion groups. Discourse data was analysed using positioning theory and thematic analysis to assess whether desirable change had occurred.

Results: People living with dementia were empowered to identify the requirements for positive verbal positioning using three phases of Appreciative Inquiry. An original positioning theory framework was developed for the analysis of discrete discourse in relation to this 'ideal' positioning.Other societal groups were directly influenced by the outcomes of the Appreciative Inquiry, resulting in more positive discourse concerning people living with dementia.

Conclusions: Appreciative Inquiry can be reconfigured to involve different participants across phases, retaining its generative and transformative potential, without foregoing its underpinning principles. People living with dementia can successfully complete an Appreciative Inquiry exercise with outcomes that have the power to transform the discourse of other members of society. Social action can be influenced by people living with dementia using this adaptation of the Appreciative Inquiry methodology.

23

Testing the delivery of post-diagnostic support from primary care – learning from an improvement programme

Ms Julie Miller
Healthcare Improvement Scotland, Glasgow, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

From April 2018 to March 2021, Focus on Dementia, a national improvement programme, selected three GP cluster sites to explore whether relocation of dementia expertise into primary care would make dementia support more accessible and ''normalised" to people. And, whether this would encourage earlier presentation for a dementia diagnosis and provision of high quality support from dementia-friendly practices.

Currently most PDS practitioners are based within community mental health teams and diagnosis of dementia largely continues to be made from psychiatry. Three clusters were selected to become innovation sites and participated in a series of educational workshops on dementia and quality improvement methodology. Progress at each site was monitored monthly and an external evaluation was commissioned from Scottish Government.

Aims/objectives of the programme:

People present earlier for diagnosis when pre and post dementia diagnosis support is accessible from primary care

- People receive a more timely diagnosis
- There is greater uptake of PDS when it is offered from primary care
- Accessing PDS from primary care is a positive experience
- Primary care staff have increased skills and confidence in recognising and responding to dementia.

The presentation will share the findings of the evaluation, which publishes in November 2021. Interim data from surveys and case studies includes:

- East Edinburgh improved key information summary (KIS) completion and earlier take up of assessment for diagnosis.
- Nithsdale reduced wait time for from 9 months to 6 weeks since implementation of nurse/OT led diagnosis in primary care clinics.
- Shetland increased the uptake of PDS by 40%.



24

Exploring the Meaningful Engagement and Social Inclusion of Persons Living with Advanced Dementia Through the Namaste Care Program: Experiences of Two Canadian Long-Term Care Homes

Ms Marie-Lee Yous[1], Dr Sheila Boamah[1], Ms Danielle Just[2,1], Dr Paulette V. Hunter[3], Dr Sharon Kaasalainen[1]

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Aim: To describe how social and sensory environmental changes influence meaningful engagement and social inclusion of persons with advanced dementia by implementing the Namaste Care program in long-term care homes. Namaste Care is a multisensory, person-centred program that advocates a slow pace, high-touch approach and sensorial activities designed for advanced dementia.

Methods: For this qualitative study we conducted focus groups and interviews at baseline and 1-6 months after Namaste Care implementation with family members, volunteers, staff (e.g., nurses, personal support workers, kitchen personnel) and people in administrative roles (e.g., directors of care, volunteer coordinators) at two long-term care homes in Canada. The Comprehensive Process Model of Engagement, which considers personal, stimulus, and environmental attributes that lead to engagement was used as a coding framework. We used NVivo software for coding.

Results: With respect to environmental attributes to support engagement participants emphasized that a lower level of stimulation was helpful (i.e., a designated quiet space and a small group format). Regarding stimuli, the familiarity of the activities delivered in the program was emphasized. Finally, with respect to personal attributes, participants emphasized program leaders' capacity to deliver individualized care (i.e., knowledge residents' unique needs and preferences).

Conclusion: Meaningful engagement is important to the personhood and well-being of persons with advanced dementia. Using the Comprehensive Process Model of Engagement revealed that a low-stimulation small-group program that includes high-familiarity activities provided by staff who have knowledge of each residents' unique needs and preferences is important to facilitate meaningful engagement for persons with advanced dementia.

25

"What if we talk about Alzheimer's disease?" - An educational booklet for children

Mrs Lorène Gilly
France Alzheimer and related diseases, Paris, France

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

On the occasion of World Alzheimer's Day on September 21, 2020, France Alzheimer and the association "Les Petits Citoyens" (Little Citizens) have published an educational booklet on the disease for children aged 7 to 11.

Finding the right words to explain the mechanisms of the disease and its consequences from an early age is a major challenge in fostering an inclusive society.

This is why we wanted to raise awareness among the youngest by developing the booklet "*What if we talk about Alzheimer's disease?".*Designed in a ludic and educational way, with simple words, comic book characters that children can identify with and cartoons, this booklet helps start the discussion with children.

Moreover, this is the will of the association "*Les Petits Citoyens*", which "by arousing questioning, debate and curiosity through texts and illustrations, hopes that this collection will contribute to the development of active citizenship from the younger age and will give children a taste for reading and thinking".

Thanks to this booklet, children will understand more about Alzheimer's disease through discussions between Arthur, Agathe, Gary, Sarah and P'tite Marianne. Over the 10 illustrated stories, they discover that this disease affects memory, but also language and behavior.

This booklet, edited in more than 50,000 copies, has been distributed since September 2020 in the schools and leisure centers of the network of "*Les Petits Citoyens*" and thanks to the local branches of France Alzheimer and related diseases.



26

Counselling and dialogue unit

Mrs Lorène Gilly
France Alzheimer and related diseases, Paris, France

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

With the Covid-19 pandemic, visitation restrictions, slipping phenomenon and end-of-life support which have become more complex, tensions have arisen between families and the management team of the nursing homes. Indeed, a lot of families have experienced incomprehension and feelings of abandonment of their relatives, in particular those of the residents living with dementia.

To address this situation, under the aegis of the Regional Health Agency (ARS) of Nouvelle Aquitaine, a counselling and dialogue ethical unit has been set up. It is run by the ethical reflection space of Nouvelle Aquitaine (ERENA) and France Alzheimer Dordogne.

This unit, place of listening and dialogue, can be consulted at the request of families or nursing homes, whenever tensions arise, linked to the pandemic and the health restrictions defined by the government. It is all about listening to the suffering of families, understanding the difficulties encountered by the managerial team and re-establishing the dialogue between the two.

The unit mobilizes two or three people representing ERENA and France Alzheimer for each request. They make the necessary contacts with the protagonists to set a meeting date.

This project, originating from the first feedback from the field, was modeled and is being led by Doctor Geneviève Demoures, retired geriatrician and president of France Alzheimer Dordogne and by Professor Roger Gil, from ERENA.

Set up in October 2020, the unit has already answered to 150 solicitation (data as of April 30, 2021). Projects of deployment of the initiative in other French areas are conducted.

27

Culture, Alzheimer and Covid-19 pandemic

Mr Volodia Tourtchine, **Mrs Lorène Gilly**

France Alzheimer and related diseases, Paris, France

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

The Covid-19 pandemic has been a terrific period for people living with dementia and their family caregivers. Isolation, emotional exhaustion, increase of cognitive impairments... were among the most important consequences.

Since June, 2020, France Alzheimer, in partnership with The Swisslife Foundation, has decided to organize virtual visits for people with dementia and their caregivers. These events are organize as videoconferencing meetings of approximately two hours long. Several Parisian partner museums answered our request and followed us in this adventure like *Jeu de Paume*, *Palais de Tokyo*, or *Musée Picasso.*

There are two kinds of virtual visits:

- from home, people can attend a live visit of the museum by watching pieces,
- the cultural mediator presents the pieces outside of the museum.
- In all cases, participants can communicate together and with the mediator.

Already nearly 150 people participated to these virtual visits until April 2021.

These visits made it possible to maintain the link with people living with dementia and their family. Among the favorite things listed by the participants during the visit, we find the quality of the speaker, the explanation of the pieces and the listening of the participants.

Moreover, this new system of visits enabled families from all over France to take part in visits of famous Parisian museums. The virtual visits were also open to medical institutions like nursing homes.

With our partner The SwissLife Foundation, our wish is to keep on establishing this kind of events, even after the end of the pandemic.



28

Learning in spite of the crisis

Mr Volodia Tourtchine, Mrs Lorène Gilly

France Alzheimer and related diseases, Paris, France

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Since many years, France Alzheimer's Institute trains healthcare professionals and France Alzheimer's volunteers to bring the right support and care to people living with dementia. Until the beginning of the health crisis, these training were only provided face-to-face.

In France, as in other european countries, the lockdown began in mid-march 2020. Health care professionals we used to support with our face-to-face training found themselves in the front-line of the pandemic, taking care of the people in need in unique circumstances.

In April 2020, France Alzheimer's Institute tried to find solutions to help these professionals. After discussions with partners (trainers, professionals, employees…), the Association decided to launch short-time webinars (30-45 minutes) about specific problematics related to the epidemic crisis, for professionals in nursing home and home care professionals.

"How to improve the communication with people with Dementia" and "End of life and mourning in the context of the health crisis" are examples of the seven subjects suggested in our webinars between April 24 and May 19, 2020. Nearly 500 professionals participated to these events with an 85% satisfaction rate.

France Alzheimer's Institute decided to also keep on training volunteers with the format of the virtual classes. The Association trained 185 people in 2020 and more than 500 people for the half-year 2021!

The crisis somehow helped accelerate the transformation of France Alzheimer Institute's trainings offer.

29

Partnership with the French Table Tennis Federation

Mrs Lorène Gilly, **Mr Kevin Rabiant**

France Alzheimer and related diseases, Paris, France

Topic

Dementia risk reduction: Dementia and sport

Abstract

Since February 2020, the French Table Tennis Federation (FFTT) and France Alzheimer have decided to join forces in order to pool their strengths and promote adapted sport activities, in support of people living with dementia and their caregivers.

In view of the actions developed by one of the departmental clubs of the FFTT with the implementation of specific sessions for people living with disabilities, our two structures have become aware of their complementarity.

Table tennis is indeed beneficial for those affected by Alzheimer's disease. Beyond its virtues of socialization and its benefits on concentration, the perception of visual space and motor coordination, it stimulates the cognitive system and helps develop the hippocampus, an area of the brain weakened by the disease.

This partnership aims in particular to:

- promote this sporting activity to all audiences including people living with dementia and their caregivers,
- develop a local offer throughout France,
- build together coherent offers that meet the needs of people with dementia and their families.

This partnership is fully in line with the fight against the prejudices which affect the families concerned on a daily basis. All of the actions implemented will enrich the support and well-being of people living with Alzheimer's disease and their caregivers. It also helps us move together towards a more inclusive society.



30

Add-on Effects of Transcranial Pulse Stimulation (TPS) in State-of-the-art Treated Alzheimer's Patients

Dr Prof. Roland Beisteiner
Medical University of Vienna, Vienna, Austria

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: Very recently, a novel therapeutic approach has been developed as non-invasive add-on therapy which attracted massive international interest : Transcranial Pulse Stimulation TPS (Beisteiner et al. AdvSci 2019, Abbasi JAMA 2020, Beisteiner & Lozano AdvSci 2020, Popescu et al. A&D 2021).

Methods: TPS applies repeated ultrashort pressure pulses in the ultrasound frequency range. TPS is the first brain stimulation technique which allows precise targeting of deep and superficial areas of grossly changed pathological brains. Clinical effects in patient cohorts with Alzheimer's and Neurodgenerative Disease will be presented. Statistical analyses are based on the CERAD score for documentation of cognitive improvements, BDI-II for documentation of mood improvement and UPDRS for documentation of motor improvements. In all studies, only state-of-the-art treated patients are included.

Results: In the AD study with 35 patients a significant improvement of CERAD scores was found, lasting 3 months. Improvements correlated with improved functional connectivity values within the Default Mode Network (fMRI data). In the Depression study (18 AD patients with Depression as comorbidity), we found significant improvement in BDI-II after TPS therapy. Functional connectivity (fMRI data) showed a normalization of the FC between the salience network (right anterior insula) and the ventromedial network (left frontal orbital cortex). In the running PD study, preliminary analysis of observational data show significant improvements in UDRS scores in patients with optimized medications. Final PD analyses will be presented.

Conclusion: First evidence indicates, that Transcranial Pulse Stimulation TPS may show beneficial add-on effects in state-of-the-art treated AD and neurodegeneration patients.

33

Healthcare Workers' Perceptions and Attitudes towards Physical Restraints Free Care in Residential Care Home for the Elderly in Hong Kong: A Descriptive Qualitative Study

Mr Wai Kit Kan, Ms Tsz Yan Cheung, Ms Yuk Yan Cheung, Mr Ka Ho Fung, Ms Wing Yan Luk, Ms Hiu Ching Tam, Ms Chun Chu Wei, Ms Ming Wai Yip, Mr Chun Yin Andy Chong, Dr Cho Kwan Rebecca Pang

School of Nursing and Health Studies, Hong Kong Metropolitan University, Hong Kong, Hong Kong

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aims: This study aims to explore the healthcare workers' perceptions and attitudes towards physical restraint (PR) free care in Residential Care Homes for the Elderly (RCHEs) in Hong Kong. The objectives are 1) exploring the perceptions of PRs among healthcare workers; 2) exploring the attitudes towards PR free care among healthcare workers; 3) elucidating how their perceptions of PRs affect their attitudes towards PR free care in RCHEs in Hong Kong.

Method: A descriptive qualitative design was adopted, and 10 healthcare workers in RCHEs were recruited as informants with purposive and snowball sampling in this study. Data was collected by using individual semi-structured interviews. The duration of each interview lasted about 30 to 60 minutes. All interviews were audio-taped and transcribed verbatim. Data was then analysed by thematic analysis.

Results: Three main themes have emerged from the data. They are 1) perceptions of PRs among healthcare workers; 2) challenges encountered when practising PR free care; 3) struggles between using PRs and practising PR free care.

Conclusion: PR free care is not the mainstream practice in Hong Kong, and PRs are still widely used by the healthcare workers in RCHEs. This study explored healthcare workers' perceptions and attitudes towards PRs in Hong Kong RCHEs. The findings of this study have provided new insights to different stakeholders to promote PR free care in RCHEs.



35

Implementation of a training program to increase knowledge, improve attitudes and reduce nursing care omissions towards patients with dementia in hospital settings: a mixed method study.

Dr Melina Evripidou, Dr Papastavrou Evridiki, Dr Charalambous Andreas, Dr Anastasios Merkouris

Cyprus University of Technology, Limassol, Cyprus

Topic

Dementia diagnosis, treatment, care and support: Dementia and dignity

Abstract

Aims: The aim of the study is to investigate the knowledge and attitudes of nurses regarding the care of PwD, to evaluate the care that PwD receive and to identify any omissions. The study concluded with the implementation of a training program that increased knowledge and improved nurses' attitudes.

Methods: This is a mixed method study constituted of three stages: 1) cross sectional study among all the Cypriot nurses, 2) observation study, among 13 hospitalized PwD and 3) the implementation of a training program, addressing to 40 nurses.

Results: During the first stage of the study low level of knowledge and non-favourable attitudes towards PwD were revealed among Cypriot nurses. The observation study identified 4 thematicsa) fundamental patient needs remain unmet, b) several cases of dignity violation during nursing care, c) communication deficiencies and d) nursing care techniques were lacking. Timing of patient contact lasted from 5 to 7 minutes. Many care omissions were identified during nursing care.Regarding the third stage of the study the training program has indicated remarkable improvements on both variables, which lasted three months after the intervention.

Conclusion: Many of patients basic needs remain unmet and this raises considerable ethical issues. This vulnerable group of patients is "at risk" for dignity and human rights violations, during hospitalization.



36

Towards hope and purpose: Empowerment through cognitive rehabilitation

Ms Emily Ong
Dementia Alliance International, Singapore, Singapore

Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

In this presentation, I will talk about the importance of purpose to people living with dementia, and perhaps more crucially – how cognitive rehabilitation can empower us with its focus on what we can still do.

We all need a sense of purpose. Why should dementia make this any different?

Despite decades of advocacy, diagnoses of dementia still come with advice to give up our pre-diagnosis lives and sort out our end-of-life affairs. My family was told to consider hiring full-time help to replace my role as homemaker because I would no longer be capable of it.

Instead, I chose to live my life to the fullest each day by working to maintain my remaining abilities, and compensating for my increasing disabilities with interventions to sustain my independence. I continue to cook, and in this presentation, I will discuss how behaviour modifications, compensatory aids, and strategies make this possible with a video from my very own kitchen. This video demonstrates the key principles of cognitive rehabilitation: that, given the correct tools, people living with dementia can continue with not only our activities of daily living but so much more.

In closing, I will share how cognitive rehabilitation is an effective method to support people living with mild-to-moderate dementia in living positively, with added benefits of cost-effectiveness and scalability. By maintaining daily living functioning and independence, we can not only improve quality of life, but also provide an essential hope for a life similar to pre-diagnosis, adapted to who we currently are.



37

The Magic and Power of Reading for Individuals Living with Dementia

Mrs Susan Ostrowski
Reading2Connect®, Niantic, USA

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

This session refutes three conventional preconceptions involving:

1. The belief of what adult text should look like.
2. Ideas about what it means to read.
3. The notion that those living with dementia can no longer read in a meaningful way.

Participants will learn to;

- Identify the effects of cognitive change on our ability to read.
- Compensate for the barriers to reading that people living with dementia encounter.
- Lightly facilitate independent, self-directed reading experiences for adults living with dementia.

Participants will practice modifying standard, published articles for individuals living with dementia.

Participants will view multiple videos of people living with dementia interacting with highly readable books.

Participants will discuss if and how accessible reading material can stimulate imaginations, nurture communication, and foster a sense of agency. Participants will view people living with dementia engaged in peer reading groups, initiating, contributing, and helping each other, without direct assistance, enriching the social-emotional well-being of people living with dementia and their support partners.

We will conclude by discussing how to use dementia-friendly reading to facilitate pandemic-safe, social experiences, and to foster diversity and inclusion in any setting.

39

Developing dementia friendly research consent

Dr Alison Ward, **Dr Michelle Pyer**

University of Northampton, Northampton, United Kingdom

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Aims: This project informs the design of a dementia friendly research consent form.

Background: People with dementia and service providers can find the standard research consent form challenging. It can result in individual's ability to consent to participate in research complex. While work has been undertaken to make research participant information sheets in dementia easier to read and understand, there has been less research undertaken on how to design dementia friendly consent forms.

Methods: Semi-structured interviews were undertaken with people with dementia, families, dementia service providers and researchers to explore experiences of using dementia consent forms and to design a consent form that met ethical requirements and would support the consent process. Using three draft designs the consent form was discussed, and a new design was created. This design was then shared with research ethics committee members to ensure compliance with ethical requirements, leading to a final design.

Results: Use of language and the style and format of the consent forms was identified to aid understanding. Identifying ways to meet ethical criteria and provided sufficient information to enable potential research participants to give their consent were confirmed.

Conclusion: A final co-designed consent form provides a dementia friendly option for use in research.



40

Control beliefs following a recent dementia diagnosis: The need for fostering resilience.

Mr Addam Scott Reynolds[1], Dr Takashi Amano[2], Ms Clara Scher[1], Dr Yuane Jia[3]

[1]Rutgers University - School of Social Work, New Brunswick, USA. [2]Department of Social Work - Rutgers University, Newark, USA. [3]Department of Interdisciplinary Studies - Rutgers Biomedical and Health Sciences, Newark, USA

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Positive adaptation, like higher control beliefs, following a disability diagnosis is important to buffer against negative health outcomes and minimize excess disability. Despite the utility of control beliefs on numerous outcomes, no study has examined how the recent diagnosis of a stigmatized condition like Alzheimer's disease and related dementias (ADRD) impacts control beliefs. The current study addresses this gap in the literature.

Method: We use data from the 2012-2016 waves of the Health and Retirement Study (HRS), a nationally representative survey of older adults ages 51 and over living in the United States. Propensity score weighting was used to address the systematic selection of an ADRD diagnosis to understand how control beliefs (both perceived constraints and mastery) are impacted two years following an ADRD diagnosis.

Results: A new diagnosis of ADRD was associated with a lower mastery score two years later, regardless of baseline functional ability ($b=-0.92$, $p<0.001$). After controlling for baseline mastery, a new diagnosis of ADRD was associated with steeper declines in mastery two years later ($b=-0.78$, $p<0.001$). No associations were noted between a new ADRD diagnosis and perceived constraints ($b=0.34$, $p=0.13$).

Discussion: Our results suggest that a recent diagnosis of ADRD has negative implications for mastery, which may impact condition trajectory and facilitate excess disability. Allied health professionals and informal caregivers should consider how declined mastery after a new diagnosis would affect the lives of recipients and how to facilitate positive adaptation to an ADRD diagnosis.

41

Dementia as a public health Crisis

Ms Maria Louise Turner
Dementia Alliance International, Chicago, USA. Alzheimer's association, Chicago, USA. PAC, Chicago, USA

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Alzheimer's and other dementias are among the most significant health crises of the 21stcentury. In this presentation, I will address the profound impact of the worldwide pandemic, SARS-CoV-2 (COVID-19) on people currently living with Alzheimer's and other dementias and on those who potentially face the diagnosis in the future.

The many physical and psychosocial challenges faced from grief, loss, social isolation, disruptions of crucial routines, social perceptions and the stigma of dementia are some of the hallmarks of this presentation.

Despite the many negatives of the pandemic, there have been significant positives, as well, specifically in the areas of technology and virtual connections. For those living with Alzheimer's and dementia, surviving (and thriving),have depended on these virtual connections that PLWD have had to rely on for many years.

Covid-19 has made life more accessible and has provided unique opportunities and "silver-lining moments" for enhanced communications and connections which bring information, comfort and hope.

"Life doesn't end with a dementia diagnosis, a new life begins" Maria Turner ADI 33rd conference Chicago 2018



42

Factors which build cognitive reserve are differentially associated with incident dementia and cognitive ageing trajectories in men and women.

Dr Joanne Ryan, Ms Danushika Hashini Pandigama, Mr Zimu Wu, Dr Peter Fransquet, Dr Robyn Woods, Dr Alice Owen, Dr Suzanne Orchard

Monash University, Melbourne, Australia

Topic

Dementia research and innovation: Sex and gender - impact, research, policy

Abstract

Aim: To investigate potential gender-specific associations between composite cognitive reserve (CR) measures and the risk of dementia and trajectories of cognitive change over time in older individuals.

Methods: 10,391 initially relatively healthy 70+ year old Australians were followed for up to 7 years with longitudinal cognitive assessments (of global cognition, verbal fluency, memory and processing speed). Dementia was diagnosed by an expert team of gerontologists and neurologists (according to DSM-IV criteria). From 22 individual questions, factor analysis was used to identify seven unique CR proxy measures, labelled as socioeconomic position (SEP), social activity, external outings, creative-leisure activities, mental-leisure activities, passive-leisure activities and physical activity.

Results: Joint modelling of cognitive performance over time identified three patterns of cognitive ageing: high (13.1%), average (71.4%) and low/declining (15.5%) trajectories; and 184 participants developed dementia.SEP and mental-leisure activities were consistently associated with a reduced risk of dementia and better cognitive trajectories in men and women ($p<0.001$). In contrast, among women only, social, passive and leisure activities reduced their risk of dementia and was associated with better cognitive ageing, while physical activity was a protective factor for men only.

Conclusions: Factors which are thought to build CR are strongly associated with dementia and cognitive ageing, however associations vary between men and women. This highlights the potential to modify risk of dementia by incorporating a range of activities into older adults' lifestyles, but also the need for individualised approaches. Further work is needed to understand the mechanisms underlying the gender-specific differences which have been observed.

43

Dementia knowledge among medical and dental students in Universiti Brunei Darussalam (UBD)

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: Dementia is a public health priority and the leading cause of disability among older people. The stigmatic beliefs and knowledge deficits about dementia are significant barriers in delivering appropriate care.

Aim: To assess the knowledge and awareness of dementia among students in UBD.

Methods: This was a descriptive cross sectional study among dental and medical students in UBD . A study questionnaire obtained from mhGAP dementia was used to assess their knowledge regarding dementia. A score of <60% was considered poor knowledge while 80% or more indicated good dementia knowledge.

Results: There were 61 participants. This consisted of 9 second year dental students, 27 second year medical students and 25 third year medical students. The mean knowledge score was 84.3%. The majority (72.1%) had good knowledge of dementia, while 3.3% had poor knowledge. Most participants (80%) were aware that dementia is a chronic progressive syndrome due to changes in the brain affecting memory, mood, orientation and function. More than 90% knew of the impact of dementia on society and with early recognition and support, lives of people with dementia and their carers can be significantly improved. However, more knowledge on the different approaches on management of dementia was required.

Conclusion: The overall knowledge of undergraduate dental and medical university students on dementia was good. Further assessment of the knowledge and awareness of dementia among other groups of students, especially non-health care related students may be warranted.



44

Virtual Individual Cognitive Stimulation Therapy in Hong Kong: A Mixed Methods Feasibility Study

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: The COVID-19 pandemic has led to the suspension of community-based dementia services worldwide, where Cognitive Stimulation Therapy, an established intervention for dementia, was delivered. Access to effective treatment is vital during the pandemic and beyond to maintain functioning and quality of life (QoL) in dementia.

Objective: We aimed 1) to translate and culturally adapt Virtual Individual Cognitive Stimulation Therapy (V-iCST) for the HK Chinese population; 2) to evaluate the feasibility and acceptability of V-iCST in HK.

Methods: A mixed methods case series (N=8) was used to assess V-iCST's feasibility and changes in cognition, QoL, mood, and communication. Outcome measures were administered pre and post-test. The reliable change index was calculated for each participant. Thematic analysis of post-therapy interviews and content analysis of session rating forms were used to evaluate the acceptability.

Results: V-iCST was feasible with low attrition (0%) and high attendance (100%). Most participants had reliable improvements in cognition, QoL, communication or/ and mood. More than half of the participants had improved or stable cognition. Four participants had clinically significant changes in depression. However, there were no reliable changes in QoL when self-reported and proxy scores were combined. Qualitative analyses indicated V-iCST as acceptable—convenient, stimulating, and enjoyable, but that technical assistance was required.

Conclusion: V-iCST can be adapted for HK Chinese people with mild to moderate dementia and can potentially improve cognition, QoL, mood, and communication. The intervention was well-received by participants and carers. However, larger trials are warranted to draw firm conclusions on treatment efficacy.



45

Suffering phenotypes among community-dwelling persons with severe dementia: A latent class analysis

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aims: Persons with severe dementia (PWSDs) experience suffering in multiple dimensions. Determining distinct phenotypes of suffering can guide interventions to reduce suffering. We aimed to delineate distinct suffering phenotypes among PWSDs and to assess their association with PWSD and caregiver characteristics, and one-year mortality among PWSDs.

Methods: We used baseline data from a prospectivecohort study of 215 primary informal caregivers of community-dwelling PWSDs. We identified ten indicators representing physical, emotional, and functional suffering and aggressive behaviours, and conducted latent class analysis. We assessed association between delineated suffering phenotypes and PWSDFunctional Assessment Staging Test (FAST stage),use of burdensome interventions in past 4 months; caregiveroutcomes; and PWSD one-year mortality.

Results: We delineated three suffering phenotypes - primarily agitated behaviours (phenotype 1; 34%); physical and emotional suffering with agitated behaviours (phenotype 2; 19%); high functional deficits with loss of ability to communicate (phenotype 3; 47%). Phenotype 3 had the highest proportion of PWSDs with most advanced stages of dementia (FAST stages 7B-7F (67%)). Phenotype 2 and 3 PWSDs were more likely to have received a burdensome intervention in past four months and have a greater hazard for one-year mortality. Compared to phenotype 1, caregivers of phenotype 2 PWSDs were more likely to experience adverse caregiver outcomes i.e. higher distress, burden, anticipatory grief, maladaptive coping and lower satisfaction with care received ($p<0.05$ for all).

Conclusion: The delineated suffering phenotypes will be used to inform holistic dyad-centered interventions to reduce PWSDs' suffering and its potential consequences on their caregivers.

46

Filial discrepancy: an exploration of meaning, motivation, and preparedness to care amongst offspring affected by One-Child Policy (OCP)

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Topic

Support for dementia carers: Young carers

Abstract

Aims: Due to the impact of the One-Child Policy (OCP) in China (1979-2015), there has been a diminution of family networks, rapid urbanisation, and an increase in the number of women in employment. Against this backdrop of demographic and cultural transitions, there are growing concerns around the sustainability of traditional family-based caregiving, despite the cultural value placed on Xiao (filial piety). Considering China's collectivist culture and increasing ageing population, we therefore explored howmotivation, meaning, and preparedness could influence the future caregiving responsibilities for offspring affected by OCP.

Methods: We adopted a constructivist position using a hermeneutic phenomenology approach. We interviewed 8 future carers, aged 25-35 years about care provision for parents in the future. Data were obtained through in-depth interviews, analysed using reflective thematic analysis and employed a latent level analysis(Braun & Clarke, 2020).Three themes were prominent: (i) caregiving belief (ii) caregiving process (iii) contextual factors. All were captured under an overarching theme "competing pressures-meanings, motivation and preparedness".

Result and conclusion(s): Participants perceived long term care settings as an unviable option and consequently, spoke of having to provide or organise care themselves to fulfil Xiao, despite the inherent stress. The eventual discrepancy between ideal self (filial expectations) and actual self (filial performance) could ultimately have adverse implications for the quality of care provided. Findings highlighted an urgent need for education and training, development of sensitive services as well as advance care planning.

47

Music intervention in people living with dementia presenting psycho-behavioral symptomatology: An Umbrella review.

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Background: The wide range of interventions to treat the psycho-behavioral symptoms associated with dementia, and the great quantity of literature assessing the effectiveness of music therapy, makes it difficult for the healthcare team and those responsible for health policy to determine which intervention should be recommended for individual patients or patient groups.

Aims: To determine what interventions with music can be used effectively to deal with psycho-behavioral symptoms in people with dementia. Also, to present a general review of the clinical findings from the review and provide a series of recommendations based on evidence that may be applied to clinical practice and research.

Methods: An Umbrella review. Date Sources: electronic searches were performed in JBISRIR, COCHRANE LIBRARY, CINAHL, PUBMED AND EPISTOMONIKOS from January 2010-December 2019. Review

Methods: The methodological quality of the systematic reviews was assessed independently by two reviewers using PRISMA and the JBI Check List for Umbrella Review. Two reviewers assessed each review independently, evaluating the quality and extracting data.

Results: Sixteen reviews and meta-analyses were assessed in terms of effectiveness in dealing with behavior, depression, anxiety, agitation, affect, and mood.

Conclusion: Music therapy can be effective in managing psycho-behavioral symptomatology; nevertheless, there is a need to find quality evidence in favor of its implementation and use.

Nurses should be trained in and up to date with advances in music therapy, in order to effectively create appropriate interventions to contend with the psycho-behavioral symptoms of people with dementia.



48

The APPLE-Tree trial: results from the pilot study of the first remote, video-call dementia prevention intervention, and update on progress of our pragmatic RCT

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aim: To develop a group-based, video-call, cognitive wellbeing intervention; andinvestigate its acceptability and feasibility, to inform a RCT of this dementia prevention intervention, designed to be pragmatic and scalable.

Method: We recruitedadults aged 60+ with memory concerns (without dementia) to our pilot trial. Participants completed baseline assessments and qualitative interviews/ focus groups before and after the 10-week intervention. Qualitative interview data and facilitator notes were integrated in a thematic analysis. We used findings to revise our intervention. We are currently recruiting to a large (n=704) RCT of the intervention (recruitment projected to complete April 2023).

Results: 12/17 pilot participants approached completed baseline assessments; attended 100/120 (83.3%) intervention sessions and met 140/170 (82.4%) of goals set. Most had not used video-calling before. In the thematic analysis, our overarching theme was social connectedness. Three sub-themes were: Retaining **independence and social connectedness**: social connectedness could not be at the expense of independence; Adapting social connectedness in the pandemic:participants strived to compensate for previous social connectedness, as the pandemic reduced support networks; Managing social connections within and through the intervention:although there were tensions, for example between sharing of achievements feeling supportive and competitive, participants engaged with various lifestyle changes; social connections supported group attendance and implementation of lifestyle changes.

Conclusions: Our intervention was acceptable and feasible to deliver video-call.For more vulnerable populations, messages that lifestyle change can help memory should be communicated alongside supportive, relational approaches to enabling lifestyle changes. Trial recruitment (n=242 October 2021) is proceeding successfully and preliminary data indicates inclusively.

49

Inclusive neighborhoods for dementia in Beijing: The environmental pathways to dementia-friendly neighborhoods

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

This study aims to provide comprehensive design recommendations for establishing a pilot project for dementia-friendly neighborhoods concerning the quality of life for all seniors. The study focused on an individual senior with early-stage dementia, his daily activities within everyday places and networks within the Fangchengyuan neighborhood, in Beijing, China. Employing a mixture of qualitative approaches that included procedures for collecting observations of the participant's behavior, testing his spatial cognitive capabilities, investigating abnormal behaviors, and the potential environmental risks, numerous physical and cogitative barriers were revealed. The research indicates a need for inclusive and friendly neighborhood design for seniors with early-stage dementia. The research shows problematic situations for those with early dementia while they attempted to perform daily activities. These problematic factors included: monolithic and unremarkable architectural styles, insufficient facilities servicing a high density, senior focused neighborhoods, the lack of maintained pedestrian pathways, unpredictable surface changes and obstacles, and missing or ambiguous environmental cues. The findings indicate potential strategies at all scales from Neighborhood planning to design detailing to establish a dementia-friendly neighborhood in Beijing. Recommendations include: a) creating a 15-minute walkable life service circle for those with dementia, considering issues of physical frailty b) customized design recommendations for people with dementia, c) focusing on the design details to support everyday activities for people with early-stage dementia within the neighborhoods. The dementia-friendly neighborhood is safe, accessible, and comfortable for all residents. The strategies and relevant design recommendations act as a guidance to help designers reconsider users needs and their well-being.



50

Living with a diagnosis of frontotemporal dementia: What helps and hinders?

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Topic

Dementia research and innovation: Young onset dementia

Abstract

Background: Frontotemporal dementia (FTD) is a term used to describe a spectrum of disorders associated with changes to behaviour, affect, speech and physical symptoms. Services have been developed based upon the needs of people with Alzheimer's Disease, hence, the needs of people with FTD are often unmet. The limited evidence available indicates the views of people with FTD are not heard in research. Hearing the voices of people with dementia is widely acknoweldged as fundamental to providing person-centred care. As such, the absence of voices of people with FTD is a cause for concern.

Aim: This study aims to explore the lived experience of FTD from the person's perspective and to identify what helps and hinders people to liv e well.

Method: Interpretative phenomenological analysis methodology was selected due to its committment to exploring how people make sense of life experiences. Seven people took part in semi-structured interviews culminating in 13 interviews in total.

Results: Four themes emerged from the data: the rocky road through assessment; the changing self; in touch with reality; and keeping going. The four themes and two over-arching themes of the need to hear the voices of people with FTD and the importance of them having an element of control throughout their journey emerged from the study.

Conclusions: This study addresses a gap in knowledge about the person's liv ed experience of FTD. The study informs clinicians in relation to supporting people with FTD, involves people with FTD in decision-making, and suggests directions for future research.



51

INMU at Summerset

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Bringing the best of life to people living with Dementia includes enhancing core wellbeing areas. Research shows that stimulating the senses is essential when we grow old. Our skin is the most sensitive organ and sensory stimulation is essential for our brains. At the same time, music has a direct path to our mind and body which is design for movement, and the reason why music makes us want to move.

Technology can help to stimulate senses and can be exceedingly valuable, technology that enhances care teams in the delivery of therapeutic interventions that enhances quality of life and support wellbeing areas are an integral part of true holistic approach.

Inmu is assistive technology, a sensory stimulating companion that unfolds an interactive music universe of wellbeing, joy, and social contact – in co-creation with people movements.

In 2019 Summerset in New Zealand came across the Inmu and met with the Founder to discuss trailing his devices into our care homes. Trials took place across 6 homes and completed just before the lockdown. Some centres had Inmu's available during the lockdown which helped staff to support residents living with dementia, stress, and anxiety.

Inmu has been a great tool for health promotion, the interactive sound supports holistic, body-related communication and promotes perception, communication, and movement skills. It has proven to stimulate multiple senses; it is an ideal tool for sensory stimulation and therapeutic musical engagement for senior citizens living in care.





52

Dementia and disability: the right to rights

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Topic

Dementia as a public health priority: Dementia and the Convention on Human Rights of Persons with Disabilities (CPRD)

Abstract

In 2009, Italy ratified the Convention on the Rights of Persons with Disabilities (CRPD) approved by the UN in 2006. In defining disability as the result of the interaction of physical, mental, intellectual or sensory impairments with behavioural and environmental barriers, this document indicates a new approach to protecting, promoting and guaranteeing the human rights and fundamental freedoms of disabled people.

The degradation of cognitive functions and the behavioural symptoms of the disease lead to an irreversible loss of autonomy of the person, have a profound impact on the family structure (it is estimated that in Italy about 3 million people are directly or indirectly involved in the care of family members with dementia) and a social and health cost that rises to about 10-12 billion Euros per year in Italy. The ISTAT report on the health conditions of the elderly in 2019 states that in Italy there are 600,000 over-65s with dementia living in the family (4.2% of the elderly; with peaks of 15.4% for women over 85) out of one million cases of dementia registered in the territory. This value is destined to increase due to the global ageing of the Italian population, which has in fact recorded an old age index of 165.9% in 2017 and 179.4% in 2020 (with a projection of 280% for 2051), and a dependency index of the elderly that has risen from 35% to 36.4% over the same period of time.



53

The Australian Community Home Model

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Community Home Australia, Sydney, Australia

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

The Community Home Model is an innovative model of care for people living with younger onset dementia which is based upon life. The model offers an opportunity to remain active in the local community while receiving support 24/7 from specialist staff and avoids admission to traditional residential aged care facilities (nursing homes).

The model is based in a residential house (although specially adapted), in a normal neighbourhood, surrounded by other houses, shops, parks and community amenities but with 24/7 onsite specialist staff.

Our guests continue to access local community based services with our support and actively participate in the running of the house including decision making and all daily activities.



54

Unconditional Love

Ms Natalie Ive
Dementia Australia advisory community, Melbourne, Australia

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

In my presentation, I will be sharing examples of how using a strengths based approach my daughter and I support each other to live our lives to the very best of our abilities , despite the challenges that of our conditions.

Together we face many day to day challenges and equally, many daily happy moments. As humans we sometimes take small things for granted. In our home, things that come easy to most people eg, shopping, drs appointments, medicine schedules which all require meticulous planning in advance.

Younger Onset Dementia/ Primary Progressive Aphasia is not just about memory, which is unfortunately a common misconception. I struggle with executive function, multitasking, these can at times be hard to follow and focus. As a mother daughter team we work together. My strengths help my daughter with the tasks she finds overwhelming and, where I struggle my daughter helps me get through those challenges. We're both independent women, but in turn we require each other to achieve this.

Living each day to the best of our abilities and factoring in our individual personalities and conditions can at times be difficult, however, at the end of the day we realise, that we could not do it without each other, two people utilising each other's strengths to get the best out of each of our lives.



55

Sexual health in nursing home: A scoping review

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Several studies have examined the impact of aging, health conditions and medication on the sexuality of older adults, but most of them use a biomedical perspective. However, sexuality is a multidimensional social construct that goes further than the expression of a physiological need. It includes emotional and socio-cultural components, and it is recognized as a basic human need throughout life. The disabilities that may arise during aging can affect the sexual expression of seniors without reducing their need for having a fulfilling sexuality and maintain intimate relationships (Roelofs et al., 2015). These problems are increased in nursing home where most people have a great loss of functional and cognitive autonomy.

Aim: The purpose of this scoping review was to provide an overview of current knowledge on sexual health in home care center (issues, perspectives, and interventions).

Method: A scoping review was conducted (Arksey & O'Malley, 2005). Four databases (Ageline, Medline, CINAHL, PsycInfo) and grey literature were explored to identify scientific literature and documents addressing sexual health in home care center. Review and selection were performed by two independent reviewers.

Results: 30 articles from scientific databases and nine documents from grey literature published from 2000 and 2020 were identified. Few scientific articles were identified and most of the proposed intervention concerned environmental adaptations (privacy room, door signs) or training for caregivers.

Conclusion: Results show that few scientific studies or guidelines support practices to promote sexual health of people living in home care centers.



57

Impact of Alzheimer's disease on life expectancy in people with Down syndrome

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Topic

Dementia research and innovation: Other syndromes and dementia

Abstract

AIMS: We aimed to assess whether the variability in onset of Alzheimer's disease (AD) in Down syndrome is similar to autosomal dominant Alzheimer's disease (ADAD), and its impact on mortality.

Methods: We combined a meta-analysis (PROSPERO #CRD42020203967) with the assessment of mortality data from US death certificates (77,347 subjects between 1968-2019), and from a longitudinal cohort study (889 individuals; 3.2 years of follow-up) from the Down Alzheimer Barcelona Neuroimaging Initiative (DABNI).

We conducted a meta-analysis to compare the variability in disease onset and age of death with that of ADAD. Based on these estimates, we constructed a hypothetical distribution of age at death assuming fully penetrant AD. We compared these results with real-world mortality data.

Results: The estimates of age at onset, age at death, and disease duration were 53.8, 58.4, and 4.6 years, respectively. Coefficients of variation and 95% prediction intervals were comparable to those reported in ADAD. US mortality data revealed an increase in life expectancy, but with clear ceiling effects in the highest percentiles. The mortality data matched the limits predicted by a distribution assuming fully penetrant AD in 70% of deaths, in contrast with dementia mentioned in 30% of death certificates, but in agreement with the mortality data in DABNI (78.9%). Important racial disparities persist in the lower but not in the higher percentiles.

Conclusions: The mortality data and the age at onset are compatible with fully penetrant AD. Lifespan in persons with Down syndrome will not increase until disease-modifying treatments for AD are available.



58

Care partner as teacher in the medical humanities classroom – Learning impacts of care through the voice of spousal carers supporting older persons living with dementia

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Background: It is documented that care partners of persons diagnosed with mental health conditions have heightened risks of depression and psychological distress. It is important that medical students are trained from early on to be aware of psychological needs of carers. The move in current teaching practices towards involving care partners as teacher in psychiatric education is shown to benefit students' deeper learning for students and carers' sense of empowerment.

Objectives: By the end of a workshop, undergraduate medical students would be able to identify stressors in the care journey, demonstrate empathetic understanding of the lived experience of care partners, and reflect upon meanings of humanistic care.

Practices: At The University of Hong Kong, third-year and fourth-year MBBS students received a face-to-face medical humanities workshop in 2017-18 and 2019-20 respectively. Each comprised a presentation on care journey by the spouse of an older person diagnosed with dementia, followed by dialogue sessions. After class, students each produced a handwritten personal note addressing their insights gained, which were graded by carers.

Observations: 187 third-year and 34 fourth-year MBBS students participated in the activity and completed surveys after randomly selected sessions. Students found strong relevance to their personal development as a doctor (mean score of 2.85/3 on a 4-point Likert scale reported in both cohorts). They especially appreciated carer's perspective into healing.

Implications: By engaging care partner's voice in a medical humanities class, future doctors can be more attuned to the psychological needs of this important group of health stakeholders.



60

The importance of Early dementia Detection and Early Intervention in aged care planning- changing the demand curve on residential care by slowing cognitive decline through better public policies and health promotion investment in lifestyle risk changes and community engagement

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Topic

Dementia as a public health priority: Successful healthcare policy interventions

Abstract

Early dementia Detection and Early Intervention in aged care planning can reduce demand on residential care, slow cognitive decline through better public policies and health promotion investment in lifestyle risk changes, carer support, respite and memory cafe engagement and dementia friendly communities.

The number of older Australians will double over the next 40 years. Recommendations of the Royal Commission into Age Care Quality are focused on how individuals can live longer and more independently in the home, however there needs to be a renewed focus on early detection and earlier lifestyle risk factor changes and cognitive engagement to slow the decline. The WA Sustainable Health Review highlighted the importance of patient pathways between acute care, step up, step down and community care.

The paper will explain how early diagnosis is critical to future health/aged care planning

The early diagnosis of Alzheimer's could be further improved by the recent discovery of a biomarker/ unique brain protein detected in the blood. This ground-breaking finding could be the key to diagnosing Alzheimer's disease before symptoms start to develop, according to new Edith Cowan University (ECU) research, published in Nature journal *Translational Psychiatry*. The study is the first in Australia to find that people with elevated glial fibrillary acidic protein (GFAP) in the blood also have increased amyloid beta in the brain GFAP blood levels rise at least 20 years before the onset of symptoms which would allow for sufficient time to implement interventions to alter the trajectory of the disease.





61

The Israeli "Dementia friends" program: A longitudinal evaluation research

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: As in other countries worldwide, the Israeli "Dementia friends" program operated by EMDA and funded by Joint-Israel Eshel and the Ministry of Health as part of the National Program to Address Alzheimer's Disease and Other Dementias is aimed at increasing knowledge about dementia and decreasing stigma. The program provides training about dementia to volunteers in order to increase awareness of dementia in their communities.

Aim: To evaluate the effectiveness of the Israeli "Dementia friends" program, on laypersons.

Method: A total of 218 participants (70.4% female, mean age = 61, range 18-91) completed a structured questionnaire prior to dementia training and 3 months thereafter. Measures included objective and subjective knowledge about dementia, emotional and behavioral stigmatic attributes associated with dementia, perceived threat of dementia and demographic characteristics.

Results: A significant positive effect was found in objective and subjective knowledge about dementia,emotional stigmatic attributes associated with dementia and perceived threat. There was no change in behavioral stigmatic attributes associated with dementia.

Conclusions: The Israeli "Dementia friends" program is effective in producing significant improvements in knowledge and in decreasing stigma associated with dementia. However, the program does not seem to be sufficient to bring about change in all parameters of these measures.



62

Living in uncertainty while a partner is undergoing a cognitive assessment – Voices of older spouses

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aim: To describe older spouses' experiences of living with a partner undergoing a cognitive assessment.

Method: We conducted a qualitative interview study with sevenspouses to partners undergoing a cognitive assessment. The interviews were semi-structured and carried out before and after the cognitive assessment. In the data-analysis an abductive approach was applied.

Preliminary Results: Participants' experiences were permeated by uncertainty. Antecedents of uncertainty were related to living with cognitive impairment and other health issues, access to care and support, family situation and relationships. Attributes of uncertainty included having a sense of competence and meaning in caring and support, and emotional reactions to the situation. Strategies applied to manage uncertainty encompassed seeking and gaining knowledge, providing support, promoting health, and maintaining normality.

Conclusions: In this study spouses' sense of uncertainty concerned lack of knowledge and psychosocial and existential issues. The results indicated how spouses may require further support to help identify aspects of uncertainty which otherwise could remain undetected. Potential support offered to spouses should include information, psychosocial and existential support. Information provided should cover the assessment process, neurocognitive conditions, and available support. Examples of possible psychosocial and existential support for spouses could include peer or/and professional support individually or in a group context.

63

Dementia clinical encounters in Brunei from 2015 to 2021

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Topic

Dementia research and innovation: Epidemiology

Abstract

Background: Brunei has a rapidly ageing population, with a high rate of non-communicable diseases. An increasing number of people with dementia locally is predicted. A review of clinical encounters for clinical services by people with dementia is described.

Method: The Brunei Health Information Management System (Bru-HIMS) is a nationwide medical electronic record used in all government health facilities. All clinical encounters require manual entry of ICD-10 codes by the clinician. Patient encounters related to all ICD-10 codes for dementia were identified for the years 2015 to 2021 (up to 15th October 2021).

Results: From 2015 to 2019, there was an annual progressive increase in the number of patients and clinical encounters related to an ICD-10 diagnosis of a dementia subtype. However, there was a plateau or decrease in the number of encounters in 2020 and 2021, possibly due to the COVID-19 pandemic. The mean number of clinical encounters for dementia was 500 annually, with a mean of 115 new patients annually. The most common ICD-10 dementia diagnosis given was unspecified dementia (39.8%), followed by Alzheimer's disease (37.5%), vascular dementia (16.6%) and Parkinson's disease dementia (5.7%). In 2015, the majority of clinical encounters were with psychiatry (72.2%), followed by neurology (17.2%) and geriatrics (5.7%). However, by 2020, geriatrics provided 47.2% of the clinical encounters for dementia, followed by psychiatry (24.8%) and neurology (21.5%).

Conclusion: A dementia registry is warranted to observe the demographic change of the increasing number of older people with dementia locally over time.



64

Dementia and COVID: from pandemic to syndrome

Mr Luca Croci
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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

The ISS report of July 2021 shows that in Italy 23.6% of patients who died SARS-CoV2 positive in hospital also had dementia (34% of those over 80). Studies have measured a higher risk of contracting the virus and mortality from Covid-19 in patients with dementia than in the general population - also in relation to age and a clinical picture often complicated by other pathologies (more than 67% of positive decedents in Italy since the start of the epidemic had 3 or more pathologies). The WHO immediately warned about the effects of the disease on mental health and identified people with dementia as particularly fragile, in whom confinement can aggravate anxiety, anger and agitation (an Italian study showed a worsening of neuropsychiatric symptoms in about 60% of cases).

Complex comorbidities, atypical manifestations of SARS-CoV2 disease, difficulty in accessing accurate information, inability to understand containment measures and hygiene precautions combined with lack of memory resources to apply them effectively are all conditions that make people with dementia particularly vulnerable and more exposed to infection.

Confinement and isolation, at home or in medical care facilities, are a certain factor in aggravating the symptoms of dementia: difficult to implement, quarantine is for the dementia patient an abrupt alteration of the life picture with consequent accentuation of stress and agitation. . The neurological symptoms of long Covid and the ability of infection-related brain inflammation to accelerate the progression of dementia where it is already present are also alarming and being actively studied.

66

How do research in telepresence robots open doors for meaningful engagement of people living with dementia?

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[1]UBC IDEA Lab, University of British Columbia, Vancouver, Canada. [2]Alzheimer Society of Canada, Toronto, Canada

Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Heightened isolation during the pandemic has exacerbated the stress, anxiety, and adverse consequences through the loss of family connections older people experience in long-term care (LTC). Using a Collaborative Action Research (CAR) approach, our project aims to assess the implementation of a telepresence robot (telerobot) to help residents connect with their families. The project involves three phases. During phase one, we worked with two Canadian LTC homes in British Columbia to perform small trials to observe possible issues during implementation. Not only can telerobots be used for resident-family connections, but they can also engage our research team members, including members living with dementia, to conduct virtual interviews for research projects. COVID-19 has challenged in-person research work, especially for people living with dementia and family partners to participate in research on site. CAR emphasizes research with, rather than research on people. It is crucial to engage people living with dementia, family partners, frontline staff, and decision-makers meaningfully throughout the project. Telerobots open doors for our team members to "be present" on sites to conduct "face-to-face" interviews. The project also demonstrates how engineering and nursing disciplines can collaborate to address complex societal challenges under the pandemic. Our team member with an engineering background provides training and ongoing support for people living with dementia and family partners to control the robots for remote interviews. While the impact of telerobots on resident-family connections is yet to be explored, we discovered how they could bring meaningful engagement to our research projects.



67

Improving dementia mate wareware services in Aotearoa New Zealand

Ms Catherine Hall
Alzheimers NZ, Wellington, New Zealand

Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Alzheimers New Zealand represents people living with dementia at a national level by raising awareness of dementia, providing information and resources, advocating for high quality services, and promoting research about prevention, treatment, and care. This paper will present an overview of our efforts to improve dementia mate wareware services. A key focus of that work has been our collaborative work to develop and gain support for the first bicultural Dementia Mate Wareware Action Plan for Aotearoa New Zealand. That work has required strong relationships with people living with dementia and with Māori. Alongside this work we have built a national suite of dementia friendly services and programmes designed to support people living with dementia to live their best possible lives. New Zealand research which underpins these efforts will also be presented.



70

Changes in handwriting under the influence of Alzheimer's disease as markers for its early detection and severity assessment

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Topic

Dementia research and innovation: Clinical trials

Abstract

Aim: Handwriting is a complex process that includes fine motor skills, cognitive and linguistic activity. It is sensitive to the changes of the person's medical condition, including Alzheimer's disease (AD). Existing tests of handwriting cover mostly linguistic problems or pure motoric functions. That allows only much undifferentiated, trivial

Results: Besides, they are applicable at much-progressed phases of AD. The authors present two comprehensive tests:HS-AD for detecting of AD and HS-DC for evaluation of individual handwriting changes due to AD. The aim of the study was to validate both tests, especially at earlier stages of AD.

Method:AD-HS includes three linguistic and 36 handwriting characteristics. Based on the number of characteristics present in individual handwriting, a special Z-factor is evaluated. It serves as a quantitative marker for AD.All subjects had been diagnosed with AD. In group A (16 subjects), every subject provided a sample of present handwriting and an old one (10-20 years). In group B (26 subjects) the time of samples was unknown. All samples were evaluated with HSDetect system for computer-aided handwriting analysis.

Results: By all subjects but two, Z-factor was significantly higher than the control value (average of hundreds evaluated handwriting samples out of the HSDetect database). Besides, the correlation between Z-factor and the severity of AD by subjects was high (0.62).

AD-HC (group A) indicated in average 10 handwriting changes.

Conclusions: Tests demonstrated good validity. They could be in particular useful for early detection, as a trigger for profound medical investigation.



72

Online Counselling for People Living with Dementia and Their Caregivers during COVID-19 Pandemic in Medan, Indonesia

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Background and Purpose: There are various ways of supporting caregivers of people with dementia (PWD) but some of these are challenging during the COVID-19 pandemic. The aim of the project was to increase the quality of life of PWD and their caregivers by providing online counselling.

Project Plan: We planned to conduct personal and group online counselling session with family and PWD. There would be one psychologist and one physician (a neurologist or senior neurology resident) for each dyad for personal counselling session, while the group session would be led by a psychologist and followed by discussion.

Outcomes: Each personal session lasted for at least 30 minutes duration and began with the carer sharing about the condition of the PWD and got medical advice regarding that from the physician, then followed by sharing about their challenges and got feedback from the psychologist. The group counselling session lasted for about 90 minutes during which every carer that attended was given a chance to share their experience and got response by the psychologist. The personal session was more effective in terms of consultation about the medical aspect as well as the sharing experience from the carers. It required more resources than the group session, but the carers felt supported and found these sessions quite beneficial.

Conclusion: Although the online counselling session cannot replace in-person consultation with medical provider, it yielded support for carers in providing them knowledge and advice that can help them providing better care for PWD during the pandemic.

73

Post Diagnosis support in a world where people think it is difficult to assist a person if there is not a medical cure.

Mrs Tania Martínez
None, Madrid, Spain

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

As we could see in the Covid 19 crisis, it is very difficult to assist somebody if we think that nothing can be done for them within the medical sphere.

We are living in a Society in which we have pills to be administered to each illness as well as a series of rules and protocols to follow. This fact has complicated how to see the person underneath the disease.

Alzheimer is one of the worst diagnoses someone can receive nowadays and it 's not only because there is no cure, it is because neither there are protocols to accompany the person during the post diagnosis. And why is that? Maybe it is because the person is not always able to remember he or she is still alive and is worthy of love?

We have to remember that they are human beings, that we must assist them and we have to be able to create a pathway to facilitate their life: with changes in their nutrition, physical activities, with music, with meditation, …. with love.

Most of these items are not tested as we test a pill but I can assure you, because I assist my father, that these types of protocols help the person living with Alzheimer.

And we have to incorporate them in the post diagnosis treatment.

They deserve to be accompanied for the medical community, for the society itself and not only for the caregiver that is trying to maintain itself alive too.



74

A Care Pathway in a Sangha

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

The founding master Jih-Chang establishedBliss and Wisdom Sangha in Taiwan in 1991 and made great efforts to propagate Mahayana Buddhism alsoactivities that benefit the society. His successor mentor Zhen-Ru, while expanding both the Sangha and all related Buddhist endeavors, realized the growing impact of global aging. So the Bliss and Wisdom Buddhism Foundation developed classes and support programs for the elderly and people with dementia in years to promote aging healthily and delaying dementia progression.

The Sangha now has five Buddhist communities in Taiwan, and Singapore, Canada one each, totally over 800 monks and nuns. This article will share a care story in the Hu-shan branch. Master Jing-Tong was born in 1933, he accessed to Buddhism from juvenile and joined Buddhistmonasticismat 54. He devoted himself without hesitation to cultivate Sangha locally and overseas after Master Jih-Chang. Master Jing-Tong was a person with highly self-discipline. Even diagnosed with dementia at later life, he still tried the best to practice until the last moment in July 2021 at age 88.

We will focus on the Master Jing-Tong to illustrate 1. His daily routine in 34 years 2. The attitude of maintaining well-being and piety during 15 years of disease journey 3. His altruistic feelings including participating in the research of dementia medication. We then discuss the viewpoints of care value, challenges and life inspiration from those who cared for him, individually or as a group within a religious environment.

75

Dementia prevalence, incidence, and associations with cardiovascular risk factors in Latin American and Caribbean population. A 10/66 Dementia Research Group population-based cohort study

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Topic

Dementia risk reduction: Risk factors

Abstract

Background: Latin America and the Caribbean (LAC) countries are experiencing unprecedentedly rapid demographic ageing. The present study aimed to examine the prevalence, incidence and associations of socioeconomic determinants and cardiovascular risk factors with dementia across six LAC countries.

Methods: The 10/66 Dementia Research Group has carried out population-based catchment area surveys, using a common protocol, in six Latin-American countries Cuba, Dominican Republic, Mexico, Peru, Puerto Rico and Venezuela of all over 65 year old (n= 12 704). An incidence wave was conducted 4 -5 years after cohort inception, 8 502 participants were reinterviewed, contributing 34 000 person-years of follow-up. An index of modifiable CVH factors (ranging from 0 to 14) was calculated. Incident dementia was modeled using competing risks regression to adjust for risk of death.

Results: The prevalence of dementia varied widely across different countries, ranging from 4.8% in Peru and 11.7% in Puerto Rico and the Dominican Republic. Incidence of 10/66 dementia varied between 18.2 (95% CI 14.3–23.0) per 1000 person-years in Peru to 30.4 (25.5–36.3) per 1000 person-years in Mexico. Compared to poor CVH, participants with moderate and ideal levels of CVH had a significantly lower risk of dementia both in the unadjusted (subhazard ratio for moderate: 0.77; ideal: 0.59) and adjusted models (moderate: 0.73; ideal: 0.66).

Conclusions: The prevalence and incidence of dementia in the older Latin American and Caribbean population is high. These findings may inform health promotion efforts within dementia national plans adopted recently in some Latin American countries



77

3NDWG Response to Coronavirus - Educational Webinars run by people living with dementia

Mr Nigel Hullah, Ms Adele Leighton

Alzheimer's Society, London, United Kingdom

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

When the pandemic began in March 2020 3NDWG (3 Nations Dementia Working Group www.3ndwg.org.uk) were already used to meeting via Zoom. As a response to many people asking how the sudden lock down was impacting people affected by dementia 3NDWG held a one off webinar discussing the impact C19 was having on people with dementia. 156 people joined this inaugural webinar and asked for a second instalment. Almost 2 years later 3NDWG are still delivering bi-weekly webinars. Subjects vary from Faith & Dementia, Use of language in the media and Cultural Sensitivity in Dementia Care. Each webinar is designed, organised and delivered by people living with dementia. Evaluation of the webinars shows 84% of attendees are professionals working with people affected by dementia, 8% are family carers and the remainder are people with dementia. Attendees state reason they join is to hear first-hand from people with dementia about topics that matter to them.

An additional benefit of the webinars that has occurred is the networking that occurs between health care workers in the chat box, many citing professional links they have made as a result of joining the webinars.

Webinars are delivered live and made available to watch afterwards. Live attendance ranges from 80 to 140 people, on average each webinar is watched between 300 – 400 times in the 3 months after it is available for download.

This presentation will discuss how people with dementia design and deliver each webinar, avoiding tokenism and ensuring a broad range of topics and opinions.

78

Ten years of creating Dementia Friendly Communities: Achievements and challenges ahead.

Mr Jeremy Hughes, Ms Angela Rippon

Prime Minister's Champion Group, London, United Kingdom

Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

At the 2012 G8 Dementia Summit, UK Prime Minister David Cameron set up the 'Prime Minister's Dementia Friendly Communities Champion Group'. His leadership and engagement has continued with successor Prime Ministers. With members across business sectors as well as public service and charities, the Champion Group has driven action on becoming dementia friendly across society - from travel to banking, museums to supermarkets. Much has been achieved, lessons learnt and new challenges identified. This presentation reviews some of those achievements including looking at what was particularly difficult and what other countries can learn. We look ahead at new challenges and opportunities, not least as we rebuild after the COVID pandemic.



80

Don't forget to love me: from the birth of a song to the Dementia Friends movement in Italy

Mr Mario Possenti, Mrs Francesca Arosio, **Dr Alessia Rossetti**

Federazione Alzheimer Italia, Milano, Italy

Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

The protagonist of the 10th World Month in Italy was the #Nontiscordaredivolermibene campaign.

Lorenzo Baglioni, singer-songwriter and family caregiver, Paolo Ruffini, famous actor chose to donate the song entitled 'Non scordare di volermi bene' (Don't forget to love me) to Federazione Alzheimer Italia. From this generous gift started a real campaign entitled #Nontiscordaredivolermibene with the aim of raising awareness and inviting people to become "Dementia Friends".

The great commitment of the local associations, a mailing list and a focused campaign on Facebook, have made possible to reach almost 3 million people in Italy. Among these an important number of people have decided to get involved and start a training path to become "Dementia Friends" by visiting the websitewww.dementiafriendly.it .

This website provides simple and useful information on how to recognize, behave and relate to a person with dementia; with the aim to create in Italy a group of citizens who are aware and informed about dementia.

Through a quiz it is possible to test the knowledge of dementia and at the end receive a certificate that certifies one's commitment as a Friend.

The strengths of this campaign were, above all, the song that narrates the progressive loss of memory and the choice of two important testimonials who, alongside Federazione Alzheimer Italia, turned the spotlight on hope that more and more people understand how important it is to learn about dementia and to work to fight the loneliness and stigma that often surround people living with dementia and their families.

81

Homeless, older and experiencing memory problems (HOME): An ethnographic study exploring how to better support a multiply disadvantaged population.

Dr Penny Rapaport[1], Mr Garrett Kidd[1], Dr Martin Knapp[2], Dr Jill Manthorpe[3], Dr Caroline Shulman[1], Dr Gill Livingston[1]

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Topic

Dementia awareness and friendliness: Diverse populations – inclusion, equality, cultural issues

Abstract

Background and aims: Globally, homeless people are amongst the most disadvantaged and vulnerable groups and yet they are largely absent from dementia policies, despitewidening inequality in dementia. The older homeless population living with memory problems and dementia is growing, yet their complex health, housing and care needs remain largely undelineated and unmet. Staff in homelessness services are an overlooked dementia care workforce and some hostels may be inadvertent 'dementia communities'. Only one project from Australia has explored, delivered and evaluated potential solutions. In our study, we aim to address a critical gap in what can improve the care, support and experiences of older people experiencing homelessness and living with memory problems.

Methods: We are undertaking an in-depth qualitative ethnographic study, conducting interviews with older people with memory problems experiencing homelessness, hostel staff and managers, and practitioners, alongside participant observations in hostels focussing upon interactions between older residents and those supporting them. Data will be analysed thematically informed by a critical realist perspective.

Results: We will present our analysis of how practitioners, hostel workers and those living with memory problems understand and experience care and support, with a particular focus on what works, what are meaningful outcomes, cost implications, what factors determine current support and what can facilitate a shift in these factors. We will explore this from individual, relational, organisational, legal and political perspectives.

Conclusions - We will discuss these findings with 'experts by experience', using findings to inform policy and the co-design and initial testing of a care and support intervention.



82

How can we make a research review process more inclusive for people living with dementia?

Dr Diane O'Doherty, Dr Laura O'Philbin, Ms Ciara O'Reilly

The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

The Alzheimer Society of Ireland (ASI) prides itself in excellence and inclusion across all aspects of our work, including research The ASI funds internal and external research and as part of our research review process, we involve at least one person living with dementia and one carer/supporter as part of our research review committee. Research proposals are often complex and highly detailed which can pose significant challenges for public reviewers.

1. In the spirit of Person Patient Involvement (PPI) and co-design, The ASI is reviewing and reimagining the research review process. Components to be considered include:
2. Review of the current research review process will be completed in partnership with people living with dementia and their care partners. This will enable the design of a research review process that is collegial and avoids tokenism.
3. Testing the process: We will utilise historical applications as case studies, reviewing cases of varying levels of difficulty.

New flexible scoring forms for applications will be devised, which will be inclusive of all people's level of ability while ensuring rigour.

In reviewing our research review practices, this will ensure that we actively strive for excellence in research, with the groundwork being co-developed with people living with dementia. Their voices help to shape research and research priorities, allowing us to determine best practices to ensure that all our processes are inclusive and accessible, and that all members feel supported and welcome to become involved.

83

Transforming a research process into policy practice: A case for dementia policy in Ireland

Dr Diane O'Doherty, Dr Laura O'Philbin

The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

The Alzheimer Society of Ireland (ASI) seeks to create change through research and policy advancements to ensure that people living with dementia and their care partners are valued and supported. Chronic Disease Management Programmes (CDMPs) are often seen as a means of managing chronic diseases such as Type 2 diabetes and cardiovascular diseases. There is, however, scope for including dementia as part of these CDMPs. In undertaking policy work, it is important to document this process, identifying challenges and risks.

In 2019, The ASI commissioned a comprehensive policy paper examining the case for including dementia as in a revised CDMP for General Practitioners. This, however, was just one part of the overall process. It is essential to understand if this can/should work in practice and we did so by consulting essential stakeholders including people with dementia and their families and the medical professionals.

In involving multiple stakeholders across primary and secondary care, in conjunction with people living with dementia and their care partners, this allowed ASI the scope to acknowledge work that has paved the way for dementia care in Ireland. It allowed us to demonstrate the importance of the research process as a catalyst for re-examining health policies, particularly its impact on people living with dementia and their care partners.

In reflecting on moving research processes into policy practices, this not only allows us to present best practices, but also offers us reflection so we can identify how to include more voices to the conversation around dementia policies.



84

Hope: a tool for working with families living with dementia during the COVID-19 pandemic

Miss Amy Pepper
Dementia UK, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

This presentation aims to explore the use of hope-based approaches as a tool for working therapeutically with families living with dementia during the COVID-19 pandemic, using existing literature and case examples drawn from experience working on the Admiral Nurse Dementia Helpline during the pandemic.

The presentation is from a nursing perspective, but the approaches described will be applicable to others working within health and social care roles. The presentation will provide an overview of one of the main models of hope in the healthcare literature, (Snyder's Hope Model) and will go on to explore the literature on hope more widely, using case examples of the types of calls received on the Admiral Nurse Helpline during the pandemic, to articulate how practice has been adapted, and might continue to be developed through the pandemic and beyond.

The presentation aims to describe practical, evidence based approaches that can be used to support families living with dementia to maintain hope.

85

Is it worth it? Carers' views and expectations of residential respite

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

The Covid-19 pandemic has taken a heavy toll on many people living with dementia and carers. Caring for a person living with dementia at home with limited or no breaks challenged many. Care homes in England were closed to visitors and often to temporary residents. We investigated views and expectations of carers of people living with dementia about residential respite in this context.

Online interviews with 35 carers in England were conducted March–December 2020; 30 women and 5 men, some co-resident, with ages ranging 30 to 83 years. Interviews covered experiences, views of residential respite, and expectations post-Covid. Data were thematically analysed. Salient concepts were discussed with an advisory group of care home providers and people living with dementia.

Three themes were identified: (1) Carers *negotiated risks and stresses of Covid*, weighing up infection prevention and changing family arrangements to facilitate this; (2) Carers *balanced different needs*, prioritising those of their relative amid cumulative caregivingresponsibilities. (3) *Uncertainty about future residential respite*continued, regarding availability, ongoing restrictions and trustworthy information sources.

Residential respite is a positive, acceptable option for some carers and people living with dementia who need a break. Covid-19 has heighted some stressors, and individual confidence to use respite services may need to be rebuilt. Professionals could assist in providing practical information, and offer to accompany people on initial visits. Peer support groups may also provide advice and suggestions. Care home providers need to recognise possible heightened anxiety about taking up respite and address individual apprehensions.



86

Exploring the use of validated measures with people with dementia – seen from the perspective of the healthcare professionals

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Aims: To explore the experiences of healthcare professionals who use validated measures with people with dementia.

Background: Little research explores what occurs when a person with dementia takes part in assessments using validated measures, or how best to support people to participate in these situations. People with dementia can find this process stressful, and that it highlights the changes they experience through their diagnosis. They also recognize the need for such measures to take place. The perspective of healthcare professionals who administrator these assessments is also under explored. In understanding what occurs during these interactions, we may find a way to support the person with dementia and the health professional to navigate these complex assessments.

Methods: Focus groups were conducted with healthcare professionals who have used validated measures, as part of their practice, with people with dementia. Twenty-one healthcare professionals participated from the UK, Norway and Denmark to provide a European perspective. The experience of the practitioner and perceived experience of the person with dementia was explored and data was thematically analyzed.

Results: Themes identified challenges experienced by both, but that there is value in using these measures to gain insight into what it means to live with dementia. However, the way they are presented and carried out depends on the individual, and that issues of ethics and transparency and must be carefully considered.

Conclusion: The outcome of this research provides guidance on ways to support the person with dementia and the assessor in an assessment situation.

87

Housing for cognitive health: a pilot study in co-design using virtual reality, remotely

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

The use of virtual reality (VR) in the field of dementia and ageing has mainly been limited to experimental therapeutic interventions. However, the capability of VR to enable full-scale immersive experiences of architectural proposals, provides the opportunity for underrepresented groups, such as older people (50+) and people living with dementia, to become active participants in the architectural design process.

Good quality, cognitively supportive, housing design is an important determinant of health and well-being for people living with dementia and their care partners. Yet the availability of age-friendly housing that can support healthy cognitive ageing is very limited. In the UK where this research took place, the majority of housing is constructed by large commercial developers. Consequently, new housing focusses almost exclusively on provision for families and younger professionals, broadly ignoring the needs of a rapidly ageing society and those with cognitive decline.

This paper discusses findings from a pilot research project, undertaken during lockdown restrictions in the UK, to explore the potential role of VR in the co-design of age and dementia friendly house types. This includes key methodological considerations in the use of VR to facilitate co-design involving a geographically dispersed cohort of older people (50+) as well as the potential opportunities and challenges in using this methodology as a means of involving this under-represented group, in both research and architectural design. We conclude with examples of the design recommendations from the research, that could help address housing needs and preferences of older people and people living with dementia.



88

AID-COMp: An intensive Speech-Language intervention for persons with early-stage major neurocognitive disorder

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Aims: People with major neurocognitive disorder (PwMND) usually present communication difficulties that impact patient-family carer relationship. Since communication is essential to maintain relationships, the communication problems of PwMND should be addressed. The aim of this pilot study is to explore the qualitative and quantitativeeffects of a speech-language intensive intervention "AID-COMp", designed for PwMND.

Methods: Four dyads, including PwMND and a family carer participated. Familycarerswere only involved in the evaluations. Participants were tested before and after AIDCOMp. Measures comprised language, communication, cognitive and well-being tests. AID-COMp was provided to the PwMND only, three times per week for ten sessions. AID-COMp involved the use of a memory book, semantic and phonological therapy, discourse therapy focused on macrostructure and microstructure analyses, and PACE therapy for generalization. After therapy, PwMND and family carers were interviewed qualitatively. Paired *t*-tests compared test scores before and after therapy. Interviews were transcribed verbatim and analysed qualitatively.

Results: After therapy, improvements occurred in picture naming, cognition, and the test of well-being for PwMND. Family carer scores showed improvements in their perception of PwMND's communication. The qualitative analysis showed that overall, participants and family carers were able to understand what therapy was about and mentioned positive changes that occurred in the everyday life of the PwMND.

Conclusions: AID-COMp appears to have improved some of the PwMNDs' cognitive and language skills as well as their well-being. These preliminary results warrant further studies with more participants.

89

Unpaid carers' experiences of caring for a person living with dementia during COVID-19

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: This study aimed to explore unpaid carers' experiences of supporting a family member or friend with dementia through COVID-19 and investigate the role of hope and resilience during this time.

Method: Data were collected through 26 digitally recorded, semi-structured interviews conducted during the COVID-19 pandemic. Thirteen carers undertook two interviews each, approximately eight weeks apart, to capture any COVID-19 related changes. Data were analysed using Reflexive Thematic Analysis.

Results: Four themes were developed from the data: COVID-19 impacted negatively upon everyday living, adapting to COVID-19, analysis of risk: safeguarding the person with dementia, and thinking about the future. Carers had to fill the gap left by dementia services temporarily closing during COVID-19, this has negative implications for their lives. Participants described adapting to COVID-19 and implementing positive techniques to support their own wellbeing (e.g., the use of technology to stay connected). Participants were concerned about the person living with dementia catching COVID-19 and based decisions on reducing this risk, which sometimes had negative implications for their own wellbeing (e.g., stopping paid carers from entering the home and taking over the caring responsibilities themselves). There was also much uncertainty about the future; carers were unsure if things would get back to normal and COVID-19 had taken away hope for some carers.

Conclusions: There is a need to ensure unpaid carers can still access support during any future lockdowns or similar events, to support their own wellbeing and their ability to provide care for the person living with dementia.



90

Development and validation of a mobile phone application designed for the prediction and management of dementia risk: The 'Five Lives' application

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

The incidence of dementia is substantially increasing worldwide with no effective treatments available. Methods to prevent and delay the onset of dementia, as well as an increased understanding of the individual-level modifiable risk factors are crucial to improving the management of the condition. The identification of individuals at an increased risk of dementia would allow for more efficient targeting of available preventive measures than currently possible.

Five Live's mission is to improve the quality of life and brain health outcomes for millions of people by assessing the risk of cognitive decline earlier than current methods and providing targeted lifestyle risk factor interventions at the user's fingertips. The Five Lives mobile application aims to provide a validated digital self-assessment that provides users with information about their 10-year risk of developing dementia based on both background and modifiable risk factors reported in scientific research. This will be achieved through machine learning, using health and lifestyle data collected through a questionnaire, and cognitive data collected through gamified cognitive tests that aim to increase user engagement.

From this risk score, we aim to provide a holistic brain health platform, coaching users through their risk management journey through a series of personalised interventions that focus on five lifestyle pillars associated with risk modification: diet, physical activity, stress and mood, sleep, and mental stimulation. This presentation will outline the research methods used to develop the application, the development of the current ML algorithm used and the protocol for validation research.

91

Communication and empathy among caregivers of individuals affected by dementia in Italian-speaking Switzerland: A qualitative study.

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aim: To explore how caregivers identify and attribute meaning to the emotions of people affected by AD or FTD, common dementia subtypes. Seeking to investigate how caregivers experience and manage deficits in emotion expression of individuals affected by dementia.

Method: A qualitative study with 20 caregivers of individuals affected by dementia (ten AD, eight FTP, and two undefined subtype). Individual semi-structured, phone and in person interviews were analyzed using a thematic analytical approach.

Results: Three main overarching themes: contextual challenges, caregivers reported an ambivalence in dealing with the relationship context. This caused confusion and inconsistencies between intended, appropriate, and enacted communication with the person with dementia, with a prominence of non-verbal communication and of explicit reference to present matters in FTD and AD, respectively. The second theme refers to the lived experience of caregiving, two caregiving experiences emerged: one with and a second without a sense of self- identity and efficacy. The former was associated with preserved self-reported cognitive and affective empathy, while empathy seemed altered for the latter caregiving typology. The third theme refers to coping strategies. Three different ways to cope: participants used a balanced coping, characterized by coping strategies which were emotional and problem focused, and an excessively emotion-focus and a delegation-oriented coping modality, both dysfunctional and potentially detrimental for the communication process.

Conclusion(s): Our investigation suggests that the mutual link between amimia, and cognitive and affective empathy is intrinsically complex. Mixed-methods approaches are warranted to study the contribution of and relationships between these three variables.



92

A Qualitative Evaluation of the Dementia Friends Programme delivered to Undergraduate Medical and Nursing Students in Northern Ireland.

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: To consider how student nurses and doctors apply The Dementia Friends Programme as developed by the Alzheimer's Society into their practice when caring for people living with dementia.

Methods: Seven focus-group interviews were conducted with 36 nursing students and 14 medical students at one university in Northern Ireland. All students(n=50) who participated in focus-groups had attended the programme at least 12 months prior to the focus group date. People living with dementia co-designed the interview guides. Interviews were audio-recorded, transcribed verbatim and analysed using thematic analysis. Ethical approval was obtained for this study prior to data collection.

Results: Four themes emerged across both professional groups: *'reframing dementia'*: how the programme had enabled students to actively empower and support people living with dementia in practice; *'dementia friendly design'*: how students modified the clinical environments when providing care for people living with dementia; *'creative communication'*: how students used learning from the programme to adapt their verbal and non-verbal communication with people living with dementia and *'realities of advanced dementia': this included student suggestions for incorporating* practices in end-of-life care within their current curriculum.

Conclusion: This study provides an evidence-base that supports the provision of 'dementia friends' programme to healthcare professional students. The study highlights how a two-hour face-to-face session actively influences how nursing and medical students support people living with dementia in their practice in the months after education.

93

The me in dementia: Exploring the psychological impact of dementia on selfhood

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aims: Through exploring the psychological symptoms of dementia, we aim to advance our understanding of how dementia impacts experiences of selfhood. This will aid development of tailored psychological support.

Gaps in autobiographical memory and self-knowledge can lead to feelings of identity loss in dementia. Research has shown that this can be extremely distressing. However, there is comparatively little understanding of how agency (the feeling of being in control of our body) is affected in dementia. This is important, as existing interventions supporting selfhood in dementia focus on prompts for reminiscence or self-knowledge, neglecting the sense of agency which is central to selfhood.

Methods: Working with 54 people living with a diagnosis of dementia registered with Join Dementia Research UK, and 54 age-matched controls; we ran a series of psychological tests designed to measure autobiographical memory, self-knowledge, agency and the ability to form new event memories. We also interviewed 10 people with dementia to listen to their personal experiences, and to help us to create a short film explaining the importance of agency for selfhood.

Results: People living with the early stages of dementia retain the ability to access autobiographical memories and self-knowledge. However, they may perceive less control over their actions than their peers, and we found evidence to suggest this may disrupt their ability to make new event memories.

Conclusions: Disruptions in agency may be experienced as a psychological symptom of dementia. Consequently, greater understanding of the self as an embodied construct has important implications for effective dementia care.



94

Clinical research in Dementia: A Perspective on Implementing Innovation

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

The increasing global prevalence of dementia demands concrete actions strategically aimed to optimize the processes driving clinical innovation into clinical practice. Outlining hurdles hampering the transition from research to practice is a necessary first step to finding solutions and making translational research more efficient. A critical hurdle consists of communication mismatches among the different parties needed to support the whole translational process. Methodological gaps lead to generating experimental data that are not adequate to support evidence-based decision making. Finally, decisional models are often limited by data insufficient to provide reliable estimates of long-term health benefits and costs. Pilot projects are tackling some of these gaps, but many methods still need to be devised or adapted to the dementia field.

Tackling such gaps may help overcome the cliff separating research and translation into clinics. To get there, we need a consistent implementation perspective along the whole translational continuum, explicitly spelled out and shared by the different stakeholders involved in dementia research. Concrete first steps in this direction may consist of providing tools supporting effective participation of heterogeneous stakeholders, and of agreeing on a definition of clinical significance allowing to select and assess relevant outcomes and address the needs of the community.

95

Capturing positive emotions, experiences and relationships in dementia research: The development and evaluation of two positive psychology outcome measures for people living with dementia

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: Quality of life is recognised as an essential outcome. However, there can often still be an overriding focus on deficits over strengths in dementia. There has been little room for evaluating positive emotions or traits that people with dementia use to maintain or enhance their own wellbeing. Thus, the aim of this research was to develop measures that captured the positive experiences of people with dementia.

Methods: Using stakeholder engagement, qualitative and quantitative methodology, two measures rooted in positive psychology principles were developed. Concepts covered in these measures were identified by stakeholders and conceptualised using in-depth qualitative research. The resulting Positive Psychology Outcome Measure and the Engagement and Independence in Dementia Questionnaire were evaluated in a sample of 225 people living with dementia in the United Kingdom.

Results: Psychometric analysis of the PPOM and EID-Q indicated excellent ($\alpha = 0.94$ and $\alpha = 0.921$ respectively) internal consistency and convergent validity with quality of life ($r = 0.682$; $r = 6.27$, both $p < .001$) and depression ($r = -0.699$; $r = -0.741$, both $p < .001$).

Conclusions: People with dementia were involved in every stage of development of the PPOM and EID-Q, resulting in outcomes that people with dementia felt were relevant and important for wellbeing. As a result of this study, their importance has now been documented quantitatively. It is hoped that these measures are the first step in a new wave of research where the development and evaluation of positive outcomes are prioritised.



96

Enhancing registered and student nurse attitudes toward dementia through an artist-produced photobook

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: There is a demonstrable need for a greater understanding among healthcare professionals working with people who have dementia. Although there are a variety of educational interventions designed to support healthcare professionals in person-centred dementia care, artist-produced photobooks are an underused resource. The aim of this study was to explore the perceptions of registered and student nurses who had access to an artist-produced photobook to learn about dementia.

Methods: Between December 2020 and February 2021, four focus groups were held with registered and student nurses (n=22) from Northern Ireland who had accessed an artist-produced photobook about dementia. The audio-recorded data were transcribed verbatim and analysed thematically. Ethical approval was obtained for this study prior to data collection.

Results: Following a thematic analysis of the transcripts, three themes emerged. First, the artist-produced photobook helped participants to humanise the person living with dementia. Second, the photobook supported participants to actively construct their own meanings about dementia based on their previous professional and personal experiences. Third, the photobook could be successfully used to complement existing dementia education in the future.

Conclusions: The use of an artist-produced photobook in nursing education helped registered and student nurses understand how to empathise with and support people who have dementia. It proved to be an innovative tool in a constructivist pedagogy which can effectively complement professional education about dementia. When paired with a facilitated group discussion, photobooks have the potential foster personal reflection and enhance skills of collaboration, which contributes toward developing a practice of person-centred care.

97

Neuroprotective potential of ceftriaxone alone and in combination with minocycline against ICV-STZ induced sporadic Alzheimer's disease

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Topic

Dementia research and innovation: Mild Cognitive Impairment (MCI)

Abstract

Alzheimer's disease is a chronic progressive neurodegenerative disease linked with the atrophy of the brain and death of brain cells. It is the second most common form of dementia that slowly affects memory, thinking, and other cognitive functions of the brain. Alzheimer's is most common in old age people. There are a number of hypotheses suggesting initiation of AD such as deposition of abnormal proteins, decreased clearance of toxic proteins, and other metabolic disturbances. Scientists are currently working in search of developing newer therapeutics, newer techniques in view of early diagnosis and treatment of AD. The current research is focused on repurposing the drugs. Repurposing of drugs will be a cost-effective approach with known PK-PD properties of the drugs. New research suggests the use of antibiotics in various diseases associated with brain damage such as ALS, stroke, epilepsy, and dementia. Thus the present study was designed to evaluate the individual and synergistic effects of ceftriaxone and minocycline in ICV-STZ induced sporadic Alzheimer's disease. We observed that the combination showed better effects in restoring memory and cognitive functions. The observation and analysis was based on biochemical, oxidative stress parameters, and neurochemical analysis.



98

Dementia Research Advisory Team members collaborate in Running our Own Research Project

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Topic

Dementia as a public health priority: Engaging people with dementia and carers in policy

Abstract

Established in 2019, the Dementia Research Advisory Team (DRAT) is a group of people living with dementia and caregivers who are involved in dementia research as co-researchers. Experts by Experience, we influence, advise, and work with researchers across Ireland as co-contributors. The team also engages in capacity-building workshops.

As a natural progression from the co-contributor role, the DRAT decided to use our unique insights and personal experiences to plan and design a research study of our own. We sought todetermine the feasibility of conducting research on a topic of interest and value to us.

In this presentation we will discuss the learnings from this project, from the perspective of The ASI and the members of the DRAT.

Four consultations were carried out. Members living with dementia and caregivers met separately to discuss the practicalities of the project and to suggest possible research areas. A collaborative workshop was then held during which the collated suggestions were presented and a final choice democratically selected - How a diagnosis of dementia changes the life not just of the individual receiving it but also their family members.

The purpose of the DRAT is to ensure the voice of those affected by dementia guides research being carried out in this field. Conducting our own research builds on previous work to date, with a strong focus on empowering the team and building capacity through sharing the tasks required to complete a project of this kind. Overall ownership of the project rests with the DRAT.

99

An Intergenerational Dementia Intervention – the Buddy Programme

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Day Care Centres are the most common form of community-based care available to people living with dementia (PLWD) in Ireland. However, the traditional Day Centre environment is not suited to all PLWD for various reasons eg. transport, personal preferences. Therefore, a greater variety of person-centred alternative supports, in which the PLWD can still reap the cognitive and social benefits of engagement, must be devised.

The aim of this work is to co-develop an Intergenerational Buddy Programme that enables PLWD to spend time with 16 year old students to reduce stigma, foster a peer supportive environment, improve understanding / awareness about dementia and enhance the quality of life of the person living with the condition. Participating in an intergenerational programme is known to benefit both cohorts, positively influencing opinions on aging and ability through knowledge and experience exchange.

The Buddy Programme will pair (by mutual interest) PLWD with a 16 year old student buddy for a 6 week intervention. They will meet each week for 1 hour via Zoom during which they will engage in a shared, meaningful activity relating to their common interest (eg. art, music, sport). Structured activities can be decided in advance with freeform spontaneity also welcome.

It is hoped that this intervention will not only benefit students, family carers and PLWD but also work to combat ageism, highlight the importance of social connectedness and accessibility. It may also allow brainstorming of ways in which the project could be further developed and rolled out beyond its initial geographic scope.



100

Exploring policymaker perspectives on dementia prevention

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Aim: There is a growing body of evidence that a proportion of dementia is preventable, with a number of modifiable risk factors identified. There is also increasing recognition in a range of policy areas of the important contribution of population-level primary prevention strategies, in addition to those targeting conscious behaviour change amongst high-risk individuals. However, it is unclear to what extent these two knowledge bases are influencing national and local policymaking on dementia. The aim of this qualitative study is to explore the understanding of, and attitudes to, dementia risk reduction and population-level prevention strategies amongst policymakers at national, regional, and local level.

Methods: Semi-structured interviews with a range of dementia and prevention policymakers, using Stevenage, Hertfordshire, England as a case study. Invited policymakers included elected members and officials from local (borough and county) and national government, health system leaders, and academic experts. Analysis of audio transcripts to be undertaken by thematic analysis.

Results: This is an ongoing research study, reporting in March/April 2022. Invitations have been sent to 32 experts. To date, 13 interviewees have consented, and interviews with these participants have commenced.

Anticipated contribution: Policy change is a complex process resulting from the interactions between multiple actors and influences. The understanding and attitudes of policymakers is therefore an important factor in translating evidence into practice. The findings of this study will help to gauge system readiness for implementation, and potential barriers and enablers for influencing policy.



101

How can urban environments support dementia risk reduction? A multi-disciplinary qualitative study

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Interventions to reduce risk of cognitive decline and dementia largely focus on individual-level strategies. To maximize risk reduction, it is also necessary to consider the environment. With the majority of older people living in cities, we explored how urban environments could support risk reduction.

Method: In our qualitative study, we conducted semi-structured interviews with community members aged ≥65 years and stakeholders, all living in Leipzig, Germany. Interview guides were informed by the framework on modifiable risk factors for dementia of the Lancet Commission on Dementia Prevention, Intervention, and Care. Interviews were audio-recorded, verbatim-transcribed, and thematically analysed.

Results: Community members (*n*=10) were *M*=73.7 (*SD*=6.0) years old and 50% were women. Stakeholders (*n*=10) were aged 39-72 years, and 70% were women. Stakeholders' fields included architecture, cultural/arts education, environmental sciences, geriatrics, health policy, IT, philosophy, psychology, public health, and urban sociology. Across interviews with both older individuals and stakeholders, three main themes were identified: (i) social participation and inclusion (emphasizing social contacts, social housing, intergenerationality, neighbourhood assistance, information and orientation, digital and technological literacy, lifelong learning, co-creation/co-design), (ii) proximity and accessibility (emphasizing proximity and reachability, mobility, affordability, access to health care, access to cultural events, public toilets), (iii) local recreation and wellbeing (emphasizing safety in traffic, security, cleanliness and environmental protection, urban greenery, climate change and heat waves, outdoor physical activity).

Conclusion: The design of urban environments holds large potential to create favourable conditions for community-dwelling individuals to practice lifestyles that promote brain health.Public policy should involve community members in co-creating such environments.



103

CARA: A pioneering lifestyle and community digital membership platform for persons living with dementia and carers

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

In Singapore, an estimated 82,000 people are living with dementia, and this number is expected to exceed 100,000 by 2030. The 2019 national survey on dementia by the Singapore Management University and Dementia Singapore found that 3 in 4 persons with dementia feel rejection and loneliness, and nearly 30% of carers feel embarrassed while caring for their loved ones with dementia in public. Wandering is also often a concern expressed by family carers and, while common, wandering can be dangerous and even life-threatening. The stress of the risk also weighs heavily on carers and family.

Working with service users and community partners, Dementia Singapore co-created a digital solution to address service gaps via a scalable model. CARA was developed to further reduce the stigma of dementia, encourage persons living with dementia and carers to live in-place normally for as long as possible, and enhance the assurance of a supportive community.

CARA is a lifestyle membership platform that provides access for persons living with dementia and carers to connect to an ecosystem of solutions via a mobile application (iOS and Android). CARA stands for Community, Assurance, Rewards and Acceptance.

Functionalities include providing a unique identifier for persons living with dementia, a safe return function to connect public members to family carers, care circle relationships, tailored rewards, and access to an ecosystem of solutions and resources. CARA collaborates with the National Council of Social Service, Agency for Integrated Care, Land Transport Authority, and Singapore Police Force.

104

Long-term results of Alzheimers' dementia after Transcranial Pulse Stimulation (TPS) of the brain with focused extracorporeal shock waves (ESW).

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Objectives: The introduction of an ESW generator with navigation system (Neurolith, Storz Medical) is a breakthrough for the precise treatment of brain structures with TPS. After a 3 month study with people living with Alzheimer's dementia, we now present case histories with long-term follow-up after TPS treatment as a critical undertaking for future treatments.

Methods: 6 persons living with mild Alzheimer's dementia (Mini mental status >18) were treatedinitially 6 times during 2 weeks with TPS. Subsequently, they received one TPS session monthly over 3 years. Theresults were assessed with the CERAD Plus score andcompared with the data of the natural development with standard medication to be expected for these persons (Hallikainen 2013).

Results: While cognitive skills improved by 12% over 12 months, outcomes returned to the baseline in the second year. A two-week booster of 6 sessions with TPS improved outcomes again by 4.5 % compared to the baseline. After 3 years, the results were at the level of the expected natural development with standard medication.

Conclusions: A symptomatic improvement of Alzheimer's symptoms with low-energy TPS over several years seems to be possible. It was a methodological mistake not to examine the patients more frequently neuropsychologically. It is conceivable that more frequent testing and earlier boosters would achieve a better long-term result.



105

A scale to measure positive caregiving outcomes in family caregivers of persons with severe dementia

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aims: Positive outcomes in dementia caregiving are important yet, to our knowledge, there is no validated scale to assess positive caregiving outcomes in severe dementia. We examined the psychometric properties of Gains in Alzheimer's care INstrument (GAIN) in a population comprising family caregivers of persons with severe dementia (PWSDs).

Methods: Family caregivers of community-dwelling PWSDs recruited from seven major public restructured hospitals, six home care foundations and two hospices in Singapore were administered a questionnaire with GAIN and other measures. The psychometric properties of GAIN were examined, in particular, exploratory factor analysis and internal consistency of the scale.

Results: 215 caregivers completed the survey. Most caregivers (74.8%) were caring for their parents . The average age of the PWSDs was 82.9 years and most had received no formal education (50.7%) or only primary school education (22.8%). The mean GAIN score was 32.9 (SD±6.1). Internal consistency of GAIN by Cronbach's α coefficient was good at 0.866 [95% CI: 0.826, 0.891]. The α coefficients for each subscale of GAIN, namely, personal gains, gains in relationship, and higher-level gains were 0.811 [95% CI: 0.761, 0.852], 0.694 [95% CI: 0.595, 0.775], and 0.692 [95% CI: 0.588, 0.775] respectively. Principal component analysis revealed a single component with an eigenvalue >1 at 4.855, accounting for 48.5% of the variance.

Conclusions: In family caregivers of PWSDs, GAIN has good internal consistency and a single-dimensional factor for measuring gains in dementia caregiving, which confirms its validity for assessing positive caregiving outcomes in severe dementia.

106

What factors are associated with positive caregiving outcomes in family caregivers of persons with severe dementia?

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Positive outcomes experienced in dementia caregiving are important but rarely explored. We assessed factors related to the caregiver, person with severe dementia (PWSD), or the caregiving situation that are associated with the experience of gains in family caregivers of PWSDs.

Methods: Family caregivers of community-dwelling PWSDs recruited from seven major public restructured hospitals, six home care foundations and two hospices in Singapore were administered a questionnaire that assessed gains in dementia caregiving, factors related to the PWSD (agitation, suffering, functional status, use of medical interventions), factors related to the caregiver (perceived negative impact, psychological distress, anticipatory grief, resilience, and emotional closeness to PWSD), and situational factors (financial resources and time spent on caregiving responsibilities). Univariate analyses were performed to investigate the relationship of the above factors with gains in dementia caregiving, and significant variables were entered into a multivariable linear regression model.

Results: 215 caregivers completed the survey. Increased gains in the experience of dementia caregiving were associated with caregivers having fewer depressive symptoms ($p < .01$), greater emotional closeness to PWSD ($p < .01$) and lower perceived negative impact ($p = .04$), as well as use of fewer medical interventions by the PWSD ($p = 0.04$). In the multivariable regression model, only caregiver emotional closeness to PWSD was significantly associated with gains (adjusted R2 14.23%, $F = 9.88$, $p < .01$).

Conclusions: These results have important implications for caregiver interventions in severe dementia, which should target treatment of depressive symptoms, ameliorating negative effects of caregiving and enhancing emotional closeness with PWSDs.



107

The effects of Rooibos 'tea' on cognitive signs of Alzheimer's Disease and its relationship to early life adversity.

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Medicinal plants are an important source of traditional healthcare and economic viability in Africa and are even more vital in communities living under conditions of adversity.In South Africa, the fynbos plant *Aspalathus linearis,*or Rooibos*,* has been used for centuries as a restorative herbal tea. Over the past few decades, the immuno-modulating properties of Rooibos have been firmly established with studies demonstrating potent antioxidant, anti-inflammatory, and anti-cancer properties. These indications suggest that Rooibos may be promising in Alzheimer's Disease (AD) prevention, however, its overall efficacy may depend on individual differences in neuro-inflammatory priming, which tends to occur in early development as a result of stress. Ina double-blind, placebo-controlled intervention trial, we aimed to investigate the effects of 12 weeks' supplementation with green or fermented rooibos following a washout period on biophysical and behavioural risk profiles for AD. Using a mixed-factorial design in a sample of 340 adults, we assessed early life stress history and evaluatedclinical signs of neurodegenerationusing a standardised neuropsychological battery, and cognitive effort based on a pupil dilation task. Biochemical profiles were assessed using patient plasma samplesfor indices of antioxidant and anti-inflammatory activity using ELISAs. Results are currently pending.This study contributes to our growing understanding of the medicinal properties of Rooibos and how early life stress influences neuro-immune processes. Given that tea drinking is an economical and widely adopted social-cultural practice across all age groups, tea is ideal to target in designing low-cost dietary interventions for neurodegenerative diseases like Alzheimer's.

108

Evaluating a digital life story app in a nursing home context

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aims: To evaluate how digital life stories may support person-centred care seen from the perspective of the healthcare professionals and the management team in a nursing home context.

Background: The identity of people living with dementia and a person-centred care can be supported by using life story work. Digital life stories can also provide an opportunity to share the life story between people living with dementia, the family members and the healthcare professionals. Thus, it combines different types of multimedia as pictures, sounds, videos etc.

Methods: Eight members of the healthcare and management team at a nursing home in Denmark were recruited. Participant observation with field notes, informal and formal qualitative interviews were used as data collection **Methods:** A thematic qualitative analysis of the data was conducted.

Results: Themes revealed were(1) Person-centred care and life story work as interrelated approaches; (2) Pros and cons related to the use of digital life stories; and how (3) Time and information and communication technology (ICT) can restrict the life story work.

Conclusion: The person-centred care can be supported by the use of digital life stories. However, challenges exist when using digital life stories as it is important to ensure that the healthcare professionals have time and the competences needed together with support and encouragement by the management team. It is important the life story work is embedded in the culture and everyday work of the nursing home to succeed and involve the person living with dementia and family members if possible.



109

Observations of people living with dementia's response to being assessed with validated measures

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Aims: To explore the assessment process when using validated measures with people living with dementia.

Background: There is little research about what occurs during assessments using validated measures with people living with dementia. People living with dementia can find the process stressful and challenging, but also feel positive in being able to contribute to research and having an opportunity to talk about their experiences and life.

Methods: Ten people living with dementia were video recorded undertaking pre-outcome measures as part of a wider study to explore the impact of a non-pharmacological dementia friendly lifelong learning intervention, using cognitive stimulation and training. A pilot analysis of the videos was undertaken to identify the viability of using this approach to explore their experiences in the assessment process.

Results: Themes identified related to coping strategies adopted by the participants living with dementia to manage the situation, such as reflection and humour, differences in personality and mood could impact on the assessment. Furthermore, personal stories were emerging through the assessment.

Conclusion: Although the assessment process can be challenging and emotional, often highlighting a decline in their condition, people living with dementia want to be active participants in research and want to show what it means to live with dementia to be able to support others. It is therefore important to reflect on how best to support these assessments.

110

Designing for Dementia. An in depth look at how to create safe and homely environments for those living with Dementia. This can be for either Care Home design or for those living in their own homes.

Mrs Gilly S Craft
BIID, London, United Kingdom

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

It has been proven that good design helps people live well. You have to consider the usual issues of age as well as the challenges of Dementia. A person with Dementia needs to feel safe. Being frightened and confused is normal but if not addressed as far as is possible, challenging behaviour can be the consequence. Correct use of colour, texture and layout of space will help people live with Dementia.

What should the designer take into consideration when designing for Dementia?

Create a homely feel.

Communal rooms with good visual access allowing therapeutic and meaningful activities that provide flexibility and choice.

Create areas for quiet moments, conversation or games, with additional areas for watching tv or films.

Selection of flooring should reduce injurious falls without causing confusion due to sudden and unexpected changes in flooring type and/or feel.

LRV /Light Reflectance Value is paramount. All colours have an LRV value, hue, saturation and tone. There should be thirty points of difference between colours on floors to walls to ceilings.

Furniture needs to be appropriate for the activities in the room. We have to think about failing eyesight as well as Dementia.

When specifying fabrics, think about the perception of the environment by the individual. Try not to use literal designs, use stylised or abstract designs.

Contrast the seating from the flooring and walls. Seniors need three times more light than younger people to see and have diminished depth perception. The scheme should be stimulating but not disturbing.



111

The impact of Covid-19 on people with dementia

Ms Kate Swaffer
Dementia Alliance International, Adelaide, Australia. University of Wollongong, Wollongong, Australia

Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

This presentation will discuss the significant impact of the COVID-19 pandemic on people with dementia, their families, and care partners or advocates, and on older persons with and without dementia requiring care in the community or in residential aged care specifically related to BPSD. It will discuss the impact of the pandemic on isolation, discrimination, stigma, ageism, and will reveal the significant positive and negative impact of covid-19 on the behavioural and psychological symptoms of dementia (BPSD), also referred to unmet needs, challenging behaviours, or responsive behaviours.

It will begin with the anonymous anecdotal evidence recorded from two years of responses and reactions expressed by people living with dementia and their families or care partners and advocates and will illuminate the human cost to these groups, as well as the positive impact it has had for some people. It will also examine and analyse the cumulative data now available on the impact of covid-19 on these cohorts. In closing, I will discuss opportunities for unpaid care partners and families, paid care workers, and health care professionals to use these experiences and this data to impact positive change.

112

Pilot of Geriatric Medicine Virtual Dementia Clinic in RIPAS Hospital, Brunei.

Dr Nadzirah Rosli, **Dr Shyh Poh Teo**

RIPAS Hospital, Bandar Seri Begawan, Brunei Darussalam

Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aims: To describe a pilot of a Geriatric Medicine virtual dementia clinic in RIPAS Hospital, Brunei.

Method: All Geriatric Medicine outpatients were contacted by phone regarding cancellation of clinics due to the COVID-19 second wave affecting Brunei. For those who requested to see a doctor, an appointment was given for a pilot zoom clinic consultation.

Results: Among the 10 patients, mean age was 83.1 years and majority were female. All required assistance from family to connect to the virtual consultation. Six of the patients were new referrals. Most patients had a dementia diagnosis and subtype given by the end of clinic except for two; one who recovered from delirium requiring further follow-up, and another requiring treatment for depression. Majority (80%) had a history of falls. The virtual clinic provided a means to assess and observe behaviour, cognition, function, mobility and the home environment. The zoom platform also facilitated the ability to share test results, medication lists and information sheets. Family discussions for diagnosis and/or advance care planning and advice regarding self-management and cares were given online. Limitations included technical issues encountered, such as unmuting themselves, delays in audio connection at the start of the consultation and focusing the camera for assessment of specific aspects of function.

Conclusion: A Geriatric Medicine virtual dementia clinic using zoom is feasible with the assistance of family and carers to overcome technical difficulties. This virtual approach is a safer alternative to in-person consultation or appointment cancellation during a pandemic situation.



113

Lithium: Possible role in the prophylaxis of Alzheimer's Disease?

Dr Digvijay Singh Goel
Mental Health, Addictions & Intellectual Disability Services, Southland Hospital, Invercargill 9840, New Zealand

Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Background: The use of lithium is declining even as the evidence for its efficacy in the treatment and prophylaxis of bipolar disorder continues to grow. Bipolar patients treated with lithium are at significantly lower risk of developing dementia even when manic symptoms do not completely abate. Given this context, is there a possible role for lithium in the prophylaxis of *Alzheimer's Disease* (AD)?

Objectives: Evaluateevidence indicating the efficacy of lithium in attenuating the conversion of *mild cognitive impairment* (MCI) into AD, along with overview of related research indicating novel uses for *psychiatry's aspirin!*

Methods: Literature review to identify and critically evaluate relevant research studies.

Results: Lithium reduces risk of dementia in patients of bipolar disorder, indicating a possible role in the treatment of neurodegenerative disorders like Alzheimer's, despite incomplete understanding of its mechanisms of action. Lithium-induced inhibition of GSK3B hampers the formation of amyloid plaques and neurofibrillary tangles, increases BDNF levels in patients with early AD, and reduces CSF *P-tau* in subjects with MCI who eventually do not convert to AD. This has obvious clinical implications in the prevention of AD. A recent meta-analysis addresses exaggerated fears regarding lithium toxicity and reaffirms its overall safety.

Conclusion: Lithium's declining use despite increasing evidence regarding its efficacy and safety might be attributable to the pharmaceutical industry's disinterest, misplaced fears regarding *toxicity*, and inadequate training in its use. Its possible prophylactic role in Alzheimer's Disease strengthens the case for public health funded research in this crucial domain.

114

Genetic risk scores and dementia risk across different ethnic groups in UK Biobank

Dr Naaheed Mukadam[1], Dr Olga Giannakopoulou[2], Dr Nick Bass[1], Dr Karoline Kuchenbaecker[1], Dr Andrew McQuillin[1]

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Topic

Dementia research and innovation: Epidemiology

Abstract

Introduction: Genetic Risk Scores (GRS) for predicting dementia risk have mostly been used in people of European ancestry with limited testing of their validity in other ancestry groups.

Methods: We conducted a logistic regression with all-cause dementia as the outcome and z-standardised GRS as the exposure across diverse ethnic groups.

Results: There was variation in frequency of APOE alleles across ethnic groups. Per standard deviation (SD) increase in z-GRS including APOE, the odds ratio (OR) for dementia was 1.73 (95%CI 1.69-1.77). Z-GRS excluding APOE also increased dementia risk (OR 1.21 per SD increase, 95% CI 1.18-1.24) and there was no evidence that ethnicity modified this association.

Discussion: z-GRS derived from studies in people of European ancestry is valid for measuring genetic risk in people from more diverse ancestry groups. Urgent work is needed to include people from diverse ancestries in future genetic risk studies to make this field more inclusive.



115

The persistence and longitudinal impacts of sleep disturbances in care home residents living with dementia

Dr Lucy A Webster[1], Dr Sergi G Costafreda[1], Dr Julie A Barber[1], Dr Simon D Kyle[2], Dr Gill Livingston[1]

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aim: Sleep disturbances affect around 40% of people living with dementia and maybe the reason people with dementia move into a care home. However, there is little research into the persistence and long-term impacts of sleep disturbances in this population, which has practical implications on if and how these disturbances should be treated, and we aimed to investigate this.

Method: We used data from the MARQUE (Managing Agitation and Raising QUality of lifE) longitudinal cohort study of 1483 care home residents with dementia. Outcomes were collected every 4-months for 16-months, including quality of life, hospital admissions, mortality, medication, and clinically significant cases of sleep disturbances; defined as score≥4 on the Neuropsychiatric Inventory sleep item).

Results: Athird of residents (31%) hada clinically significant case during the study, and of thoseat baseline, 16% remained persistent cases, 46% fluctuated, and 38% did not have a clinically significant case again.Furthermore, residents with clinically significant cases longitudinally had a lower quality of life (regression coefficient -3.94, 95% confident intervals (CI) -4.82–-3.06) and were more likely to be prescribed sleep medications (odds ratio (OR) 1.57, CI 1.02–2.42). Residents who had a clinically significant case at baseline were more likely to have a future hospital admission but were not more likely to die during the study.

Conclusions: As sleep disturbances fluctuate or persist in most residents who have them, and have longitudinal negative impacts, this highlights the importance of treatment, particularly as the disturbances will mostly not resolve without it.



116

COVID Lessons Learned: Fostering Inclusivity and Social Connection in Long-Term Care

Ms Susan Ryan
The Green House Project, Linthicum, Maryland, USA

Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

Strict COVID-19 lockdowns illustrated the importance of maintaining social connections for all people living in long-term care settings, but the challenges were even greater for people living with dementia. Using both academic research and individual case studies, Susan Ryan of The Green House Project will illustrate how the small-home model — where people of all physical and cognitive abilities interact freely with family, friends, and each other — can improve both physical and mental wellbeing. Care models and physical designs tailored to people living with dementia benefit all people in a community, and once health care providers and policymakers take this reality to heart, we can create truly empowering and inclusive care environments for everyone.



117

Virtual Cognitive Stimulation Therapy (vCST) for dementia: The development, feasibility and initial outcomes of a global framework.

Dr Aimee Spector[1], Mr Luke Perkins[1], Ms Emily R Fisher[1], Ms Cerne Felstead[1], Dr Gloria HY Wong[2], Dr Ruizhi Dai[2], Dr Sridhar Vaitheswaran[3], Ms Nirupama Natarajan[3], Dr Daniel Mograbi[4], Dr Joshua Stott[1]

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: Group Cognitive Stimulation Therapy (CST) is the most widely implemented post-diagnostic intervention for dementia in the UK. This presentation describes the development and initial testing of a virtual group Cognitive Stimulation Therapy (vCST) programme for people with dementia, developed as a result of services moving online during the COVID-19 pandemic.

Method: The vCST protocol was developed using the existing group CST manual, through stakeholder consultation with people living with dementia, caregivers, CST group facilitators and dementia service managers. This protocol was then field-tested with ten groups of people living with dementia in the Brazil, China (Hong Kong), India, Ireland and the UK, and feedback on the protocol was gathered from 14 facilitators.

Results: Field testing in five countries indicated acceptability to group facilitators and participants. Feedback from these groups was used to refine the developed protocol. Initial quantitative and qualitative findings from the UK study (n=22) are presented, demonstrating the feasibility, acceptability and perceived benefits of these virtual groups.

Conclusion: The final vCST protocol is proposed, including session materials for delivery of CST over video conferencing and a framework for offering CST virtually in global settings. vCST is an acceptable online intervention for many people living with dementia globally. We recommend that it is offered to those unable to access traditional in-person CST for health reasons, lack of transport or COVID-19 restrictions. Further research is needed to explore if participant outcomes are comparable to in-person CST groups.



118

Identifying Prognostic Indicators of Cognitive Stimulation Therapy (CST) for dementia Treatment Outcomes: A Systematic Review and Individual Participant Data Meta-Analysis in partnership with CST-International

Mr Dominic Crawley[1], Dr Aimee Spector[2], Dr Rob Saunders[2], Dr Joshua Buckman[2]

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Background: Cognitive Stimulation Therapy (CST) is the only non-pharmacological intervention for dementia recommended by the National Institute for Clinical Excellence (NICE), due to multiple, global trials demonstrating cognitive improvement in people diagnosed with mild to moderate dementia. There is limited understanding, however, of the potential prognostic indicators associated with treatment outcomes. Prognostic analysis helps clinicians to anticipate treatment outcome and therefore specify treatment approach.

Aims: Identify the potential prognostic indicators for the CST treatment outcome, cognition.

Methods: A systematic review was conducted with searches of the following bibliographic databases: MEDLINE, Embase, and PsycINFO from inception to December 2021. Authors of studies meeting inclusion criteria were then contacted and data sought. Following dataset harmonisation, mixed effect linear regression models were constructed to explore the relationship between the prognostic indicators of interest (age, sex, dementia subtype, baseline cognition, and education) and post-treatment cognition.

Results: At the time of writing, analysis is ongoing with anticipated completion by January 2022. Eight studies (n=622) have been analysed thus far. Those with moderate dementia exhibited greater cognitive improvement than those with milder conditions (β=-0.245 P<0.001), otherwisepost-treatment cognition was found to be independent of age (β=-0.021 P=0.246), sex (β =-0.012 P=0.641), education (β=-0.048 P=0.210), and dementia subtype.

Conclusion: The identification of baseline cognition as a prognostic indicator is a new finding and should encourage greater inclusion of those with moderate dementia into CST groups. Otherwise, sociodemographic categories were not found to be prognostic indicators however, only a limited number of variables were available for analysis.



119

Care arrangements and care needs for people living with dementia in Northern Tanzania, findings from CST-International

Miss May Alice Galbraith-Olive[1], Dr Richard Walker[2,1], Dr Aimee Spector[3], Dr Catherine Dotchin[2,1], Dr William Keith Gray[2], Mr Ssenku Safic[4]

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Background: Care for people living with dementia (PLwD) in low and middle-income countries is often provided by young female family members and is associated with a high impact. However, there are limited data on caregiving for PLwD in Sub-Saharan Africa.

Aims:

- To understand the care arrangements, care needs and impact of supporting PLwD in Tanzania.
- To trial the new Dementia Caregiver Experience Schedule (DemCareES), developed in India, to measure the impact of support PLwD in Tanzania.

Methods: Older people attending the outpatient department of Mount Meru Hospital were screened for dementia. Those with mild to moderate dementia, who consented to receive Cognitive Stimulation Therapy, were recruited. Data were collected before intervention. Data included PLwD and carer demographics, independence in activities of daily living (ADLs) and impact of supporting PLwD, using the Zarit Burden Interview and DemCareES.

Results: Fifty-three PLwD and their carers participated. Thirty-six (68%) carers were female and 44 (83%) of a younger generation than the PLwD. Instrumental ADL needs, measured using a locally validated tool, were higher compared to basic ADL needs. Impact of supporting PLwD was high and being a female care partner was significantly, and independently, associated with higher impact (odds ratio 3.683).

Conclusions: This is the first study to explore care needs of PLwD in Tanzania, including measurement of instrumental ADLs needs which were high. The impact of caring was high especially for female care partners. It is important to use a contextually appropriate tool to measure the impact of supporting PLwD in future studies.

120

Olfactory Function in Motoric Cognitive Risk Syndrome

Mr Nigel Kravatz[1], **Ms Emmeline Ayers**[1], Dr David A. Bennett[2], Dr Joe Verghese[1]

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: To examine associations between olfactory function, Alzheimer's disease (AD) pathology, and motoric cognitive risk syndrome (MCR), a predementia syndrome characterized by cognitive complaints and slow gait that is associated with risk for AD.

Methods: We conducted a prospective cohort study to examine the association between olfactory function and incident MCR in 1,119 adults aged 60 and older (75.1% female). The association between performance on the Brief Smell Identification Test (BSIT) and incident MCR risk was computed using Cox models and reported as Hazard ratio (HR) with 95% confidence intervals (CI) adjusted for demographic, comorbidity, and cognitive factors. We assessed the relationship between olfactory function at the time of MCR diagnosis and postmortem AD pathology measures using linear regression models adjusted for sex, education, age at death, and time from diagnosis to death.

Results: Over a median of 3.94 years, 48.6% participants developed MCR. Lower BSIT scores were associated with an increased risk of incident MCR (HR 0.92; 95% CI, 0.88-0.96) in fully adjusted models. Those with hyposmia had increased risk of MCR (HR 1.44; 95% CI, 1.19-1.74) compared to those with normal olfaction. A composite measure of global AD burden accounted for >20.5% of the variation in olfaction in participants at the time of incident MCR diagnosis. tangle density in these participants was inversely associated with olfaction after controlling for mild cognitive impairment.

Conclusions: The results provide evidence that olfactory dysfunction precedes the transition from normal cognition to MCR and such dysfunction is related to AD pathology.



121

NeuroEPO in mild-to-moderate Alzheimer's disease: Results of a phase 2-3 randomized controlled trial.

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Topic

Dementia research and innovation: Clinical trials

Abstract

Aims: Evaluate the safety and efficacy of NeuroEPO in the treatment of patients with mild-to-moderate Alzheimer's clinical syndrome.

Method: A double-blind, randomized, placebo-controlled trial enrolled 174 subjects with mild-to-moderate Alzheimer's clinical syndrome, was conducted.Patients were randomized to NeuroEPO 0.5mg or 1.0mg or placebo, and treated3 times/week for 48 weeks. Primary endpoint was thechange from baselinein the 11-item AD Assessment Scale-Cognitive subscale (ADAS-Cog11). Secondary endpoints included CIBIC+,GDS, MoCA, NPI, neuropsychological battery,EGG and cerebral perfusion.

Results: NeuroEPO treatment reduced ADAS-Cog11 in -4.0 ± 4.0 and -5.0 ± 5.0 units respectively for the groups of 0.5 and 1.0mg dose, while placebo group increased ADAS-Cog11, as expected, in4.0 ± 6.0. NeuroEPO treatment also induced a statistically significant improvement in clinical secondary endpoints as compared to placebo.Interestingly, and in agreement with the clinical effects observed, NeuroEPO treatment also improve some physical measurements of functional relevance in AD patients. Particularly72% of the NeuroEPO-treated patientsstabilized or decreased the values of EEGand 56%of the NeuroEPO-treatedpatientsimproved their temporoparietal perfusion measured by SPECT. As in previous clinical trials,no serious adverse events related with NeuroEPO were reported.

Conclusions: Overallthis study provides solid clinical evidence of the efficacy and safety of intranasal NeuroEPO in the treatment of patients with mild-to-moderate Alzheimer'sclinical syndrome. Further studies using established molecular biomarkers and using an active control will be needed to evaluate the full therapeutic potential of intranasal NeuroEPO in AD patients.

122

The STUDICODE project – Setting-up an online learning course to foster interprofessional collaboration in dementia care

Mrs Lea Pfaeffel
Technical University of Munich, School of Medicine, Munich, Germany

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Due to population ageing, dementia is a top health challenge across Europe. For an appropriate management of dementia, the collaboration of various professions is needed. Yet, students of relevant disciplines are not optimally prepared to perform interprofessional tasks. This gap can be closed by modern didactic concepts using e-learning tools. However, such methods have not yet been applied to dementia education in South-Eastern Europe and are not available in local languages.

On this background, four partners in higher education and training have joined forces. STUDICODE (STepping-Up DIgital COmpetence in Dementia Education) is a transnational initiative comprising the Memory Centre Bratislava (SK), the University of Ljubljana - Faculty of Medicine (SI), the "Carol Davila" University of Medicine and Pharmacy Bucharest (RO) as well as the Technical University of Munich - School of Medicine (DE).

Within the next two years, a multilingual online course will be developed focusing on an interprofessional and person-centred concept of dementia care for students of medicine, nursing, psychology, social work and speech therapy at the pre-graduate stage. The course will be implemented at partner sites and evaluated by 200 students. Furthermore, by strengthening the digital competence of lecturers, the project tries to stimulate the creation of additional courses in similar fields of medicine.

The course evaluation will be presented to deans of study, policy makers as well as patient organisations with the aims of implementing the online course in regular curricula and supporting national dementia plans.

STUDICODE is co-funded by the European Union through the programme "Erasmus+ Strategic Partnerships".



123

Service use and self-efficacy of family carers participating in a rural primary health care memory clinic assessment

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University of Saskatchewan, Saskatoon, Canada

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: In collaboration with three primary health care teams, 1-day rural memory clinics were implemented to provide diagnosis and management for persons living with dementia in Saskatchewan, Canada. Family carers participate in a half-day memory assessment to share information, receive support, and learn about available services. The aim of the ongoing study is to assess the effect of participation on carer service use and self-efficacy.

Method: The first semi-structured interview is conducted in-person at the memory assessment and second interview by telephone at 1-month. Results from the first interview are presented, with more results expected as data collection continues. Quantitative data were analysed with descriptive statistics and open-ended questions with thematic analysis.

Results: To date, the first interview was completed by 16 carers [64.9+15.1 (37-85 yrs); 8 female]. Prior to assessment, 50% of carers used education/information, 19% home help, 13% support group, 6% counselling, and 6% day respite. Carers reported no difficulties accessing services and positive experiences with services overall. Sixty-nine percent of carers identified services not yet received that may be beneficial (e.g., housecleaning). On a 4-item self-efficacy measure, 56% of carers expressed confidence they could manage future caregiving challenges and 88% agreed they knew where to get the services they need.

Conclusions: Findings show low use of services among carers prior to memory assessment, possibly indicative of early carer stage. However, most carers identified services they had not yet used that may be beneficial. This ongoing study will assist with addressing carer needs in rural memory clinics.

124

Employer approaches to Employee Dementia and Mild Cognitive Impairment (MCI) in the workplace: How can employers be "Dementia Friendly" to employees?

Mr James Carino[1], Dr Philip Taylor[1], Dr Damian Morgan[2]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

The term "Dementia Friendly" has been adopted by organisations to indicate that their staff are aware of and understand this condition. Organisations claim to be "Dementia Friendly" when it comes to dealing with the community and customers, but to what extent do they afford the same sensitivity to their employees?

This presentation describes a qualitative study based on interviews with representatives from employers, employer support organisations and professional bodies. Others interviewed were support professionals with direct experience of individuals with dementia in the workplace and those who have recently left work due to dementia or mild cognitive impairment.

The study aim was to explore a range of perspectives concerning the management of dementia or mild cognitive impairment in the workplace. Specifically, the study sought to identify that may assist or support individuals with dementia or mild cognitive impairment and to enable them to maintain employment for a longer period where desired.

Identified factors were the nature of the work, the pace of condition progression, knowledge and awareness of involved parties, behavioural factors, organisational acceptance of diversity, availability and use of expertise, perceived risk/consequence of ongoing work roles, and the types and levels of support given by employers.

From the study, recommendations are proposed for improving the sense of control held by individuals with dementia or mild cognitive impairment in their work, and for extending employer claims of "Dementia Friendliness" to all stakeholders.



125

Development of tracking technology to facilitate the development of dementia friendly community

Ms Bel Wong[1], Ms Florence Ho[1], Dr Timothy Kwok[1,2]

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Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Getting lost affects the quality life of community-dwelling people with dementia and their caregivers. After getting lost episodes, 41.4% caregivers would restrict the care recipients from going out of home, 7.0% would send them to old age homes. The caregivers increasingly use GPS or tracking device to search the lost care recipients, indicating a demand of development of such technology.

Thanks to the donation from The Hong Kong Jockey Club Charities Trust, Jockey Club Centre for Positing Ageing collaborated with The Hong Kong University of Science and Technology and St James Settlement to develop a tracking device using blue tooth and crowdsourcing machine learning technology. The tracking device was battery-saving (lasting one year), it could be put into a wallet or attached onto a walking stick to lower the resistance of people with dementia to carry the device. A smartphone which installed our designated app could detect the tracking device in short distance (50m). The location (GPS signal) of the smartphone would then be anonymously sent to our cloud-based programme that would estimate the location of the person.

2,307 people with dementia have obtained our tracking device, and over 23,400 citizens have downloaded our app to help the searching. Over 6,000 citizens have joined our dementia friendliness educational talks, 97.7% respondents claimed that they would be more willing to help people with dementia who get lost. The high acceptance of our tracking technology encourages us to further develop initiatives related to getting lost in our upcoming dementia friendliness projects.

126

Person Centred Virtual Visiting: keeping people with dementia in hospital connected with family and friends through video-calling during the COVID-19 pandemic

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

This presentation will provide an overview of the introduction of Person-Centred Virtual Visiting (PCVV) in NHS Scotland. The COVID-19 pandemic resulted in immediate changes to hospital visiting, with visiting either restricted or stopped completely. The impact of this for all patients was difficult, but especially for patients with dementia who gain reassurance through seeing familiar faces of relatives and friends. PCVV is the ability to connect hospital patients with their family and friends using devices such as tablets and smartphones, using video-calling platforms. This connection enables patients to maintain meaningful relationships with family and friends whilst in hospital, even though they cannot visit.

The authors worked closely with eHealth leads in their organisations to secure and set up equipment, technology and processes to introduce video-calling across in-patient hospital settings. Consultation with people with dementia and their family and friends allowed identification of suitable video-calling platforms.

PCVV has minimised stress and distress for the person with dementia, family members and staff. It has supported the overall wellbeing of the person with dementia encompassing the five elements of personhood: comfort, attachment, inclusion, occupation and identity. PCVV has provided reassurance and supported personalised care for people with dementia.

PCVV provides innovative delivery of person-centred hospital visits. It maintains meaningful connections and relationships for patients with dementia in hospital during COVID-19.Even though hospital visiting has been reinstated, PCVV is a legacy of the COVID-19 pandemic. It continues to be used across NHS Scotland, with scope to be adopted in other settings.



127

'Pad cultures' and their consequences: Findings from an ethnographic study into continence care for people living with dementia in hospital

Dr Andy Northcott, Dr Paula Boddington, Dr Katie Featherstone

Geller Institute of Ageing and Memory, University of West London, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Dementia and dignity

Abstract

People living with dementia are highly vulnerable within the hospital setting: their health can significantly and suddenly worsen during an admission, with outcomes typically worse compared to similar patients without dementia. Up to half of all acute UK hospital beds are occupied by a person living with dementia, typically for a condition unrelated to their dementia. Evidence is required to inform improvements in the care of people living with dementia in the acute setting.

This paper draws on 180 days of ethnographic (observational) research, alongside 562 ethnographic interviews, collected over 12 months fromsix wards within three hospitals across England and Wales, selected to represent a range of geographic and socio-economic catchments.

This study identified continence care as an invisible, silenced, but important feature of the everyday care of people living with dementia during an acute admission, with significant consequences and impacts on patients, during and following admission. We observed an embedded practice within acute wards of 'pad cultures': the routine use of continence pads in the care of all people living with dementia as a precautionary strategy. The organisational rationale to provide safeguards, ensure containment, and prevent incontinent episodes, informed an expectation that patients living with dementia not only wear pads, but could and should use them. Pad cultures were associated with high levels of distress in the person, with significant impacts on dignity, personhood, and identity.

These findings are informing education and training in collaboration with people living with dementia and specialists in dementia care and continence.

128

Cost of care in Alzheimer's disease: 5-year ALSOVA follow-up

Mrs Viivi Maria Jetsonen[1], Mrs Virpi Kuvaja-Köllner[2], Dr Tarja Välimäki[3], Mr Tuomas Selander[4], Dr Janne Martikainen[5], Dr Anne Maria Koivisto[6,7,8]

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Topic

Dementia as a public health priority: Economics of dementia

Abstract

Aims: We investigated costs of total, formal and informal care in relation to Alzheimer's disease (AD) progression. This multidisciplinary study is a part of the ALSOVA-project conducted by University of Eastern Finland, Department of Neurology.

Methods: 231 persons with AD and a care partner were followed up for 5 years. At baseline, the study participants were at early or mild stages of AD. The progression of AD was measured with The Clinical Dementia Rating Scale – Sum of Boxes (CDR-SB), which assesses both cognitive and functional dimensions of the disease.

Results: Total cost of care in early-stage AD (CDR-SB ≤ 4) was 16,448 euros (95% CI 13,722-19,716) annually. In mild (CDR-SB 4.5-9), moderate (CDR-SB 9.5-15.5), and severe (CDR-SB ≥ 16) AD, the total costs were 2.3, 3.4, and 4.4 times higher, respectively. A 1-unit increase in CDR-SB increased the total, formal, and informal costs by 15%, 11%, and 18 %, respectively.

Conclusions: Costs of total, formal and informal care of AD increase significantly already in transition from early to mild AD. Furthermore, increase in cost of informal care is steeper than that of formal care. These findings emphasize early diagnosis, interventions, and family support for persons with AD and their care partners.

Original publication:

Total cost of care increases significantly from early to mild Alzheimer's disease: 5-year ALSOVA follow-up.

Jetsonen V., Kuvaja-Köllner V., Välimäki T., Selander T., Martikainen J., Koivisto AM.

Age and Ageing. 2021 July 10. DOI:10.1093/ageing/afab144. PMID:34255025.



129

From "Face to Face" to Zoom- Virtual Support Groups for caregivers

Dr Nati Blum, **Mr Hadas Bar-El Fremder**

EMDA, Kfar Saba, Israel

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Purpose: With the outburst of the COVID 19 EMDA stopped holding face-to-face support groups. The COVID 19 crisis had significant effects on PWD and caregiversneeded the support group more than ever. In this situation we decided to hold the support group virtually via "Zoom".

Methods: Within a few weeks EMDA`s staff held the virtual meetings. The senior team had training on how to hold these meeting virtually. The groups were run nationwide. Each group was created for caregivers with a criterion in common such as: spouses, children living abroad, families of people with early onset dementia, and more.

Findings: Virtual support groups held via "Zoom" are a very successful. In the past year and a half over sixty zoom support groups were opened.

In the sessions a bond was formed between the participants, which led to deep intimacy. The zoom meetings attracted people who before COVID never joined support groups such as spouses who had no one who could stay with the PWD . These groups continue to this day.The support groups became an additional permanent service given by EMDA throughout the country and in large areas where holding face-to-face sessions is a challenge.

Conclusions: During the past year and a half in which virtual support groups have been held EMDA`s staff has been holding training sessions for the group`s facilitators and continuing to learn and improve. The following aspects helped the Zoom groups succeed:The use of a group contract, confidentiality, guest expert lectures and more.

130

"The show must go on": Early Career Researchers' reflections on recruitment and data collection during COVID-19

Ms Aisling Flynn, Ms Wei Qi Koh, Ms Dympna Casey

National University of Ireland, Galway, Galway, Ireland

Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

The Covid-19 pandemic joins another ongoing pandemic which has been referenced for decades; dementia. The introduction of physical distancing and 'cocooning' measures during the ongoing Covid-19 pandemic have significantly affected the lives of people with dementia and their care partners. It has also had a knock-on effect on dementia research, where these restrictions have impacted the recruitment and involvement of people living with dementia in research activities. During Covid-19 researchers were advised to continue research protocols where possible, particularly those which may have therapeutic outcomes for people with dementia. As such, conducting research in the field of dementia during Covid-19 have posed, and are continuing to pose significant challenges. With such challenges come an opportunity to find solutions which may advance the field of dementia research. As early-stage researchers in dementia research, we reflect on the challenges of recruiting, involving and conducting research with people with dementia and their care partners. We will discuss the adaptations that were made, such as the adjustment to the use of virtual platforms. The challenges and benefits of these adaptations will be discussed. Finally, we will also share recommendations for other dementia researchers, particularly early-stage researchers. Future virtual research and suggestions for transitioning back to physical data collection after these uncertain times will be provided.



131

Adaptation of dementia survey into Indonesian Context in North Sumatra

Dr Fasihah Irfani Fitri[1,2], Dr Ika Mariana Gultom[1,2], Dr Eka Mahendrayana[1,2], Dr Engki Irawan[1,2], Dr Tara Puspitarini Sani[3,4], Dr Yuda Turana[3,4], Mrs Imelda Theresia[4], Dr Nicolas Farina[5]

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: North Sumatra is one of the two provinces in Indonesia in which the study on prevalence and dementia cost of care will be conducted as part of the STRiDE program. The toolkit for this purpose has been cross-culturally adapted from English into Bahasa Indonesia. We aimed to do a pre testing as a way to maximize the cultural appropriateness of the toolkit.

Methods: The translated toolkit included cognitive, functional and quality of life measures aimed at older adults and their informants (e.g., family member). The toolkit was pre-tested to 10 older adult-informant dyads. The interviewer asked each component of the toolkit in full, making notes on certain questions that need to be clarified and any items that were associated with culture context. Data included observation, interviews, verbatim quotes which were constructed in the form of field-notes.

Results: Several questions and items needed to be paraphrased to achieve greater clarity and make sure that they were in line with the original meanings. It was mainly due to the translatability of the word that can be linguistic or cultural. Translating a text from English to Bahasa Indonesia may also almost impossibly be carried out literally because of the different ways of ellipsis, which is a phenomenon of missing phrasal component, operated in both languages.

Conclusion: Cross-cultural adaptation and cognitive-testing process played an important role to ensure the toolkit was interpreted as it was originally intended. The STRIDE toolkit was generally accepted and understood, although several items need further explanation or examples.

132

Can technology enhance the social participation of older adults with dementia living in the community?

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Due to the COVID-19 pandemic, the prevalence of social isolation among community-dwelling people with dementia has rapidly increased worldwide. As social isolation can negatively affect health and well-being, psychosocial interventions that target social participation are increasingly gaining importance. To date, however, little attention has been paid to the potential of technology. Therefore, a systematic review aimed to explore the effects of technological interventions in promoting social participation among older adults with and without dementia. The scientific databases Medline (PubMed), CINAHL, PsycINFO, the Cochrane Library, and Web of Science were systematically searched. A total of 36 studies was included in a narrative synthesis. Included studies ranged widely in methodological quality, study design, type of technology, and outcomes measured. The majority of included studies evaluated social networking technology or training programs for Information Communication Technology (ICT). Only three studies focused on people living with dementia. While quantitative findings showed limited effects on loneliness, social isolation, and social support, qualitative findings identified several benefits related to social participation (e.g. improved companionship). Overall, technological interventions have shown the potential to alleviate social isolation and loneliness, and to enhance social support among older adults.However, a major finding of the review was the inconsistent use of terms and concepts related to social participation, leading to limited comparability of research findings.The research presented in this abstract was carried out as part of the Marie Curie Innovative Training Network (ITN) action, H2020-MSCA-ITN-2018, under grant agreement number 813196.



133

Helping Older People Engage in Social care (HOPES) Study: Understanding How Mental Health Support Workers Improve Engagement in Social Care Amongst Older People with Mental Health Needs

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Aim: To understand how mental health support workers improve engagement in social care amongst older people.

Method: Semi-structured interviews with support workers within Community Mental Health Teams (n=22), home care workers (n=4), carer partners (n=5) and a service user. We also held two focus groups with supervisors and managers of support worker within Community Mental Health Teams.

Results: Three overarching themes were identified:

1. Building trusting relationships- overall, support workers who were successful in encouraging engagement followed 3 steps to gain trust these were:

- Drawing attention to the 'familiar'. i.e trying to find common ground with the service user and carer they are aiming to support.
- Being predictable, dependable, and reliable, through the good and bad times
- Working towards a shared goal (when the SU or carer is more trusting of the support workers actions)

2. Re-framing care – Offering care in a way that was consistent with the older person's beliefs and motivations was found to be more likely to lead to confident action

3. Building supportive networks – This came in two forms, which were: building support alongside the care the support worker was delivering as well as managing transfers of care in a way that prevents regressing back to a lack of engagement.

Conclusion - Despite the complexity of improving service user engagement, key principles for effective engagement of older adults with mental health needs in social care were identified; primarily the importance of being patient, whilst developing trust to support the delivery of care.

134

Life after the diagnosis:

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Once a person gets diagnosed with dementia life starts to change: days become more difficult and sad. The family embarks in a challenging and stressful experiences, that gets, day by day, more complicated, due to the difficulties in communication and the BPSD. The family as a whole (the person diagnosed with dementia and the other family members) enters in a loop that, without the proper support, impacts dramatically their quality of life (QoL). On top of the dementia symptoms, the person diagnosed with dementia feels not empowered, lonely and often bored. The other family members feel lost, and lack of knowledge and effective tools to support someone living with dementia. With this research we would like to share preliminary qualitative findings of phsyco-social programs run in Italy and based mainly on creative and occupational activities. Programs involve the whole family as beneficiaries of the intervention. Activities included in the programs are based on a "person centred approach" applied to the entire family and take into consideration the evolution of their QoL. The proposed programs, whose activities are managed by the family at home with the support of experts, are adapted to the evolving needs of the family and they are aimed at empowering the family members, giving them instruments to contribute to the QoL of the entire family. In addition to this, through hands on activities proposed to the entire family, we aim at coping with BPSD while stimulating the residual abilities of people diagnosed with dementia.



135

The McGill University Dementia Education Program - Bridging Academia and Community

Mrs Claire Webster, **Dr Serge Gauthier**, Dr José A. Morais, Dr Pedro Rosa-Neto

McGill University, Montreal, Canada

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

The mission of McGill University is the advancement of learning and the creation and dissemination of knowledge, by offering the best possible education, by carrying out research and scholarly activities judged to be excellent by the highest international standards, and by providing service to society. As age-related diseases increase, care is moving from hospitals into homes, and family care partners are at the centre of a crisis.There is a need to bridge academia and the community, and more specifically to make medical and other healthcare students aware of the impact of dementia on persons with symptoms are their families.

To respond to this need, the McGill Dementia Education Program was founded in 2017 by Mrs. Claire Webster, a former care partner and Dementia Care Consultant and is led by a team of leading health care experts comprising of Dr. Serge Gauthier CM, MD, FRCPC, Dr. Jose Morais MD, and Dr. Pedro Rosa Neto MD, PhD. What beganas simple community workshops has blossomed into a comprehensive educational program that has reached thousands of family and informal care partners, medical students, allied health care professionals and the public at large.

Our program brings together a team of multi-disciplinary health care professionals from Canada's #1 rated medical school to provide in-class workshops using simulation scenarios, a bi-weekly webcast and podcast series called "McGill Cares", public education webinars, and downloadable educational booklets and guides in order to ensure that every care partner has access to the FREE resources they need.

www.mcgill.ca/dementia

136

Developing and Validating for Cognitive Screening Tools for Identifying and Intervening Dementia among Older Persons in Rural Uganda.

Mr Haruna Batange[1,2], Dr Isaac Ddumba[3,4]

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Although risk of developing dementia increase in later years, identification and assessment of older persons with dementia in developing countries is still low. Access to easy and user friendly cognitive screening tools by the health care professional in developing countries is difficult. The study aimed to develop, validate and field test the cognitive screening tool for use in outpatient departments within health facilities in Uganda.

Methods: In the rural eastern region of Uganda, twenty-three (23) purposively selected health facilities and administered a scientifically derived cognitive screening tools to all eligible older persons. We conducted an inter-rater reliability in all the health facilities using three raters. Diagnosis of dementia (DSM-IV) was classified as a major cognitive impairment and was quality checked by physiatrist who were blinded to results of the screening assessment.

Results: The area under the receiver operating characterizes (AUROC) curve in health facilities was 0.912. The inter-rater reliability was good (Intra-class correlation coefficient of 0.692 to 0.734). the predictive accuracy of the tool to discriminate between dementia and other cognitive impairment was 0.892. In regression modal, the cognitive screening tool, didn't appear to be biased by age.

Conclusion: The cognitive screening tool if performed well among the older persons, can be proved useful for screening dementia in other developing countries.



137

Silence au temps du Covid

Dr Ghalia Khadhar, Ms Laetitia Soumaya, Mrs Neila Hajem, Mrs Chaima Aounallah, Ms Meissa Ghabri, Dr Leila Alouane

Association Alzheimer Tunisie, Tunis, Tunisia

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

C'est un truisme de parler de silence à propos de la maladie d'Alzheimer, mais en parler au temps du COVID revêt un sens nouveau jusque-là inédit.Car si la maladie plonge le malade dans le monde du silence, ce silence reste intérieur, tandis que depuis le confinement, le silence touche aussi bien le malade que son entourage.

Il revient à l'aidant à prendre en charge les mesures sanitaires et les difficultés liées à la réclusion et à l'isolement.Et ces changements entraînent chez l'aidant proche du stress et de l'anxiété: peur de la contamination, crainte d'un confinement prolongé, ou encore d'abandon de son proche en cas de mise en quarantaine ou d'hospitalisation.

Face aux difficultés d'intervention de l'association Alzheimer Tunisie auprès de ces personnes pendant le confinement, les membres de l'association ont mis en place des outils de communication à distance pour résoudre les problèmes avec les aidants naturels.

Des séances de musicothérapies et d'art-thérapie à dominante plastique ont été réalisées par téléconsultation, en collaboration avec les aidants.Un suivi régulier de l'impact de ces séances sur les fonctions cognitives et les troubles comportementaux ont été évalués par AAT.

Cette pandémie nous permet d'évaluer mieux les conséquences psychologiques du confinement sur les personnes atteintes de la MA et de leurs aidants, et de mieux adapter les outils de communication pour rompre leur isolement au sein de l'association Alzheimer Tunisie.



138

Biomarker modelling of Alzheimer's disease using in vivo Braak staging

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Alzheimer's disease (AD) is the leading cause of dementia worldwide and can be detected *in vivo*using biomarkers of amyloid-b and tau. Gold standard diagnostic methods for AD rely on staging systems to measure disease severity, which have not yet been incorporated into the *in vivo*biological research framework for AD. The topographical information conferred by tau-PET offers the potential to translate the gold standard histopathological Braak staging system to living individuals.

Methods: Using [^{18}F]MK6240 tau-PET, we applied the Braak staging model to 345 individuals. We measured amyloid-PET, cerebrospinal fluid (CSF) and plasma phosphorylated tau (pTau) epitopes, neurodegeneration and neuropsychological function in relation to *in vivo* Braak stage. ANOVA assessed relationships between Braak stage with biomarker and clinical changes. Progression of *in vivo* Braak stage was assessed in 163 individuals with follow-up [^{18}F]MK6240 scans.

Results: Advancing *in vivo* Braak stage was associated rising plasma pTau species, as well as rise and plateau of amyloid-PET & CSF pTau species. Early Braak stages were associated with isolated memory impairment, while later Braak stages were closely associated with the severity of dementia. Follow up tau-PET scans indicated sequential progression of *in vivo* Braak stages over time, with substantially higher rates of progression in amyloid-b+ individuals.

Conclusions: *In vivo* Braak stages had stage-specific associations with the severity of amyloid-b deposition, CSF measures of pTau and clinical function. *In vivo* Braak staging contributes to the understanding of the natural history of biological AD and provides a framework to measure AD severity in living humans.



139

Promoting and Supporting Independence in People Living with Mild Dementia: The PRIDE-app

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University of Nottingham, Nottingham, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: Promoting Independence in Dementia App (PRIDE-app)encourages people living with mild dementia to participant in cognitive, physical, and social activities to improve their independence and quality of life. Delivered via an online handbook, users work in collaboration with facilitators to complete interactive activities and discussion points across three sessions. This poster reports an ongoing RE-AIM study into the PRIDE-app to explore its accessibility, effectiveness and adoption.

Methods: Participants were recruited from five NHS sites, Join Dementia Research or self-referred. Through three intervention sessions, delivered within a two-month periods, participants were encouraged by researchers to incorporate the PRIDE-app in their daily lives. Outcome measures on well-being, daily activities and quality of life were collected at baseline, three and six months. Interviews were completed with participants, facilitators and service staffto explore their experiences and perspectives on the PRIDE-app.

Results: Preliminary feedback suggests that the PRIDE-app is of a usable standard and can promote acceptance of diagnosis and psychological independence in people living with dementia. Further developments have been recommended to ease the login process.

Conclusion: Independence is often viewed in terms of practical abilities, but the importance of autonomy in dementia often has a psychological link. With further development and testing, the PRIDE-app has the potential to support and promote positive activities and behaviour changes in people living with mild dementia. Due to the impact of COVID-19, evidence-based apps such as the PRIDE-app may become more widely adopted by the public than pre-pandemic.



140

Serious games to stimulate emotional and social intelligence in people with dementia: Proof of concept

Mrs Rakel Berenbaum[1], Prof Chariklia Tziraki[1], Mr Reem Baum[2], Ms Judith Abikhzer[1], Mrs Dvora Marcus[1], Mr Adi Rosen[1], Mr Tuvia Reback[1], Ms Daphna Naparstek[1], Prof Boaz Ben David[2,3,4]

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Aims: Currently, research relating to people with dementia (PwD) focuses on the deterioration of cognitive abilities. More innovative is focusing on remaining capacities such as emotional and social intelligence (ESI), to maintain and improve functionality, communication and quality of life of PwD. We developed gamification strategies to enhance these capacities. This study aimed to explore whether a low cost, easy to deploy serious game for dementia (SG4D), co-designed with PwD, enhances ESI.

Methods: 27 PwD, participated in a 12 weeks pilot, proof of concept study using a tablet SG4D. Quantitative performance data was collected automatically during game sessions. Each session was also observed and documented by one of ten researchers. We present qualitative and quantitative analysis of their observations using an assessment tool including key domains of the Bar-On Model of ESI (Intrapersonal, Interpersonal and adaptability).

Results: Quantitative data revealed that average ESI scores were similar for both PwD with high and low MoCA scores. Qualitative analysis revealed that PwD demonstrated 9 sub-components of the Bar-On ESI Model (self-regard, emotional self-awareness, assertiveness, self-actualization, empathy, social responsibility, interpersonal relationships, reality testing, problem solving).

Conclusion: Despite declining cognitive abilities, our study shows that a SG4D can stimulate PwD's ESI evoking responses in self-awareness, empathy, and social/communication capacities.

Using SG4D to exercise and maintain social skills may improve quality of life, improve social connectivity, and bridge the gap between care partners and PwD, possibly impacting cognitive functioning as well. More research is needed with larger sample sizes and in various care settings.





141

Gait aid use for people with and without dementia: A comparison of practice between health and non-health professionals among Australian community care staff

Dr Den-Ching Angel Lee[1], Dr Elissa Burton[2], Dr Claudia Meyer[3], Dr Susan W. Hunter[4], Dr Plaiwan Suttanon[5], Prof Keith D Hill[1]

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Aims: To understand/compare community care staff practice (health vs non-health professionals) for gait aid use by people with and without dementia.

Method: A cross-sectional survey of 1) closed/open-ended questions exploring staff practice for people with/without dementia, and assessments/procedures health professionals used for people with dementia, 2) Likert-scale items gauging staff agreement on factors that influenced their decisions regarding gait aid use for people with dementia. Univariate logistic regression analyses examined staff practice for people with/without dementia and their interaction effects, and factors for deciding gait aid use for people with dementia.

Results: Compared to non-health professionals (n=138), health professionals (n=109) were more likely to: 1) refer the person without dementia [odds ratio, 95% CI: 23.9 (12.1, 47.3)] and person with dementia [27.8 (12.5, 61.7)] to a physiotherapist for gait aid assessment, 2) agree with gait aid use if the personwith dementia: (a) lives with someone who can monitor gait aid safety [coefficient, 95% CI: -0.75 (-1.29, -0.21)], (b) performs well on a cognitive functional screen [-0.68 (-1.20, -0.16)], and (c) gives feedback about gait aid use [-0.64 (-1.15, -0.12)]. No interaction effects existed between health/non-health professionals and whether the person had dementia/no dementia on the practice options examined.

Conclusion: Community care staff practice to improve mobility and reduce falls risk were different between health and non-health professionals, but not dependent on whether the person had dementia or not. Strategies such as developing decision aid tool(s) may guide mobility practice in community care.

142

Seeing is Believing: The use of online theatre to facilitate an understanding of the complexities of living with dementia

Mr Donald G. Baker
Act 2 Studio Works, Toronto, Canada

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Seeing is Believing: Theuse ofonline theatre to facilitate an understanding ofthe complexities ofliving with dementia

Employingthe power of research-based theatre, we challenge attitudes and create understanding about the day-to-day experiences of persons living with dementia, medical professionals, formal caregivers, and care partners.

We, at Act 2 Studio Works,are a Canadian, not-for-profit, theatre production and touring company. Our volunteer crews, playwrights, directors, and performers are all seniors and students of theatre.

Over the past 16 years, our research-based stage play on living with dementia called *"I'm Still Here!"* had been presented 231 times to groups, large and small, who deal with dementia.

Suddenly the Covid 19 epidemic put a halt to our touring.

In this presentation I will briefly describe:

- How we PIVOTED to creating pre-recorded VIDEO scenes for webinar presentations, making them accessible worldwide
- the social-science research informing our presentations
- the video topics covering the dementia journey from young onset to long-term care
- their adaptability to translation for accessibility, using voiceover and close captioning
- the range of organizations which share our online video presentations with their staffs and the people they serve
- how we employ "live" interaction with our audiences, during feedback sessions co-facilitated with dementia experts
- the impact of our theatrical messages as measured by audience feedback

I will also: play a representative scene of approximately 1 ½ minutes and respond to questions during a 3-minute feedback session with the conference attendees



143

The trajectory of coexistence with anomie for persons living with dementia in early stage

Miss Pen-Chen KUNG[1,2,3], Prof Yea-Ing Lotus SHYU[4], Prof Huei-Ling HUANG[1], Dr Wen-Chuin HSU[5]

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Topic

Dementia research and innovation: Mild Cognitive Impairment (MCI)

Abstract

Aims: Persons living with dementia are affected by various complex stress factors, leading them to develop different coping tendencies in their lifestyle. This study was designed to construct a theoretical framework for the adaptation process of persons in the early stages of dementia.

Method: A grounded theory was used to track the three-year dynamic adaptation trajectory changes in people with mild cognitive impairment (MCI) with a longitudinal research design. Data were obtained from 30 dyads of individuals with mild dementia and the family caregiver.

Results: The core category was "Coexistence with anomie: Progressive disappointment and striving." Coexistence with anomie comprised three subcategories: awareness, feeling down, coping and adjustment. The developmental context of coexistence with anomie was found to be affected by factors such as personal perceptions of dementia, cognitive progressive conditions, caregiving patterns, and social interaction experiences. Particularly, individuals living with dementia who have better awareness must pay more attention to their feelings and opinions.

Conclusion: The adaptation process of a person diagnosed with dementia is often crucial for determining the quality of life and happiness; however, it is often ignored. Understanding the feelings of individuals with dementia and the factors that influence this condition helps patients establish a positive attitude and create coping strategies. Our findings can be used as a guide for professional and family carers to promote the development and adaptability of patients living with dementia.

144

Coordinated Psychological Care for People with Dementia During COVID-19 Pandemic.

Miss Wan-Ling Lin[1], Miss Ting-Yun Chou[1], Miss Yu-Chun Chi[1], Miss Meng-Zhu Shen[1], Miss Syue-Jing Li[1,2], Mr Chih-Yu Lo[1], Miss Yan-Yu Shen[1], Miss Hsiao-Wen Wu[1], Prof Chi-Cheng Yang[1,2]

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Objectives: BecauseTaiwan government has issued a Level-III alert for COVID-19 since May to July 2021. Many people living with dementia cannot go to any community care centers for activities. Given the potential difficulties above, this study aims to combine the technological devices with psychological care for people living with dementia and their families, and further explore the effectiveness of this combination of psychological service and technology during this pandemic.

Method: A total of 94 people with dementia and their 112 family members was recruited in this study. Allpsychological care services, held online during May to July 2021, including (1) Online videos of home-based cognitive activities uploaded on YouTube channel. (2) Online cognitive groups for people with dementia which were held two hours a week. (3) Online consecutive six-weeks support groups and 30-minutes individual consultation service for family members. The Outcome Rating Scale (ORS) in each session were evaluated.

Results: The results showed a total of 3,391 views of these 10 home-based cognitive activity videos, and 13 online cognitive groups. There were 86 people (female: 92%) participated in the online family support groups, and 11 family members took part in individual psychological consultations. Participants' personal comfort and family relationshipshowed a significant improvement after the groups.

Conclusion: Psychological care services can effectively assist people with dementia to maintain their daily activities during pandemic and family members can also get short-term breaks and professional supports. It is thus necessary to keep providing psychological care services with online technology for people living with dementia.



145

Impact of a dementia training course on staff at a new specialized center

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aim: To determine the impact of a dementia training for staff at a new specialized center for people with dementia (PwD).

Method: Single-center quasi-experimental study, with pre-post design. The training was a 12-session course (9h total), delivered online (due to Covid) by dementia experts from health and social care, law and research. It was evaluated at 3 levels of Kirkpatrick's Evaluation Framework: staff reaction/satisfaction (level 1), skills/learning (level 2) and behaviour change (level 3).An online questionnaire measured satisfaction with training (5-point Likert-scale), knowledge/learning (1 perceived knowledge question and 24 multiple choice questions), attitudes towards dementia (Dementia Attitude Scale) and new behaviours/practices (yes/no). We used Wilcoxon signed-rank test to compare perceived knowledge and T-test for paired samples to compare attitudes.

Results: Of 92 participants, 79 completed pre- and post-test questionnaires (median age=31, IRQ=16; 91% female). Most had no prior dementia training (65%).Satisfaction with training was high (median=4, IQR=1). Perceived knowledge improved (median 3, IQR 1 to 4, IQR 1; $p<0.001$). Median score in the knowledge test was 68% (IQR=19). After training, participants showed better attitudes toward PwD (mean=116.5, SD=10.3 to mean=122.2, SD=11.5; $p<0.001$). Most (93%) said their behavior or practice changed after the training and 95% said they would do so in the future.

Conclusions: Our short online dementia training course had positive impact in all dimensions evaluated, suggesting it is an effective way of providing first-level training to staff in new specialized centers. Second-level training (intermediate course) will follow.

146

Scotland's commitment to dementia friendly homes and support infrastructure: our National COVID Action Plan

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

In December 2020, the Scottish Government launched a 'Dementia and Covid-19 National Action Plan - to continue to support recovery for people with dementia and their carers'; a bridging plan which sits alongside the existing third National Dementia Strategy. The Plan makes 21 commitments to strengthen resilience across Scotland to recover as individuals and as a community through the pandemic.

'Commitment 6' seeks to 'support people with dementia to live well and safely in their own home, connected to their local community, for as long as possible…'. To deliver upon this commitment the Scottish Government established a Housing and dementia Forum co-chaired by two independent specialists in housing and dementia for the purposes of: identifying gaps and opportunities; share best policy and practice; inform policy development (including future national dementia strategies); and build upon the range of resources and models of housing support that are evident throughout Scotland.

Over 12months the forum heard evidence from organisations, individuals, specialists, and people living with dementia on the themes of:

- Housing in post-diagnostic support
- Housing options and adaptations (availability and accessibility)
- Information on housing options and support
- Relationships between housing and other sources of support in the community
- Housing as a tool to improve links with other forms of support for people living with dementia
- Reasons for moving house in later life

Our presentation will discuss the terms of the forum, summarise findings and offer recommendations for recognising housing and dementia as a national health priority which affects us all.



147

Meeting Centre Support Programme: Lessons from Singapore

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Dementia Singapore, Singapore, Singapore

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Research has demonstrated that multicomponent support programmes are more effective for persons living with dementia and their families, than single support activities. However, as there are currently no such programmes in Singapore, the Meeting Centre Support Programme (MCSP), an evidence-based multicomponent support programme, was adopted from the Netherlands and the United Kingdom, and piloted in Singapore in July 2020.

Following the introduction of two Meeting Centres in different neighbourhoods, a total of 15 families (15 persons living with mild to moderate dementia and 17 carers) have joined and meet one to two days per week. These families were referred through other programmes of Dementia Singapore and grassroots organisations. Participants' age ranges from 43 to 89 years old, and comprise 11 males (34.4%) and 21 females (65.6%).

Based on every participant's adaptation assessment, most members have identified needs to maintain a positive self-image, and their relationships with family and friends. Conversely, carers identified needs to maintain an emotional balance, and prepare for the uncertainties when their loved ones' conditions progress.

While there is potential in MCSP to support families in Singapore, these pilots also highlighted several learning points and areas for improvement: (1) Adaptations needed to account for the cultural and geographical differences between Western and local contexts; and (2) Adjustments are also needed as the pilots started amid the COVID-19 pandemic, which may have accelerated the progression of the members' condition as well.

149

Implementation of the Regional Plans for Dementia in Italy and consequences for public long term care services

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Aims: In Italy, 1,1 million people live with dementia, 600.000 of which diagnosed with Alzheimer. People living with dementia count for 60% to 80% of the whole long term care services' users: yet, public LTC services are still conceived for hosting only a limited number of people diagnosed with dementia, leading to a misalignment between service design and users' profile and needs.Building on these premises, the paper deeps dive into the implementation of the National Plan for Dementia at the regional level to investigate the policy preparedness to properlyrespond to the needs of people diagnosed with dementia and their caregiver. Plus,it selects two best practices where implementation is at an advanced stage to draw useful lessons for the country.

Method: The methodology adopted is based on the analysis of national and regional legislation on dementia and on two case studies, which were chosen for their peculiarities.

Results and Conclusions: With respect to regional legislation, as of July 2021, only 12 regions out of 21 adopted the National Plan for Dementia. These regions focused much on establishing the new service arrangement prescribed by the law, with limited focus on information systems that can support regions in detecting dementia and to plan adequate policies. Also support to caregivers is scarcely considered, together with information campaigns to citizens to prevent and increase awareness on dementia. Last, case analysis showed that dedicated resources allocation, investments on population health management systems and political support make the difference in handling dementia at the regional level.



150

A systematic review of process evaluations; The how of Randomised Controlled Trials

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Introduction: Process evaluations (PEs) can be run alongside randomised controlled trials to explainhowan intervention works.PEs identify the mechanisms through which an intervention influences change.This systematic review explored the methods used in process evaluations to evaluate how psychosocial interventions for people living with dementia (PLWD) and/or their family carers work, and the extent to which proposed causal pathways are observed in practice.

Method: This review included PEs or studies collecting evaluation data embedded into RCTs evaluating psychosocial interventions for PLWD at home. Scopus, MEDLINE, Web of Science, PsycINFO, CINAHL, and Cochrane Library databases were systematically searched to identify studies that met the inclusion criteria. A reviewer screened study title and abstracts, followed by eligible full texts against the inclusion criteria. A second reviewer independently screened 10% of studies at title and abstract stage, and 20% at full title stage. The Mixed Methods Appraisal Tool was used to assess study quality. Preliminary synthesis of extracted data was analysed using thematic analysis. Realised themes were further analysed to generate analytical themes.

Conclusion: This review provides methodological insight into how current PEs for psychosocial interventions work and explores how the causal pathways and theoretical basis of the interventions informed the PE design. The review findings will inform the research design and logic model for the PE evaluating the NIDUS-Family intervention—an Alzheimer's Society funded new manualised, multimodal psychosocial intervention to support people living with dementia to live independently at home for longer. Initial review findings and insights will be shared.

151

Targeting the leptin system to modify the course of Alzheimer's Disease

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: People living with dementia have reduced levels of the hormone leptin in their blood, and we have demonstrated that leptin has a number of neurobeneficial effects that position it as a potential drug target in the fight against neurodegeneration. Previous research has revealed that key leptin-based peptides retain the actions of the full-length molecule in promoting neuronal survival, enhancing memory and preventing accumulation of Alzheimer's-linked proteins. However, such research has focused strongly on the murine leptin sequence but the vital portion of this molecule (murine leptin116-130) bears only limited sequence homology to the human protein. This research aimed to determine whether short fragments of human leptin retained the efficacy of the full molecule.

Methods: Fragments of the human leptin protein were screened for anti-apoptotic potential in differentiated human SH-SY5Y cells and murine hippocampal neurons. This was coupled to imaging analysis of mitochondria and determination of expression levels of key mitochondrial proteins.

Results: A 9 amino acid fragment of human leptin was identified that replicates the pro-survival actions of the full hormone and prevents mitochondrial dysfunction and oxidative stress that are triggered in *in vivo* models of Alzheimer's.

Conclusions: This research demonstrates the peptide fragments based on the human leptin sequence can mirror its neuroprotective properties. Such a small peptide is amenable to both further peptide modification to generate a peptide-based prodrug or structural determination as part of a rational drug design strategy.



152

A multisensory palliative intervention for people with dementia – the OLAIA Project

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

In Portugal, palliative care is scarce, particularly for people with dementia (PwD). In 2021, our team at a specialized dementia center (CIDIFAD) started an innovation project called OLAIA (inspired in theOlaia tree "Cercis siliquastrum"), aiming to improve the well-being of people with moderate or severe dementia, through a multisensory palliative care approach. The project is funded by the "la Caixa" Foundation.

The project combines three therapies – art therapy (through ceramics), music therapy and aromatherapy – at four intervention levels – environmental, in group, individually and with family, around the theme of seasonality (spring, summer, autumn, winter) to foster orientation and contact with nature. The environmental intervention included the placement of four Olaia trees: two artificial in the indoor environment complemented with audio (sound column) and olfactory (oil diffusers) devices to stimulate senses; and two natural trees in outdoor spaces. In parallel, the therapies develop in groups of PwD (12 weekly sessions) or individually for those in more advanced disease stages, whenever possible with a family member (4 weekly sessions).

A total of 108 PwD, 36 family members and 147 professionals are expected to benefit from the OLAIA Project. An evaluation of the results will be conducted by the researchers of the center, measuring impact on the comfort and physical suffering of the PwD and grief (family members).

153

Better ways to bank: innovating to support people living with dementia to manage their day-to-day finances

Ms Natasha Morgan[1], Ms Jayne Sibley[2], **Ms Michelle Davies**[1]

[1]Alzheimer's Society, London, United Kingdom. [2]Sibstar, London, United Kingdom

Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Innovation at Alzheimer's Society is based on developing and applying new solutions to meet the needs of people affected by dementia. We are 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 helps us break out from our own limited experiences and develop new ways to take on dementia.

The first half of this presentation will discuss a partnership with Santander to co-design a dementia banking phoneline. We will demonstrate how we used a 'sprint' approach to co-design a new banking service with people affected by dementia. Involving people from the start revealed the challenges faced in managing day-to-day money including impulse purchases, scams, and difficulty accessing bank accounts while online creative workshops co-produced ideas for solutions.

The second half of the presentation will focus on Sibstar, one of our partners from Alzheimer's Society's Accelerator Programme. Inspired by its founder Jayne Sibley's personal experience of caring for her parents, this highly secure debit card and app is designed to help families living with dementia to safely manage their daily spending. Jayne will share both her experience as a carer and as an entrepreneur.

We will share our insights gathered from these projects, our future plans, and reflections on collaborating with both large and small organisations.



154

Supporting those from an ethnic minority community to access a diagnosis

Mr Kielan Arblaster
Alzheimer's Society, London, United Kingdom

Topic

Dementia awareness and friendliness: Diverse populations – inclusion, equality, cultural issues

Abstract

People from an ethnic minority community may experience an inequity of diagnosis, either by receiving one late or not at all. In September 2021, Alzheimer's Society produced a report – *Increasing access to a dementia diagnosis: ethnic minority communities.* The report investigated the barriers to diagnosis for these communities, based on interviews with services and professionals involved in diagnosis, as well as people affected by dementia. It found challenges both at community and service level contribute to this inequity.

At a community level, stigma and taboo contribute to low levels of awareness of dementia, which in turn restricts the chances people and their families have in reaching out to formal services with concerns about symptoms. Cultural perceptions around dementia as well as caregiving also present themselves as barriers to diagnosis, further inhibiting access to a diagnosis.

At a service level, a lack of culturally appropriate service provision, inappropriate cognitive tests, insufficient access to quality interpretation services as well as poor ethnicity data recording all contribute to reduce access to diagnosis for ethnic minority communities.

The recommendations targeted at integrated care systems set out in the report aim to lessen these barriers at both community and service level. A focus on reducing health inequalities is central to the remit of ICSs and provides a clear opportunity to tackle the barriers preventing ethnic minority communities accessing a timely and equitable diagnosis.



155

Reducing regional variation in diagnosis

Mr Kielan Arblaster
Alzheimer's Society, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Pre- Covid-19, England achieved the national target to diagnose at least two-thirds of all people living with dementia. However there were large variations across the country with some areas failing far short of meeting this target.

In September 2021, Alzheimer's Society produced a report – *Increasing access to a dementia diagnosis: regional variation* –which investigated the regional and systematic challenges to increasing access to a diagnosis. After interviewing services providers, professionals and commissioners involved in diagnosis, recommendations were made to address the variations found in diagnosis rates.

The report found that the regional challenges of deprivation and rurality affect the prevalence and identification of symptoms for local health systems. The systematic challenges at each step of the diagnostic pathway also affects access to a diagnosis. Increasing case-finding for dementia, smoothing referral processes, enabling primary care to have a more active role in diagnosis, and improving data reporting can all lead to increases in diagnosis rates. The recommendations therefore are aimed at overcoming regional challenges that local health systems face, as well as improving the processes at each step of the diagnosis pathway.



157

Correlation between social support and positive aspects of caregiving in dementia.

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aim: Some family caregivers reported their positive aspects of caregiving (PAC), including a sense of giving back to someone who has cared for them, the satisfaction of knowing that their loved one is getting excellent care, personal growth and increased meaning and purpose in one's life. However, the researches on PAC were relatively rare. The purpose of the study was to investigate the correlation between social support and PAC among family caregivers of person with dementia in Taiwan.

Method: A questionnaire survey design was adopted to collect the data. Family caregivers who over 20 years old and taking care of their relative with dementia (N=100, mean age = 58.47,SD=10.22).

Results: The results indicate that informal social support is a significant factor on PAC(β= .25, t=2.94,p= .004). In addition, the behavioral and psychological symptoms of dementia (BPSD) (β=-.39, t=-4.53, p<.001); spouse relationship(β= .22, t=2.50,p=.014); and need to take care of other relatives (β=-.19, t=-2.08, p=.04)have significantly impact onfamily caregivers'PAC.

Conclusions: According to the results, handling and controlling BPSD situation, increasing family caregivers' informal social support and more attention to the caregivers who need to take care of other relative might improve the caregivers' PAC.

158

Admiral Nurse Case Management within Enhanced Health in Care Homes

Mrs Zena Aldridge[1,2,3], **Dr Karen Harrison Dening**[1,2]

[1]Dementia UK, London, United Kingdom. [2]De Montfort University, Leicester, United Kingdom. [3]NHS England and NHS Improvement, Cambridge, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

The United Kingdom's (UK) older population is higher than the global average. Over the next 20 years, England will see an increase in the number of older people who have higher levels of dependency, dementia, and comorbidity many of whom may require 24-hour care. Currently it is estimated that 70% of residents in nursing and residential care homes either have dementia on admission or develop it whilst residing in the care home. The provision of high-quality care for this population is a challenge with a lack of consistency in the provision of primary care and specialist services and a known gap in knowledge and skills. The NHS Long Term Plan aims to move care closer to home and improve out of hospital care which includes people who live in care homes by introducing Enhanced Health in Care Homes (EHCH). However, such services need to be equipped with the correct skill mix to meet the needs of the care home population. Admiral Nurses are specialists in dementia care and are well placed to support the delivery of EHCH and improve access to specialist support to care home residents, their families, care home staff and the wider health and social care system. This session will discuss current gaps in service provision and how both the EHCH framework, and the inclusion of Admiral Nurses, might redress these and improve outcomes



159

Admiral Nursing in Primary Care: Peri and Post-Diagnostic Support for Families Affected by Dementia within the UK Primary Care Network Model

Mrs Zena Aldridge[1,2,3], **Dr Karen Harrison Dening**[1,2]

[1]Dementia UK, London, United Kingdom. [2]De Montfort University, Leicester, United Kingdom. [3]NHS England and NHS Improvement, Cambridge, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

The population of the United Kingdom is ageing. In 2017 approximately 18% of the UK population were aged 65 years or over and projected to grow to almost 21% by 2027 according to the Office of National Statistics. Increased age is the greatest risk factor for developing dementia. It is estimated that there are 850,000 people living with dementia in the UK and if current figures relating to incidence and prevalence are realised, this will increase to 1 million people by 2025 and 2 million by 2051.

The National Health Service (NHS) England Long Term Plan aims to move services closer to home and improve 'out of hospital' care. The overall aim being to reduce the pressure on acute hospital resources, give people more control over their own health, and more personalised care closer to home when they need it. Given the increasing number of people with dementia and their families there is a growing need to ensure primary and community services are developed to meet their often complex needs. Admiral Nurses are specialist dementia nurses that could support the delivery of the NHS Long Term Plan and improve the provision of specialist support offered to families affected by dementia within new models of care. This article aims to articulate some of the current gaps in peri and post-diagnostic support for families affected by dementia, and how the inclusion of Admiral Nurses within Primary Care Networks could be a solution to redressing some of these gaps.



160

Moving Forward Stronger: Addressing Deterioration in People with Long-Term Conditions

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Alzheimer's Society, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

During the Covid-19 pandemic, many people with pre-existing, long-term conditions including dementia saw their conditions deteriorate much faster than usual. 82% of people surveyed by Alzheimer's Society reported a deterioration in symptoms since the pandemic's start, caused by factors such as repeated lockdowns and social isolation to the closure of rehabilitative services.

Our collaborative paper *Moving Forward Stronger*, produced with 9 other health and social care charities and organisations representing allied health professionals, argues that this deterioration should be addressed through introducing a fully-funded national rehabilitation strategy.

The paper recommended that a national clinical lead for rehabilitation be appointed to implement this strategy and we are pleased to see that NHS England has since taken up this recommendation. Work now needs to be developed on how this new role will work with local partners such as local authorities and Integrated Care Systems (ICSs) to help them develop and deliver their own localised rehabilitation strategies.

The right rehabilitation enables people to manage their long-term health conditions effectively, and as a result, it can help slow down or prevent deterioration. For some, it may even reverse some of the deterioration people have experienced and help people to regain some abilities. This will only be possible, however, if there is a clear strategy and direction on rehabilitation as we move on from the COVID-19 pandemic. Such a strategy will be essential to ensure the hundreds of thousands of people living with long-term conditions in the UK have the tailored support they need.



161

Supporting Youth With A Parent Who Is Living Younger-Onset Alzheimer's: A Crucial Component In Integrated Care

Mrs Diana Shulla Cose
Lorenzo's House, Chicago, USA

Topic

Support for dementia carers: Young carers

Abstract

Lorenzo's House, a nonprofit in Chicago,focuses on a transformative approach that supports children and young adults who are living with a parent with younger-onset Alzheimer's. Youth are often affected by a parent's diagnosis at a neurobiologically vulnerable time in their lives. Youth frequently don't know how to explain their experience as a care partner with their peers, leaving them isolated and managing the ongoing change by themselves. By creating spaces specifically catered towards these young care partners, we are radically shifting the journey of what younger-onset Alzheimer's looks like for children and young adults.

We focus on the relationship between the parent diagnosed and their children, what children need as care partners, and what issues and struggles they face at a variety of ages in this journey. Our three youth programs focus on innovation to support youth living with a parent with younger-onset Alzheimer's:Lorenzo's Camp, a camp designed by youth care partners, therapists, medical professionals - intended toshare common stories and build an alliance; theLight Club, a virtual youth care partner group injected with team building and relationship development; and lastly youth-led advocacy work. Our model shifts the narrative for how youth experience being a member of a family that is navigating a younger-onset Alzheimer's diagnosis.



162

Charities supporting entrepreneurs to accelerate access to new products

Mr Simon Lord, **Ms Michelle Davies**

Alzheimer's Society, London, United Kingdom

Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

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.

The Accelerator Programme at Alzheimer's Society offers up to £100,000 in financial investment and support for new ideas that could improve the life of someone affected by dementia. The support offered is bespoke but can include facilitating testing with people affected by dementia, advises on dementia-friendly product development, works to maximise coverage and coordinate communications relating to the programme.

In the first year of the Accelerator Programme we worked to boost two exciting products to market, including Jelly Drops, hydration sweets aimed at reducing hospital admissions from dementia-related dehydration.

Our second round focused on 3 products, a secure, prepaid debit card and app for people living with dementia and their carer, a simple system that enables a person to make and receive video calls through their own television and a playful, interactive comforter designed to be cuddled by people with advanced dementia.

Working closely with these start-ups has proved mutually beneficial, helping the team identify the ways in which we can be more agile, while helping the start-ups reach market more quickly with products that have been well tested and evaluated in order to ensure they best serve people affected by dementia.





163

The association between repetitive negative thinking and blood-based biomarkers of stress, inflammation and neurodegeneration.

Miss Harriet Demnitz-King[1], Dr Amit Bansal[1], Miss Cassandre Palix[2], Dr Olga Klimecki[3], Dr Gaël Chételat[2], Dr Géraldine Poisnel[2], Dr Natalie L Marchant[1]

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Repetitive negative thinking (RNT) encompasses future-directed (i.e., worry) and past-directed (i.e., brooding) negative thoughts, and has been associated with cognitive decline, amyloid deposition and tau pathology. We aimed to elucidate the mechanism(s) through which RNT may confer increased AD risk, by investigating the association between RNT and blood-based biomarkers of: stress (cortisol), inflammation (C-reactive protein [CRP], interleukin-6 [IL-6]) and neurodegeneration (neurofilament light chain [NfL]).

Method: Baseline data from 135 cognitively unimpaired older adults enrolled in the Age-Well clinical trial were utilised. All participants completed self-report measures assessing worry (Penn State Worry Questionnaire) and brooding (Rumination Response Scale - Brooding subscale) and had blood drawn to allow quantification of cortisol in serum, high-sensitive CRP, IL-6 and NfL levels in plasma. Associationsbetween worry and brooding and blood-based biomarkers were assessed via multiple adjusted linear (cortisol and NfL) and logistic (CRP and IL-6) regressions.

Results: In linear regressions adjusted for age and sex, higher levels of worry (β=0.22, p=0.010) and brooding (β=0.17, p=0.042) were associated with elevated NfL. Results remained largely unchanged after adjusting for anxiety or depression. No associations were observed between worry or brooding and markers of stress (cortisol: p's>0.210) or inflammation (CRP: p's>0.146; IL-6: p's>0.174).

Conclusion: This study provides further support for RNT as an AD risk factor by finding a relationship with NfL, a marker of neurodegeneration. However, no associations were observed with markers of stress or inflammation, thus further research is needed to elucidate the mechanisms through which RNT may confer increased AD risk.



164

An Innovative Approach to Empowering Care Partners Living with A Loved One Diagnosed with Younger-Onset Alzheimer's

Mrs Diana Shulla Cose
Lorenzo's House, Chicago, USA

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Our innovative approach at Lorenzo's House, a nonprofit in Chicago, empowers care partners living with a loved one with younger-onset Alzheimer's.Lorenzo's Angelsis a proven model designed to create one-on-one mentor matches between care partners. This personalized match offers connection with someone who shares a similar profile and understands.Families living with a younger-onset diagnosis are often underserved and under-discussed in the Alzheimer's community. With this diagnosis comes a dramatic shift in a younger family's dynamic and they are often alienated from popular Alzheimers' resources geared towards people who are diagnosed later in life. These care partner spouses are in a uniquely important and difficult position as they are responsible for being the primary care partner to their spouse, breadwinner for the household, and for parenting independently - all while navigating the complexities of the diagnosis.

A family culture changes after a younger-onset Alzheimer's diagnosis, and there is a need for innovative care and personal connection.Werecognize that the best guidance and support for care partners often comes from people who have or are still walking the path.Weempower families by cultivating a care partner-to-care partner mentor model, building an International network of care partners matches. Our framework emphasizes social emotional wellness, practical information and resourcefulness so that families turn isolation to connectedness and darkness to light, living this journey together - never alone. By creating this framework through digital and in-person platforms, we provide sustenance to care partners everywhere living with a loved one with younger-onset Alzheimer's.





165

Feasibility of implementation for standard neuropsychological assessment in European academic memory clinics: an EADC-ISTAART survey

Ms Alice Grazia[1,2], Dr Daniele Altomare[3], Mr Lukas Preis[4], Prof Andreas U. Monsch[5], Prof Stefano Cappa[6,7], Prof Serge Gauthier[8], Prof Lutz Frölich[9], Prof Bengt Winblad[10], Prof Kathleen A. Welsh-Bohmer[11], Prof Stefan Teipel[1,12], **Dr Marina Boccardi**[1]

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Topic

Dementia research and innovation: Mild Cognitive Impairment (MCI)

Abstract

Background and aims: Standardized neuropsychological assessment wouldallow for comparability between dementia expertcenters, i.e., memory clinics,andpotentially decreasecosts.An expert consensus adapted the US NACC Uniform Dataset-3 for European memory clinics: the clinician's Uniform Dataset (cUDS).Here, we assessed the acceptability and feasibilitytoimplement the cUDS in European academic memory clinics.

Methods: An ISTAART-EADCsurvey investigated centers'practices, barriers, facilitators and willingness to implement the cUDS. Within a mixed-methods design, we performed separately qualitative and quantitative data analysis, which were later integrated to compare and interrelate **Results:** Intercoder reliability corresponded to moderate agreement (k=0.51).

Results: Fifty-one clinicians answered from 46 of the 71 eligible EADC centers (65%). Thirty-three out of fifty-one(65%) clinicianswere favorable to implement the cUDS. General barriers related to the implementation process (40%) (i.e. logistics) and clinical-methodological domains (23%) (i.e. tests'material). Favorable clinicians reported digitalization (13%) as facilitating, and unavailability of local norms (30%) as hindering. Unfavorable clinicians reported to be challenged by logistic-organizational issues (40%) (i.e. capacities and time) and facilitated by higher financial resources (15%) (e.g. insurance coverage for new tools) (Table).

Conclusions: Besides challenges, data showed moderate acceptability and requirements to improve feasibility.Next steps to ensure successfulimplementation willentail the provision of local norms and tests'material, as well as the digitalization of procedures.Consideringthe global priority of tackling

dementia, this studyprovides important insightsto implement a diagnostic proceduresupporting reliable and cost-effective early detection ofneurocognitive disorders.



166

A future for personalised care

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Alzheimer's Society, London, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

In England, prior to the Covid pandemic, decades of underfunding and neglect had led to a social care system where people with dementia were struggling to access the care they need.The pandemic has exacerbated these existing challenges, as well as creating new ones. The government has however made a commitment to fix social care.

Our discussion paper, *A future for personalised care*, looked at what a new vision for social care should be and what quality care really means for people with dementia. We reviewed evidence from policy literature, from legislation, guidance, standards and frameworksthat define quality care or drive improvement, from leading bodies across the social care sector,as well as evidence from research hubs such as the Alzheimer's Society Centres of Excellence.

We found that personalised care is key to high quality care. This is care where people have choice and control, and where care helps people to achieve the goals that matter most to them. We also found that, as the pandemic has also highlighted, relationships with loved ones are key to health and wellbeing. We considered how the social care system can be built to facilitate this good quality care and the changes that need to happen, including training for the care workforce and reform of working conditions. We included examples of good practice and presented a set of recommendations.

167

Couplehood in dementia: a scoping review

Prof Ingrid Hellström
Marie Cederschiöld University, Stockholm, Sweden

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

The presentation will report from an on-going scoping study, which draw upon a wealth of data and research/practice experience in the area of couplehood in dementia. The aim is to systematically explore and describe the breadth and nature of available research in couplehood in dementia and identify gaps in knowledge.

Most people diagnosed with dementia live in their own homes, many of them together with their long-term partner. Whilst the 'personhood' of the individual living with the condition it is important, for many partners the idea of 'couplehood' is equally significant and is an area which has informed the author's research and practice in dementia studies for over 20 years. Couples often spend considerable effort and ingenuity both in 'sustaining' their relationship and in seeking to 'maintain the involvement' of the person with dementia in the performance of everyday life and situations. Existing empirical work suggests that 'multi-dimensional and dynamic inter-relationships' between the person with dementia and the care partner occur throughout the entire experience of dementia.

A comprehensive search strategy will be developed in collaboration with an information specialist with subsequent data base searches. The study will be conducted in accordance with the PRISMA extension for scoping reviews (PRISMA-ScR).

The study will tentatively to call into question the current emphasis placed on individuality and autonomy, concepts which largely define health and social care systems, and point to the relevance of interdependence as a key influence for developing more appropriate and sensitive forms of support.



168

COGNISANCE: Experiences of people with dementia and their caregivers with post-diagnostic support

Ms Maud Simone Hevink[1,2], Dr Claire Wolfs[1,2], Prof Marjolein de Vugt[1,2], Prof Frans Verhey[1,2], Prof Joanna Rymaszewska[3], Prof Louise Robinson[4], Prof Greta Rait[5], Prof Isabel Vedel[6], Dr Meredith Gresham[7], Prof Lee-Fay Low[8], Prof Henry Brodaty[7]

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Background: Good quality Post-diagnostic support (pds) people with dementia (PwD) and their caregivers (CG) is important to increase Quality of Life (QoL) and promote living well with dementia Evidence suggests pds does not meet needs of CG adequately and evidence on experiences of PwD with pds is lacking. This study aims to provide a detailed description of PwD and CG satisfaction with pds and to examine whether PwD and CG differ in their experience of pds.

Method: A survey for PwD and one for CG was distributed in Australia, Canada, the Netherlands and Poland as part of the COGNISANCE project. The surveys assessed demographics, experiences with the diagnostic process, QoL, and experiences with pds. Analysis consisted of descriptives and chi-square tests.

Results: 91 PwD and 299 CG completed the survey. 53% (Australia) to 83% (UK) of PwD and 57% (Australia) to 89% (UK) of CP said that support after the diagnosis helped them to deal more efficiently with their concerns.PwD were more often satisfied with information on the diagnosis (59% satisfied, 41% dissatisfied) whereas CGs more often reported they were confident to ask for professional help (58% satisfied, 42% dissatisfied). PwD and CP differ from each other regarding satisfaction on information after a diagnosis and knowledge on access to support *($\chi(2) = 9.55$ $p = .008$)*.

Conclusion: As a significant minority did not have a positive experience of support, there is room for improving pds.

169

Risk of dementia in women with a history of breast cancer: a matched population-based cohort study in the United Kingdom

Dr Esha Abrol[1,2], Dr Helena Carreira[2], Prof Krishnan Bhaskaran[2]

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Women with a history of breast cancer are the largest group of cancer survivors in the UK. There are concerns that exposure to anti-cancer treatments might affect long-term cognition and risk of dementia in this group. We therefore aimed to explore the relationship between breast cancer survivorship and dementia risk in the UK.

Method: A matched cohort study using primary care data from the UK Clinical Practice Research Datalink (CPRD) GOLD database and linked hospital data was performed. Women with prior breast cancer were matched 1:4 on age, GP practice, and calendar time to women with no prior cancer. Dementia was defined using GP Read codes and prescription data. The association between history of breast cancer and dementia was assessed using Cox regression.

Results: 57 553 breast cancer survivors and 229 934 matched women with no prior cancer were included (1987-2018). Breast cancer survivors had an adjusted 13.7% lower risk of a dementia diagnosis in primary care than matched controls (HR 0.86, 95% CI 0.81-0.92). The association was similar using linked hospital data. There was evidence of effect modification by age; the association was strongest for 65-84 year-old women (HR 0.85, 95% CI 0.79-0.91) (p-interaction =0.0228).

Conclusion(s): Breast cancer survivors do not appear to have a raised risk of dementia compared with women who have never had cancer. The observed lower risk of dementia in breast cancer survivors may be explained by unmeasured or residual confounding, better pre-morbid cognitive reserve, or information bias.



170

Do national dementia guidelines consider protection against discrimination? A systematic review.

Ms Tiffeny James[1], Dr Naaheed Mukadam[1], Dr Andrew Sommerlad[1], Dr Hossein Rostami Pour[2], Dr Melanie Knowles[3], Ms Ignacia Azocar[1], Prof Gill Livingston[1]

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

Aims: We aimed to identify which countries have national clinical practice guidelines for dementia, and synthesise guideline recommendations relating to protected characteristics as defined by the UK Equality Act 2010.

Methods: We searched CINAHL, PsycINFO, Medline, and the Guideline International Network library until March 4th, 2020 for dementia guidelines in any language. We also searched Google and the national health websites of all 196 countries in English and in each country's official languages between April and September 2020. We included any guidelines for health or social care workers with recommendations about dementia approved at a national policy level.

Results: Of 46 guidelines from 44 mostly high-income countries meeting our criteria, 37 (80%) referenced protected characteristics at least once. We identified recommendations relating to age, disability, race (culture, ethnicity, or language), religion, sex, and sexual orientation. Age and race were the most frequently referenced with recommendations including specialist investigation for younger people; consideration of culture and language when assessing dementia; and consideration of age, culture, and religion when providing person-centred care. For disability recommendations were that healthcare workers consider intellectual disability and sensory impairment when assessing for dementia. Most references to sex recommend not using hormonal treatments. One guideline made one recommendation related to sexual orientation.

Conclusions: National dementia guidelines vary in their consideration of protected characteristics. We identified areas of good practice that can be considered in all future guidelines and suggest that guidelines provide specific evidence-based recommendations for protected characteristics with examples of how to implement them.

171

The effect of a mindfulness-based versus health self-management intervention on cognitive performance in older adults with subjective cognitive decline (SCD): The SCD-Well randomized controlled trial

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aims: To test the hypothesis that a Caring Mindfulness-Based Approach for Seniors (CMBAS) intervention will confer greater benefit to objective cognition than a Health Self-Management Program (HSMP) in individuals with subjective cognitive decline (SCD).

Method: This study utilized data from the SCD-Well RCT. Older adults with SCD (n=147) were recruited from memory clinics in four European countries, and randomized to an 8-week non-pharmacological intervention (CMBAS or HSMP). Objective cognition was assessed at baseline, 8-weeks, and 24-weeks using a battery of tests. Three cognitive composites were also computed - an attention composite, executive composite, and abridged Preclinical Alzheimer's Cognitive Composite 5 (PACC5Abridged). Linear mixed models estimated the change for each outcome within and between trial arms. Models were adjusted for demographics, baseline Alzheimer's disease (AD) blood biomarkers (P-tau181, NfL, and Abeta42/40), and neuropsychological retest effects.

Results: PACC5Abridged scores increased from week 0-24 in both arms of the trial ($p<.001$). The mean increase [95%CI] did not differ between arms (CMBAS=0.32, [0.17, 0.47]; HSMP=0.30, [0.15, 0.45]). Neither the attention nor executive composite scores increased in either arm. Amongst individual cognitive tests, non-differing improvements were observed in both arms for the DRS-2, RAVLT, and WAIS-IV Coding. Neither trial arm exhibited improvement for verbal fluency, Stroop nor TMT.

Conclusion: Scores on a composite sensitive to early AD-related cognitive dysfunction improved in both arms, even after accounting for retest effects. This work adds to the growing body of evidence that non-pharmacological interventions can improve cognition in individuals with SCD, a population at increased dementia risk.



173

Artful Approach: A virtual art program to train informal carers to engage people with dementia in creative experiences

Prof Anne Mondro
University of Michigan, Ann Arbor, USA

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Art-making supports dementia carers in their effort to engage with their care recipient in meaningful activities that promote personal expression and social interaction. However, art programming is often limited in availability and facilitating creative activities require skills outside the scope of most carers' comfort zone. Recognizing the need to broaden the positive impact of the arts for people living with dementia, this paper will discuss *Artful Approach*, a virtual art program for dementia carers and their care recipients. The program focuses on training family carers in a range of accessible and age-appropriate creative activities to engage with their care recipient. The paper will discuss the pilot phase of the program, which transitioned from an in-person model to a virtual one as a result of the pandemic. Aimed to provide family carers with training to confidently integrate art activities into their caregiving, the paper will discuss the successes and challenges of the three-week virtual program in meeting this goal. Using custom art kits and training materials, the paper will provide an overview of the program's activities and discuss key strategies and methods *Artful Approach* researchers used during the training sessions to encourage participants to facilitate the activities on their own. Participant feedback from the family carers will be shared as well as lessons learned for future iterations. The paper will emphasize the need to develop virtual programs to support families while presenting evidence for the ways the arts enrich the quality of life for people living with dementia.

174

Interventions supporting the psychosocial health and wellbeing of informal caregivers of people with dementia in low- and middle-income countries (LMICs): A systematic review

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: Growing incidence of dementia increases the number of informal caregivers providing support to people living with dementia. However, unmet needs of caregivers in LMICs are compounded by lack of resources and health care infrastructure. The extent to which supportive interventions are implemented in LMICs remains unclear.

Aims: To assess the nature and effectiveness of interventions supporting informal caregivers of people with dementia in LMICs regarding psychosocial outcome measures including: burden, distress, anxiety, and depression.

Method: A systematic review of 36 online global and regional databases, registries, journals and directories was conducted April–June 2021, directed by theCentre for Reviews and Dissemination guidance for undertaking systematic reviews (2009) and Cochrane Handbook for Systematic Reviews of Interventions (2021). Risk of bias was assessed using RoB 2.0 and ROBINS-I tools; data were extracted using a standardised form and synthesised using continuous caregiver outcome measures.

Peliminary Results: The search identified 1538 records. Following duplicate removal, title/abstract screening, and full text review, 35 controlled trials were included, published 2004–2021, representing 13 LMICs. Study interventions focused on three domains: dementia education; education/training on managing behavioural and psychological symptoms of dementia; management of the impact of caregiving. Preliminary results trend towards enhanced caregiver wellbeing following interventions; however, study quality was predominately 'some concerns' or 'high' risk of bias.

Conclusions: Unmet needs of informal dementia caregivers are rising in LMICs, requiring effective solutions. Further investigation into essential components of an intervention to support and significantly enhance their psychosocial health and wellbeing, is needed.



175

NEW THERAPEUTIC TOOL TO TREAT ALZHEIMER'S DISEASE

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Aims: Transcranial Pulse Stimulation (TPS) is a recently developed method to treat Alzheimer's Disease (AD). Neurolith^{R} is the tool to apply TPS and recently used in limited centers all over the world. Neurolith^{R}provide more precise targeting and arranging intensity of sound waves / shock waves. TPS has ability to reach deep target tissue compared to Transcranial Magnetic Stimulation due to conductivity effects. Here we want to give preliminary results of our experiences.

Methods: We applied the treatment procedure of six sessions to 40 patients. During this treatment procedure, we kept their drug regime as they were using before. We applied neuropsychological test batteries before and 4 weeks after the six sessions of loading dose. We gave 6000 pulse stimulations to the entire cortex with the navigation system of Neurolith^{R}.

Results: We compare the results of tests and clinical observations of ours and care partners after all. We haven't seen any side effect. We observed increased cognitive performance in all of them with various degrees. All the patients become more social and interactive with their families besides increased feeling of wellbeing.

Conclusions: TPS is a revolutionary treatment option for neurodegenerative diseases. Our study showed promising therapeutic effects. We need further controlled studies.

176

Dementia Friendly Initiatives in the U.S.A., Mainland China and Taiwan: A comparison based upon perceptions of service professional stakeholders

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Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Aims: People living with dementia (PWD) often experience stigma and social exclusion that affect their wellbeing. To address this issue, promotion of dementia friendly initiatives (DFI), one of the goals in WHO's 2017 report on *responses to the impact of dementia as public health concern,* are in place in many countries. This study aims to identify a common practice model of DFI as well as highlight differencesbased on the perceptions of stakeholders involved in DFI in the United States, mainland China, and Taiwan.

Method:A qualitative design using semi-structured interviews with 18 stakeholders in the three regions was implemented with an approval from a University Institutional Review Board. All interviews were video recorded via Zoom and transcribed for thematic analysis.

Results: Themes of DFI identified among the U.S.A, mainland China, and Taiwan include 1) features of communities involved, 2) major mission of the DFI, 3) approaches of DFI, 4) partnerships and funding resources, 5) outcomes and impacts of DFI, and 6) the responses to COVID-19 pandemic.

Conclusions: The practice of DFI in the three regions reflects a systematic approach to change the environment, and a mixed model of service provision and co-production. A systems approach entails that DFI target different populations (e.g., family members, young people, neighbors) and service sectors (e.g., health care, social care, public service) that PWD will interact with. The service provision indicates traditional service designs by service professionals provided for PWD, and co-production suggests the leadership or co-designing activities by PWD in DFI.



177

Covid-19 And a Caregivers Support Group, The Challenges

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

As we begin to evaluate the effects of COVID on our dementia population, the individuals with dementia and their care partners, the areas of social isolation, depression and loneliness has become more evident,

As a facilitator of a caregivers support group, the challenge to meet their needs has been difficult. Communication was the beginning strategy in monthly newsletters with information about COVID and open communication with phone calls. This involved strategies that helped assist care partners navigate the new environments in assisted living and long term care facilities, as well as medical issues and the difficulty with teleconferencing with the individual with dementia.

Communicating information in the newsletter, included suggestions to reduce the individual's risk of acquiring COVID which involved personal responsibilities and shared responsibilities. Preparing for special needs such as shelter (as here on Coastal Georgia the chance of evacuation due to hurricanes remains possible). Facial coverings and risk evaluation governing activities outside their homes in regard to COVID. And finally a person centered symptoms track to aid with teleconferencing with the physician.

This information also included those needing the support through prayer and their addresses for words of support. Care partners lost family members with COVID, isolation in facilities existed for those with dementia. And the needs of those special people continue to be the focus of the support group. This session will discuss and be interactive on this very important topic.

178

Engagement of People with Lived Experience of Dementia Advisory Group and Cross-Cutting Program

Ms Ellen Snowball[1], Mrs Rosette Fernandez Loughlin[2], Mrs Heather Eagleson[2], Ms Karen Myers Barnett[2], Ms Emily McLellan[2], Mr Denis O'Connor[2], Mrs Catherine Kelly[2], Ms Christine Thelker[2], Mrs Katherine McGilton[1,2,3], **Ms Jennifer Bethell**[1,2,3]

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Aims: The Engagement of People of Lived Experience of Dementia (EPLED) program was created to support persons with dementia and care partners to be actively involved in Canadian Consortium on Neurodegeneration in Aging (CCNA) research. The EPLED Advisory Group, composed of people with lived experience of dementia from across Canada, was formed to work with CCNA researchers and programs to develop new ways to further this collaboration. This presentation describes the activities, challenges and mitigation strategies, lessons learned and reflections on the importance of engagement from the first year (2020/21) of the EPLED Advisory Group.

Methods: A role profile and recruitment poster were developed and, after interviewing candidates, 17 people were invited to join the Advisory Group. Due to COVID-19, we moved all our meetings online. In the first year, the Advisory Group met four times formally and four times informally, developed a website, engaged with CCNA research projects and other activities and formulated an evaluation plan.

Results: For Advisory Group members, motivations for patient engagement included challenging stigma, making meaningful relationships and aiding research. Challenges to engagement included navigating the impacts of COVID-19; strategies to mitigate these challenges will be discussed.

Conclusion(s): EPLED and the Advisory Group found successes in the challenges of our first year together. We learned that developing trusting relationships, providing education and support, being flexible, and acknowledging tensions between research, practice and lived experience, were vital to the success of the group.



179

Challenges and clinical considerations for the assessment of suicidal ideations in informal caregivers and care partners.

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Université du Québec à Trois-Rivières, Trois-Rivières, Canada

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Our main goal in this presentation is to summarise risk factors and specific findings regarding informal caregivers and care partners who present suicidal thoughts.

Method: This presentation is based on the results of a mixed design study which was conducted in Canada. Individual interviews and a quantitative psychometric survey were used to identify risk factors and carer characteristics. The study followed rigorous clinical and ethical standards and was approved by the university's ethics board.

Results and discussion: Along with a summary of risk factors, three specific results are addressed:

1. While the majority of caregivers who reported having suicidal ideations had access to professional help, very few had spoken about their distress. None reported having been assessed for suicidal thoughts.
2. Care partners reported that suicidal ideations did not subside after the relocation or death of their partner. Rather, loss of purpose, longing, guilt and isolation were described as increasing in the days and weeks after this transition. These emotions were tied to suicidal ideations and coincided with the withdrawal of most professional services, leaving the caregiver in a vulnerable state.
3. During interviews, some carers spontaneously revealed having had homicidal ideations in conjunction with suicidal thoughts. Participants who reported homicidal ideations also described feeling captive and powerless. This situation poses ethical and clinical challenges.

Conclusions: While many caregivers report positive outcomes, some may experience distress and suicidal ideations. A better understanding of risk factors and of caregiver needs will help clinicians develop screening procedures and prevention strategies.

180

The ADel Electronic Home Assistant for older adults living with and without neurocognitive impairment: a feasibility study including family caregivers and healthcare professionals

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Introduction: ADel is a mobile care assistance platform by SoftBiomed™ to connect older adults via an audio/video-social network. ADel allows users to remain independent despite loss of autonomy. It includes video calls, panic button, fall detector, medication and appointment reminders, and a meal delivery service.

Aims: to explore the feasibility of ADel in a group of older adults with and without neurocognitive impairment, their family caregivers and healthcare professionals.

Methods: participants include 10 older adults without cognitive impairment returning home after a hospitalization and 10 older adults living with minor or major neurocognitive disorders. The perspectives of older adults, their family caregivers, and clinicians will be explored at one month and at two months of the implementation of ADel. Data regarding feasibility, utility, perceived feelings of security, frequency of use, satisfaction, and refusal rate will be measured using semistructured interviews and standardized questionnaires.

Expected results and Conclusions: the pilot study will allow sharing expertise between different stakeholders to inform the improvement of the technology across the continuum between normal aging to minor and major neurocognitive disorders. The results will help to improve and adapt this technology according to the evolution of their condition.



181

A qualitative study to explore barriers and facilitators to the implementation of pet robots in nursing homes for residents with dementia

Ms Wei Qi Koh[1], Dr Elaine Toomey[2], Ms Aisling Flynn[1], Prof Dympna Casey[1]

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: Pet robots are a technology-based substitute for animal-assisted therapy. A growing body of research shows that pet robots can positively impact the psychosocial health of people with dementia living in nursing homes. However, little is known about how these can be translated from research into real-world practice for dementia care.

Aim: To explore the barriers and facilitators to the implementation of pet robots in nursing homes for residents with dementia, from the perspectives of healthcare professionals and organisational leaders.

Method: We conducted a descriptive qualitative study that was guided using the Consolidated Framework of Implementation Research (CFIR). Purposive sampling was used to identify and recruit organisational leaders (managers and directors) and healthcare professionals (nurses, activity coordinators and therapists) from Irish nursing homes. Individual semi-structured interviews were conducted. All interviews were audio recorded, transcribed and analysed using Framework Analysis.

Results: Barriers and facilitators were identified across all five domains of the CFIR, which include 1) characteristics of pet robots, 2) organisational context, 3) external policies, 4) characteristics of individuals, and 5) implementation process. Some barriers include high costs, available resources and infection control concerns. Facilitators include the ability of pet robots to meet the needs of residents, compatibility with the existing care processes, available resources, and organisational culture.

Conclusion: This is the first study to explore the determinants of implementing of pet robots in nursing homes for dementia care. These findings can be used to develop implementation strategies to support the translation of pet robots from research to real-world practice.

183

Stress and needs of caregivers of persons with dementia during the COVID-19 pandemic

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: COVID-19 pandemic has brought unprecedented disruption to the world. The continuously evolving situation magnifies the vulnerabilities of people with dementia(PWD) and their caregivers. However, little is known about how they cope and what they need. We aimed to study the difficulties experienced by caregivers of PWD and their needs during these challenging times.

Methods: We recruited caregivers of PWD from a memory clinic in a tertiary hospital. They were invited to participate in an online survey from April 2020 until June 2020. We employed mixed-method to evaluate the change in caregiver stress, factors underlying the stressors and their needs during the pandemic. Multivariable logistic regression was used to analyze the quantitative results, and framework analysis was used to analyze the qualitative results.

Results: 101 caregivers participated in the survey. The majority(n=33,32.7%) were aged between 51 to 60 years old, and children caregivers comprised 77.2%. 66(65.4%) of the caregivers reported worsening caregiver stress. Multivariate analysis showed that factors related to the PWD and accessibility to services were significantly correlated with worsening of caregiver stress(OR=4.07,95%CI:1.57-10.51;OR=6.70,95%CI:1.69-26.55). Three main factors underpinned caregiver stress in qualitative evaluation which pertained to the PWD, caregivers and circumstantial issues respectively. Caregivers with worsened stress levels expressed the need for respite support and engagement programmes for the PWD.

Conclusion: The emotional and physical repercussions on caregivers during this pandemic are immense. Even as we institute measures to cope with the pandemic, we need to devise strategies that are responsive to their needs.



184

Improving health outcomes, well-being and care for people living with dementia in the hospital environment

Dr Claire Burley[1], Dr Anna Williams[2], Ms Jane McGuire[3], Ms Genevieve Maiden[3], Dr Patricia Reyes[3], Dr Zhixin Liu[4], Prof Henry Brodaty[1], Prof Lynn Chenoweth[1]

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aims: This collaborative study will translate an evidence-based person-centred care (PCC) model that our pilot[1] demonstrated improved health, well-being and care for people living with dementia, into the hospital in-patient setting. The outcomes for people living with dementia, healthcare staff and the hospital will be evaluated.

Method: The study involves four participant groups: people living with dementia (n=80); adult family/care partners of patients who have consented (n=80); medical, nursing, and allied health staff (n=60); and PCC Champions (n=8). The intervention includes PCC education program for Champions via a train-the-trainer approach, on-line PCC education for staff, and Champion support for staff in applying PCC in day-to-day care and management of all patients. The study is overseen by an interdisciplinary team comprising of people with lived experience of dementia, professionals from medical, allied health and nursing teams, and policy makers.

Measures: The study involves a pre/post/follow-up evaluation of person-centred care. Clinical outcomes from hospital admission to 30 days after hospital discharge will be compared with 6-month de-identified retrospective patient data matched on cognitive level and comorbidities. Program reach, acceptability, adoption, implementation, maintenance and scalability will be evaluated using a knowledge translation (KT) framework.

Conclusion: Findings and KT success factors will inform healthcare policy and practice guidelines. A set of recommendations for the transformation of nationwide hospital healthcare of people living with dementia will be produced. Involving people with lived experience of dementia and government officials in consultation throughout the study are crucial in ensuring effective implementation

186

The human need for equilibrium: Research on the ingenuity, technical competency, and changing strategies of people with dementia seeking health information

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Aim: To understand the evolution of health information needs, motivations, and information seeking behaviors of people with dementia. We sought to answer the research question: How and why do people with dementia get informed about their condition?

Method: Two people with younger-onset dementia and two university researchers took an Action Research approach to interview sixteen people living with dementia. Each hour-long session involved a semi-structured interview concerning participants' information seeking practices, and a demonstration of their search strategies. Data were analyzed using a constructivist grounded theory approach.

Results: Participants described the physiological, emotional, and social needs that motivated them to search for information on their conditions, and intentionally adapted their ways of seeking information to accommodate the changing circumstances of their dementia over time. They used the strategies of Active Search, Ongoing Search, Monitoring, Proxy Search, Information Avoidance, and Selective Exposure.

Conclusions: Participants indicated a desire to re-establish equilibrium (a state of balance between their mental framework and environment) by addressing basic physiological, social, and emotional needs, so they could best engage in life. This research unveiled the ingenuity, motivations, technical competency, changing abilities, and chosen strategies of people with dementia in their search for health information.

Our findings educate researchers, practitioners and online health resource developers on the factors that influence information seeking, to help improve services for people with dementia. Our work also guides those newly-diagnosed to better recognize their physiological, emotional and social needs so they may seek person-centered health information to address their disequilibrium.



187

Effects of bowel training and rational defecation posture on chronic functional constipation in older people with dementia: a multicenter randomized controlled trial

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Aims: This study aimed to clarify the efficacy and safety of care that combines bowel training and rational defecation posture for chronic constipation in older individuals with dementia.

Methods: In this multicenter randomized controlled trial, participants were given bowel training and rational defecation posture (establishment of regular bowel habits and leaning forward sitting posture) or regular care at random for 8 consecutive weeks. The primary endpoint was an increase in spontaneous defecation (SBM) and complete SBM (CSBM). Secondary endpoints were improvements in The Patient Assessment of Constipation Quality of Life Questionnaire (PAC-QOL) and Neuropsychiatric Inventory Nursing Home Version (NPI-NH).

Results: Of the 33 participants enrolled, 30 (mean age 88.7 years, 87% female, Mini Mental State Examination mean 10.7) completed the study. The change before and after the intervention of SBM showed no significant increase in the intervention and control groups (0.3±1.2 vs. -0.03±1.1; p=0.481). CSBM was significantly higher in the intervention group 1.3±1.4 than that in the control group -0.2±0.6 (p=0.001). PAC-QOL was significantly improvement in the intervention group than in the control group (p<0.001). NPI-NH showed a significant improvement in the intervention group compared to that in the control group (p<0.001). The frequency of severe treatment-related adverse events was 0%.

Conclusions: Bowel training and rational defecation posture increased the number of CSBMs and significantly improved quality of life and behavioral and psychological symptoms of dementia scores. These are considered to be effective as non-pharmacological interventions for chronic constipation in older people with dementia.

188

Tailored Pressure Injury Education for Caregivers (TaPIE-C) of older adults with advanced dementia

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

A pressure injury occurs when the skin and underlying tissues are damaged due to restricted blood flow from constant external forces or pressure. This is more likely to happen over bony areas, such as the sacrum and heel, and in fully dependent people, such as those with advanced dementia. During the COVID-19 pandemic, we observed an increase in older people admitted to hospital with severe pressure injuries. This was likely due to social restrictions resulting in reduced caregivers and support services, compounded by limited follow-up from community nursing visits. Within half a year, there were nine fully dependent older adults admitted with Stage 4 pressure injuries complicated by osteomyelitis. All were frail, malnourished, had advanced dementia and the clinicians had concerns regarding the care provided at home. All had moderate to severe pain and experienced prolonged hospitalisation for intravenous antibiotics and wound management. Two-thirds passed away in hospital.

We developed an educational programme for caregivers of older adults with advanced dementia called TaPIE-C (Tailored Pressure Injury Education for caregivers). It consists of a video containing the etiology, staging descriptions, risk factors and preventive measures, followed by an interactive evaluation of caregiver understanding. TaPIE-C is incorporated into virtual clinics under Geriatrics and Palliative services, and home-based nursing. It is hoped that this programme will improve the care of those fully dependent with advanced dementia and reduce the risk of developing pressure injuries.



189

Ethical and legal issues in the use of locating technologies to manage dementia-related wandering

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Wandering behaviour is common among people living with dementia. A risk associated with dementia-related wandering is becoming lost and going missing which can result in injuries or death and have negative impacts on care partners. Locating technologies such as a Global Positioning System (GPS) device can help locate missing persons with dementia quickly, thereby enhancing their safety while also supporting their participation in the activities important to them. However, the use of GPS devices has raised ethical and legal issues for care partners and health professionals. This paper examines the existing literature to understand the ethical and legal issues for care partners and health professionals in using locating technologies to manage dementia-related wandering; it provides recommendations to guide decision-making about the use of locating technologies. One concern about the use of locating technologies arise from the debates on whether people living with dementia have the capacity to provide consent. Also, there is the need to balance the safety of people living with dementia with their rights to autonomy and privacy, as well as dignity. The recommendations highlight the need for care partners and health professionals to collaborate with people living with dementia and incorporate their values and preferences when making decisions about using locating technologies. Advance directives can help ensure that the values and preferences of people living with dementia are taken into consideration when addressing issues related to consent.

190

Alzheimer's Disease Resemblance Atrophy Index in the Diagnosis of Alzheimer's Disease – A Phase Two Validation Multi-Database Study

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Alzheimer's Disease Resemblance Atrophy Index (AD-RAI) is a novel MRI-based machine-learning derived imaging biomarker that aims to comprehensively reflect the similarity of the individual brain atrophy pattern to AD. We aimed to validate and compare its performance with conventional structural imaging biomarkers in diagnosing AD with mild dementia.

Methods: We recruited 218 subjects with AD mild dementia and 1069 cognitive unimpaired(CU) subjects from 4 databases (ADNI, AIBL, OASIS 3, CU-SEEDS). We obtained the following imaging biomarkers using an automated computational tool (AccuBrain®): AD-RAI, hippocampal volume (HV), and hippocampal fraction (HF). We derived optimal cutoffs for these imaging measures from a training cohort consisting of subjects with known amyloid status. We then validated the measures in two separate cohorts, one with known and one with unknown amyloid status. We also investigated the association between the imaging measures with age and gender among CU subjects.

Results: At the derived optimal cutoffs, AD-RAI performed the best in diagnosing AD mild dementia from CU subjects in both amyloid known (AD-RAI: AUC=0.971; HV: AUC=0.944; HF: AUC=0.931) and amyloid unknown cohort (AD-RAI: AUC=0.912; HV: AUC=0.868; HF AUC=0.873). AD-RAI was not associated with age while both hippocampal measures were negatively associated with age. All three measures varied between gender.However, using age- or gender-adjusted cutoffs did not show additional improvement for AD-RAI and HF, while adjusted HV showed slightly improved performance.

Conclusion: AD-RAI is a valid MRI-based imaging measure that outperformed conventional quantitative hippocampal measures in the diagnosis of AD with mild dementia.



191

EXAMINING THE ROLE OF ARCHITECTURE IN RESIDENTIAL AGED CARE: FROM A SOCIO-SPATIAL PERSPECTIVE

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Despite the advancements in dementia friendly design, the interest in understanding the role of architecture is seldom from a socio-spatial perspective, in which architecture – as the primary spatial medium – is critically examined. In contrast, this paper uses the lens of Doreen Massey's spatial theory (Massey, 2004) to develop unique socio-spatial criteria, to critically examine the design, organisation and quality of spaces within residential aged care; by fundamentally asking:, *what might be possible ifa social value indexwas applied to designing spaces for older persons including those living with a diagnosis of dementia?* This question sits within a broader research project examining the role of architecture and the social function of environmental design in improving the lives and experiences of residents; by exploring the relationships between people, place and purpose in residential aged care communities. This builds upon the work of McLaughlin & Manolopoulou, *Losing Myself,* and the changes to spatial perception caused by dementia. The larger scope of methodologies in this research combines quantitative data of resident movements, visual material, and qualitative data about resident wellbeing and sense of place. This paper rethinks the role of architectural space and design, shifting from a functional and operational position to one which promotes and enables the wellbeing of residents. It offers a paradigm shift in thinking about the central role of space and architecture in the context of dementia friendly design, and how key understandings may be transferrable or considered in broader contexts, environments, and extended to our cities at large.

192

Audit of advance care planning in specialty clinics in Brunei for Alzheimer's disease

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Aims: To audit the documentation of advance care plans in clinical records of specialty clinics in Brunei for Alzheimer's disease (AD)

Methods: The national electronic records system, Brunei-Health Information Management System (Bru-HIMS), was used to extract a list of clinical encounters for ICD-10 diagnostic codes related to Alzheimer's disease. Each case was assessed for demographic details, type of specialty clinic and dementia severity based on the Clinical Dementia Rating (CDR) Scale. Three aspects of advance care planning were audited: discussions regarding enteral feeding, cardiopulmonary resuscitation and a named proxy decision maker.

Results: There were 168 individuals with a diagnosis of Alzheimer's disease. Median age was 80 years (Range 60 to 98 years), and 58.9% were female. The main specialties reviewing AD were geriatrics (61.3%), neurology (22%) and psychiatry (11.3%). Almost half were able to mobilise independently, while two-thirds had moderate-severe dementia. Among those with moderate-severe dementia, 9 (8.5%) received enteral feeding via nasogastric or PEG tube, and 60.4% did not have any documented discussion regarding feeding preferences. There were no documented discussions regarding preferences on cardiopulmonary resuscitation in the event of a cardiac arrest in 57 (53.8%), or a proxy decision maker in 72 (67.9%).

Conclusion: Advance care planning for people diagnosed with Alzheimer's disease could be improved in terms of initiating discussions and documenting preferences in clinical records, especially for specialty clinics and for those in moderate-severe stages of the disease.



193

Environmental design for dementia café based on Progressively Lowered Stress Threshold Model

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

'Dementia café' is a place providing dementia families with diverse services, support them living well with dementia for years. The focus of this study is to explore how planners undertake the practical design issues in real cases with design principles for dementia café.

To urge dementia families to achieve more opportunities in dementia café, the constructions of design principles was based on the Progressively Lowered Stress Threshold Model, which is for both care receivers and care partners. A focus group was recruit to discuss the contents, and 7 experts and scholars are invited to fill out expert questionnaire to sum up the design principles that should be emphasized. Finally, research team turned the principles into a checklist and assessed 4 dementia café in Taoyuan city inTaiwan, to bring all the above-mentioned issues in practice.

The research results show that the design of the dementia café should take the following principles into consideration: 1) Provide objects corresponding to the function of the area; 2) Provide interactive objects that can be used by several participants; 3) Provide ventilation equipment in the toilet and cooking area; 4) Provide space partitioning for group discussion; 5) Ensure that wheelchairs are allowed from the outside to the inside of the building.

In summary, the flexibility of use and the creation of familiarity are important to the environment of dementia café. By properly using items in place, the local lives of the dementia families and the services for them can be effectively supported in dementia café.

194

Needs of Psychological Care for People living with Dementia and Their Care Partners in Home-based Palliative Setting

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Aims: The standards of palliative care for people living with dementia in Taiwan must score 5 with Clinical Dementia Rating (CDR). Many studies have indicated that care partners and people with dementia face many emotional distress after diagnosis. This study thus analyzed the records from psychological services to understand the needs of people with dementia and their care partners in home-based palliative setting.

Methods: During 2018 to March 2019, a total of 37 participants who accepted home-based palliative care with psychological services. The demographic and clinical variables were both recorded by psychologists, which included (1) The four stages of palliative care: decision-making period, stable period, dying period, and acute grief period. (2) Themes of psychological services: care partners, people with dementia, whole family, medical teams, and others. (3) Types of psychological issues: acceptance of illness, stress response, medical communication, emotional distress, dying/death, family communication, grief counseling and other variables.

Results: People with dementia aged mostly 85-94 years old (48.6%), and only one-third of those who can actually receive psychological services. Most of patients and their care partners accept the psychological service is in stable period (67.6%). Their main psychological issues were emotional distress (27.0%). In addition, the main topic of care partners is stress response (27.0%), followed by emotional distress (16.2%).

Conclusion: People living with dementia in palliative setting have difficulty in verbal expression. Most care partners also have emotional distress and stress response, and have to assist patients to deal with conflicts and difficulties in medical decision-making.



195

Designing for Dementia - Experiences, Case Studies and Possibilities

Mr Frank Ehrenberg
Life3A, Brisbane, Australia

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

I am a Principal and National Director at Life3A.

As an advocate & leader in seniors living and aged care I have spoken on the topic of the delivery of 'age friendly & dementia friendly housing' both nationally and internationally. The global ageing issue requires a multidisciplinary approach and architecture is only a very small piece in the puzzle of finding equitable and appropriately holistic solutions. The 'World Alzheimer Report 2020: Design, Dignity, Dementia: dementia-related design and the built environment' includes three of Marchese Partners/Life3A projects (Gaynes Park,Glengara Care and Galleon Gardens) in a new International review of the best practice in design for those with dementia.

Life3A https://life3a.com/is a global consultancy dedicated to improving peoples' lives.

The organisation cares about the merits of the built environment, in the way they are designed and function so the people who live in them have choices and their wellbeing is improved. In his presentation Frank will provide a short overview of his time working in a German aged care facility, then describe the past and future landscape of aged care in Australia before moving on to explain the dementia design principles of the three projects that were included in the World Alzheimers report 2020 with a specific focus on Glengara Care. Frank will conclude with the exploration of possibilities on where the aged care sectors and models globally may evolve to in the future - based on some innovative design thinking on Life3A's global projects currently on the drawing board.

196

Ask Annie: Improving the knowledge, skills and confidence of home and community care workers through an app.

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Dementia Australia, Brisbane, Australia

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Over 70% of people living with dementia in Australia live in the community in their own homes. In parts of the world, policies are enacted to support 'ageing in place' to ensure that services are offered to support people living with dementia maintain a level of functional ability which is consistent with their basic rights and human dignities.

Care that is integrated, evidence-based and person-centred is required in all settings where people living with dementia live; this ranges from their homes, in their communities as well as long term assisted-living facilities.

For this to be successful the workforce needs to be adequately trained and qualified.

Dementia Australia recognizes the barriers that many home and community care providers experience in ensuring the workforce are adequately skilled to support the complex needs of people living with dementia to remain living in their own homes. One of those barriers includes the disruption to services to enable staff to attend face-to-face training.

Ask Annie is a mobile learning platform, which complements formal education, that uses evidence-based learning approaches of micro-learning and constructive alignment to deliver skills-based training to care workers right from their mobile phone.

This presentation will demonstrate how Ask Annie increases the dementia knowledge, skills and confidence of the home care workforce. It will also present future developments of contextualized learning content to improve the skills for a wider range of professionals who support people living with dementia across a broader range of settings.



197

Can health and ehealth literacy facilitate family carers in caring patients with dementia?

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: Carers need to take multiple health-related decisions everyday. The skills of accessing, appraise and applying information by friends, family, neighbors, healthcare professionals and other resources (e.g., websites, forums) can benefit them and enhance their quality of life. This study aims to identify associations among Health Literacy (HL) and eHealth Literacy (eHL) and other caregiving variables, such as self-efficacy, coping strategies, social support and attitudes towards caring.

Method: In total, 174 primary carers of people with dementia and 67 secondary carers participated in a descriptive correlational study, by completing a face-to-face survey for the level of HL, eHL caregiving self-efficacy (SE), coping strategies, attitudes towards caring and perceived social support.

Results: Carers reported a high level of eHL (29.21/40) and HL (13.64/16). The association of HL with eHL and SE was confirmed. Upper secondary educational attainment and above, being employed and reporting a secondary carer was associated with higher level of HL. Primary carers HL and eHL levels were not associated with secondary's HL and eHL. Three primary carers' profiles were extracted with cluster analysis.

Conclusions: Enhancement of HL and eHL could facilitate carers' in everyday caregiving. Healthcare professionals should consider measuring carers' level of HL and eHL and to enhance adequately, as this would facilitate their work and improve their communication with carers of people with dementia. Development of easy to use dementia-specific HL and eHL screening tools adapted for carers could be considered as an important next step in this research field.

198

An empirical legal study of nationwide court rulings of financial abuse involving persons with dementia

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

Aims: Persons with dementia (PWDs) can easily become a victim of financial abuse due to impaired mental capacity. This empirical legalstudy analyzes court rulings to identify characteristics of the financial abuse victim, perpetrators, and the types of assets involved in legal cases of financial abuse involving PWDs.

Methods: A computerized search of a national legal database was performed on all first-instance court rulings in Taiwan between 2010 and 2019 to establish a sample of 214 cases directly related to financial abuse involving PWDs. The bystander intervention model was used as a conceptual model to guide analysis regarding the role of bank staff in detecting cases of financial abuse involving PWDs.

Results: The majority of financial abuse perpetrators are family members, as opposed to outsiders, with half of the perpetrators being the PWDs' adult children. Transfer of real estate was found to be the most common legal issue, and land was the most common financial asset involved. Due to the traditional preference of holding onto property among Chinese older adults, the transfer of real estate was found to be the top legal issue rather than cash withdrawal.

Conclusions: Difficult intra-family relationships seem to pose a great risk of financial abuse involving PWDs since adult children were found to be the most likely perpetrators. In accordance with the bystander intervention model, bank staff were more likely to be suspicious of financial abuse involving a PWD when an outsider was regarded as the perpetrator.



199

Securing government trust, support and $AU229.4m funding for quality dementia care

Ms Maree McCabe
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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

In 2018 Dementia Australia declared a commitment to a Quality Care Initiative (QCI) in its Strategic Direction: Designing a New Future 2018-2023. Simultaneously, the need for aged care reform was formally recognised through the establishment of a Royal Commission into Aged Care Quality and Safety, September 2018-February 2021.

Aim: To secure a significant allocation of funding to transform dementia care in Australia through strategic government relations activity and leveraging the opportunity presented by Royal Commission.

The key policy document, The Roadmap for Quality Dementia Care (https://www.dementia.org.au/quality-care) was a result of the QCI and extensive consultations with people living with dementia and carers to define what quality dementia care looks like and how it should be delivered.

Tactics included: Engagement with key government stakeholders; traditional and social media; leveraging of events, and consistent championing of The Roadmap.

Results: The Final Report of the Royal Commission included all the dementia recommendations by Dementia Australia.

May 2021-2022 the Australian Government committed $229.4 million dollars over five years. A significant element will enable Dementia Australia to build clear and systemic dementia support pathways and build workforce capability.

By offering a clear solution to Government with a solid vision for the future, grounded in the input, wishes and inclusion of people of all ages living with all forms of dementia, their families and carers, Dementia Australia succeeded in securing funding for dementia that will improve the health, lifestyle and care outcomes for Australians impacted by dementia now and for many years to come.

200

SiMbok Project: Revealing the challenge of language barriers in early dementia screening

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Topic

Dementia awareness and friendliness: Language challenges and how to overcome them

Abstract

Background: Indonesia is a country consisting of thousands of islands, each with their own ethnicities and languages. Lack of public knowledge and awareness about dementia is prevalent in more remote regions of the country.

Objective: SiMbok (Lansia Lombok) Project, a collaboration between Alzheimer's Indonesia Foundation (ALZI) with its Nederland and Lombok chapters, aimed tobuild dementia awareness and early detection in the remote areas of Lombok island.

Methods: We initiated audiences with local government authorities to increase dementia awareness, conducted health and dementia screening in Taman Ayu Village, West Lombok. Thirty-five subjects underwent health checks and cognitive screenings using the Abbreviated Mental Test (AMT) - Indonesian version, which is suggested in the Minister of Health Regulation No.4, year 2019.

Results: The audiences resulted in the commitment of the local government to put dementia as a public health priority through dementia awareness programmes and education. Thirty-two elderly (mean age 71.89± 6.79 yo) were included in the analysis and 78.1% and 8% of all subjects were reported to have hypertension and hearing problems respectively. AMT mean score was 4.0± 1.6 (cutoff score <6) but might not be accurate as only 4 subjects could comprehend the Indonesian national language fluently and 90.6% were low educated.

Conclusions: This project paved the way for sustainable and collaborative dementia awareness programmes in Lombok, highlighting the need for the screening tools mentioned in the national regulation to be customized and translated into local languages to accommodate the limited comprehension of the Indonesian language in these remote areas.



201

A virtual avatar as a training tool for Caregivers

Dr Tanya Petrovich[1], **Mrs Kelly Burns**[1], Ms Jessica Norman[1], Dr Jessica Rivera-Villicana[2], Dr Maheswaree Kissoon Curumsing[2], Mr Andrew Vouliotis[2], Prof Rajesh Vasa[2], Prof Kon Mouzakis[2]

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Background: Most People Living with Dementia (PLWD) experience some form of communication impairment that reduces their ability to express their needs. When it comes to caregivers, having a conversation with a person living with dementia can be challenging.

Aims: To evaluate the effectiveness of a virtual avatar designed to educate caregivers about the importance of good communication principles when engaging with PLWD.

Methods: 23 caregivers trailed this training tool over an 8-week period. Participants were grouped in two cohorts: One using the avatar, and one using an online communication training course. After these interactions, both cohorts underwent Simulated Patient training. The evaluation methods included questionnaires and pre/post-training semi-structured interviews to assess the impact of these training tools on caregivers' communication practices.

Results: The results suggest that an avatar can improve caregivers' understanding of the impact of good communication practices on PLWD, and tends to be favoured by trainees over the online training module. Other findings are that (a) caregivers developed an emotional connection with the avatar and retained the learning after 8 weeks had elapsed, (b) caregivers implemented the learnings in their practice, and (c) the changes in care practice were well received by PLWD.

Conclusions: The avatar can be used to complement online communication training for caregivers to maximise their learning outcomes. Furthermore, the interviews in this evaluation unveiled recommendations to improve the avatar in future versions, such as the avatar's depth of conversation, more natural facial expressions, and more context regarding its background.

202

Exploration of risk factors for cognitive decline shared by couples and cognitive outcomes

Dr Hee Won Yang[1], Prof Jong Bin Bae[2,3], Prof Dae Jong Oh[3,4], Prof Bong Jo Kim[5], Prof Dong Woo Lee[6], Prof Jeong Lan Kim[1], Prof Jin Hyeong Jhoo[7], Prof Joon Hyuk Park[8], Prof Jung Jae Lee[9], Prof Kyung Phil Kwak[10], Prof Ji Won Han[2,3], Prof Ki Woong Kim[2,3,11]

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Aims: Although people and their spouses share many risk factors of cognitive disorders in their lifetime, it has been barely investigated whether shared risk factors mediate the shared risk of cognitive disorders within couples. This community-based couple cohort study identified the risk factors shared within couples and examined their mediating roles in the shared risk of cognitive disorders within couples.

Method: We included 784 older couples from the Korean Longitudinal Study on Cognitive Aging and Dementia (KLOSCAD) and a cohort of their spouses (KLOSCAD-S). We examined the mediating roles of factors shared within couples on the effects of one's cognitive disorder on spousal cognitive functions and risk of cognitive disorders using structural equation modeling. Cognitive disorder was defined as mild cognitive impairment according to the consensus criteria proposed by the International Working Group, and dementia was defined according to the Diagnostic and Statistical Manual of Mental Disorders 4th edition criteria.

Results: The cognitive disorder of the KLOSCAD participants almost doubled the risk of cognitive disorder of their spouses in the KLOSCAD-S cohort. History of head injury and age mediated the association between cognitive disorder in the KLSOCAD participants and their spouses' risk of cognitive disorder. Physical inactivity mediated the association through MDD. The risk factors shared within couples may mediate about three quarters of the spousal risk of cognitive disorders.

Conclusions: Identification and intervention of the shared risk factors of dementia within couples may reduce the risk of cognitive disorders in the spouses of people with dementia.



203

Sexuality of people living with dementia and their spousal caregivers

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Topic

Dementia research and innovation: Sex and gender - impact, research, policy

Abstract

The aim of Sexuality and dementia -survey (2019) was to find out what kind of sexual activity couple living with dementia have and what kind of worries they might have. I got responses from 22 people with dementia (PwD) and 52 spousal caregivers.

Couples living with dementia face more sexual dysfunction than other peers, but still, they seek less help with their problems. The obstacle to seeking help was both one's own shame and insecurity, but also the situation in the relationship and the disagreements between the spouses. In addition, many did not know where to contact for help.

Sex life was described as involving a lot of hugs, kisses and being close. About 30% also had coitus. The spousal caregivers see their partners differently as the disease progresses. They might have an intimate relationship with a new partner which causes both joy and guilt. More than 40% of the caregivers who responded to the survey considered the possibility of falling in love with another person.

Based on the survey and my own experience, there should be more talk about sexuality and sexuality counselling should be available to those who need it. Discussion about sexuality of PwD is very problem oriented. We might talk about hypersexuality and other problems but totally forget many welfare effects. It is important for the helper to have knowledge of both sexuality and dementia. It is essential to talk about sexuality at different stages of dementia.

204

Quantifying Resilience: Expressing therelationship between the community, the person living with dementia and unpaid carers.

Dr Julie Christie
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Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

This paper will address the issue of quantifying resilience in the context of dementia.Resilience tends to focus on the resilience of carers (Christie, 2016). Over time the resilience of the person with dementia has come into focus (Christie, 2020), amplified by the experience of COVID19 (Giebel et al.,2021).

It can be difficult to demonstrate resilience as a contributory factor or an output of programmes.Externally imposed views of resilience or what 'living well' with dementia means, can be unrealistic, and at worst, harmful. For example, a much, reduced vision of a good life to a *good enough life* which can lead to paternalistic approaches and predictable care pathways. Focus is needed on the individual person living their everyday life if we are to understand the richness of community development and community partnerships approaches to dementia support, and the role that resilience can play in this. Finding ways to make this story visible, enables learning and highlights the role that people living with dementia have, with the right opportunities, in making dementia friendly communities a reality.

The role of storied resilience (Christie, 2016) is a rich source of information in the search for resilience but so too is evidence of added value and social return on investment. This paper therefore describes a new approach to quantifying resilience, using examples from four studies: a resilience model for people living with dementia. a dementia assistance dog programme, a dementia-friendly cinema experience and an evaluation of a programme consisting of 40 dementia friendly communities.



205

Photo exhibition as a manner to increase dementia awareness in Southeast Region of Utrecht, The Netherlands

Dr Manik Kharismayekti, Mrs Amalia Fonk-Utomo

Alzheimer Indonesia Nederland Foundation, Groningen, Netherlands

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: Dementia awareness is a great importance in order to be able to identify dementia at an early stage and slow down the decline. This applies not only to the elderly community, but to different levels of society. The photo exhibition about dementia is considered as an interesting manner to improve the public awareness of dementia and encourage Dementia Friendly Community.

Aim: The photo exhibition aims to increase the public awareness of dementia in Southeast Region of Utrecht.

Methods: A photo exhibition of Cathy Greenblaat with the theme "Love, Loss and Laughter" was organized in commemorative of World Alzheimer's Month 2021 in four municipalities in Southeast Region of Utrecht, along with photo catalogue book and narration. To support the photo exhibition, various activities related to dementia were organized and managed by local organizations, such as: dialogues, sports, seminars, trainings, workshops and Alzheimer's cafes.

Result: In total, 150 photos have been distributed in various locations, both indoors and outdoors, such as on sidewalks, bookstores, libraries and senior care facilities, where people can easily reach them. There were about 5000 people who have seen this photo exhibition. This event attracted the attention of local and regional media such as radio stations, newspapers and TV. Several other areas were interested in making similar activities.

Conclusion: Photo exhibition is an effective manner to raise awareness about dementia in many levels of society. This event motivated the cooperation between local organizations and can be duplicated in other regions in The Netherlands.

206

The perspectives of people living with early Alzheimer´s disease: a person-centered assessment

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Introduction: Limited information is available on peoples' experiences of living with Alzheimer's disease (AD) at earlier stages. This study aimed to assess beliefs held by people living with AD (PLWA) about their condition and perception of quality of life (QoL).

Methods: A non-interventional, cross-sectional study was conducted in 21 hospitals in Spain. PLWA aged 50-90 years, diagnosed with prodromal or mild AD (NIA/AA criteria) and with a Mini-mental State Examination (MMSE) score of 22+, and a Clinical Dementia Rating-Global score (CDR-GS) of 0.5 or 1.0 were included. The Representations and Adjustment to Dementia Index (RADIX) was used to understand the beliefs of PLWA

Results: 149 PLWA were included (mean age: 72.3 ± 7.0 years; 50% female). Mean duration of AD was 1.3 ± 1.7 years. Mean MMSE score was 24.6 ± 2.1 and 87% had a CDR-GS score of 0.5. Most PLWA (58%) used a descriptive term relating specific symptoms to their condition (e.g., memory difficulties). 79% were aware of their diagnosis and 45% used AD as a diagnostic term. Ageing (21%), brain changes (21%), and hereditary condition (16%) were the most common reported causes. Mean QoL in AD Scale score was 37.9 ± 4.5. Stigma prevalence was 37%, 22% showed depressive symptoms and a feeling of hopelessness was found in 94%. Stigma, depression, and hopelessness, but not global cognition (MMSE) were correlated to lower quality of life.

Conclusions: A holistic understanding of the perspectives of PLWA at earlier stages may facilitate implementing optimised care that supports improved QoL.



207

Cognitive Stimulation Therapy (CST) in Mild to Moderate Dementia – Hospital Sungai Buloh, Kuala Lumpur, Malaysia.

Mrs Monica Francise Xavier
Sungai Buloh, Hospital, Kuala Lumpur, Malaysia

Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Background: The aim of CST is to stimulate and engage people with dementia, whilst providing an optimal learning environment and social benefits of a group. It consists of 14 sessions involving program of themed activities. CST program is offered as Geriatric day care services in Hospital sungai Buloh since August 2018. This cross sectional study aims to evaluate the efficacy of CST in our setting.

Method: The CST treatment involves 14 sessions of themed activities, running twice weekly. It is carried out over 7 weeks, led by trained nurses and an occupational therapist. The clinical effectiveness of CST were assesed by cognitive functions (Mini Mental State Examination-MMSE), communication (Holden communication scale-HCS) and quality of life (Quality of Life in Alzheimer's Disease-QOL-AD). Depression (Geriatric Depression Scale-GDS), activities of Daily Living (Modified Barthel Index-MBI, Lawton) and dementia behavorial functioning (Neuropsychiatric Inventory-NPI) were also assessed.

Results: 49 participants were recruited with a mean age of 71.6 years old. 60% were male. 46% were Malays, followed by 29% Indians and 25% Chinese. Paired t-Test revealed significant improvement in quality of life (p<0.00), communication(p<0.00), and behavorial functioning (NPI), (p<0.00). Significant improvement shown across the 3 communication subcategories: conversation (p<0.00), awareness and knowledge(p<0.001); and communication(p<0.00).

Conclusion: CST appeared to benefit communication, dementia behavorial functioning, and quality of life in the older persons with mild to moderate dementia. This provides evidence to support the use of CST as a routine program to complement patients with mild to moderate dementia in Hospital Sungai Buloh.

208

Dementia in Cultural Mediation - Improving quality of life through arts and culture

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Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

'Dementia in Cultural Mediation'(DCUM) is a transnational project driven by the increasing number of people living with dementia in Europe. Through learning from the rich body of knowledge and experiences in the field of arts, culture and dementia care that the involved partners from **Belgium, Denmark, Spain and The Netherlands*** have, the project has a clear ambition: *to reach out and engage local and regional cultural institutions, health and social authorities and end-user groups that want to embrace dementia in a more holistic way through cultural activities in order to create more dementia-inclusive communities.*

The 'Dementia in Cultural Mediation' initiative will deliver **three main outputs***:* an **opensource digital toolkit of good practices** shared through a customized website, audiovisual productions and social media, **didactic training material** and a **set of recommendations to contribute to future European efforts in the field of cultural mediation for people with dementia.** The recommendations are based on the project experiences and continuously reviewed by a European reference group consisting of experts in the field of dementia, research and the arts and end-users (informal caregivers and people living with dementia). In the presentation we will tell more about the project's deliverables and look ahead to future initiatives in the field of arts and culture for people with dementia based on the lessons learned.

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* *Vrije Universiteit Brussel, Belgium*
* *Odense Libraries and Citizens Service, Denmark*
* *Fundacion Instituto Gerontologico Matia-Ingema, Spain*
* *Healthy Ageing Network Northern Netherlands, The Netherlands*



209

Prevalence of sleep disturbances in people with dementia living in the community: A systematic review and meta-analysis

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aims: Sleep disturbances are common in people living with dementia. There is no systematic review or meta-analysis of the prevalence of sleep disturbance in people with dementia living at home. This study aimed to systematically review and meta-analyse the prevalence of sleep disturbances in people with dementia living in the community.

Methods: We searched Embase, MEDLINE and PsycINFO for studies reporting the prevalence of sleep disturbances in people with dementia living in the community. We meta-analysed the data and calculated the pooled prevalence of sleep disturbances. We also conducted a sub-group analysis of the prevalence in dementia subtypes and used meta-regression to investigate the effects of publication year, age, percentage of males, method of measurement, sampling strategy and study quality.

Results: Eleven studies fulfilled the inclusion criteria. The pooled prevalence of any sleep disturbance symptoms was 26% (95% confidence intervals, CI: 23-30%) and of clinically significant cases 19% (95% CI: 13-25%). The pooled prevalence of sleep disturbance symptoms was significantly lower among people with Alzheimer's disease (24%; 95% CI: 16-33%) than Lewy body dementia (49%; 95% CI: 37-61%). Meta-regression analysis revealed that none of the covariates moderated the estimates of prevalence.

Conclusion: Sleep disturbances are common among people with dementia living in the community. There was no change in prevalence over time, according to publication dates, suggesting that there remains no effective treatment. This highlights the need for the development of intervention strategies for sleep disturbances.

210

The co-design and development of a model for a National Dementia Registry: tracking meaningful outcomes to drive change

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Topic

Information systems for dementia: Registries

Abstract

Aim: The Irish National Dementia Strategy (2014) commits to increasing the evidence we have on dementia in Ireland to improve dementia care management and outcomes for people living with the condition. This project, funded by the National Dementia Office, Health Service Executive through the Department of Health, aimed to develop a national dementia registry model that is workable within an Irish context.

Method: Co-design workshops with the active and meaningful involvement of a diverse range of stakeholders including people with dementia were used to: agree the scope of the registry, key outcome measures, a minimum dataset, data collection, storage, access and analysis processes, governance and quality procedures; develop and test the most appropriate technical design; and develop an implementation business case.

Results: Key outcome measures included a focus on the dementia diagnostic process, quality of life and wellbeing of the person with dementia and of their primary caregiver, and monitoring the use of antipsychotic and dementia medication. These outcomes drove the development of a minimum dataset consisting of data relating to personal characteristics, diagnosis, treatment and care. A phased implementation of a model that is interoperable and scalable was recommended, commencing with memory clinic data.

Conclusion: Standardising data collection through a modular and web based registry application that facilitates integration with other health systems over time is essential to track meaningful outcomes that will drive change, provide a foundation for quality enhancement and add value to our health system and most importantly, to people with dementia living in Ireland.



211

Policy making for dementia care in low and middle income countries: a comparison of dementia policy making in Malaysia, India and Tanzania.

Prof Michaela Louise Goodson[1], Prof Thomas Iype[2], Dr Joackim Kessy[3], Prof V Raman Kutty[2], Prof Declare Mushi[3], Dr Roshaslina Rosli[4], Prof Maw Pin Tan[4], Prof Louise Robinson[5], Dr Susan Moloney[5]

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Aims: Approximately 50 million individuals worldwide live with Alzheimer disease or related dementias, with numbers set to rise to 75 million by 2030. Only 32 nations have National Dementia Plans (NDP) with just four being in Low and Middle Income Countries (LMIC). This study mapped national policy and policy making processes for dementia care in India Malaysia and Tanzania, to inform impact planning for LMIC dementia researchers.

Method: Rapid scoping review undertaken between Jan- April 2021. All three countries used a standardised protocol including a policy making framework of agenda setting, policy formation, implementation, evaluation and monitoring. Scoping comprised internet and literature searches and remote interviews with key stakeholders identifying procedures, people, and challenges to policy development and implementation. Findings were summarised into three descriptive case studies for comparison, each supported by an illustrative flow diagram structured around the study framework.

Results: No country had existing dementia specific policy in place. Where dementia was mentioned this was typically within current Elderly Health and/or Ageing policy. Healthcare policy making within all three countries is complex, not always consistent, and not always accessible or transparent. Whilst varying in influence across LMICs external evidence (international research, global agendas) informed policy. Country autonomy and political power were key influencers on agenda setting in particular.

Conclusions: While these countries are attempting to develop NDP and policies with a local context, a more concerted systematic effort to holistically manage care and policy making is needed to ensure the viability and success of local dementia strategies.



212

New guidance has been produced by the University of Plymouth in conjunction with the Prime Ministers Dementia Challenge August 2021 to help dentists across England offer people living with dementia a better experience when visiting their practices.

Mr Ian Kenneth Grant Sherriff[1], Prof Christopher Tredwin,[2]

[1]SUPPORTED BY THE pRIME mINISTER, Plymouth, United Kingdom. [2]University Dental School, Plymouth, United Kingdom

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Dental practices across the UK can play an increasingly pivotal role in the broader care offered to people living with dementia. Not only do dentists see patients on a regular basis and can spot changes in their health and demeanour, but they can also flag up concerns that may otherwise have gone unnoticed.

Professor Christopher Tredwin, who is Head of Peninsula Dental School at the University of Plymouth and a practising dentist and Ian Sherriff B.E.M, MA,DMS, CQSW, DipCll , point out that while people go to the GP when they are ill, they often attend the dental surgery when they are 'well' as part of routine check-ups.

"Dentists see people over and over again and see how people develop over the years," he says. "When you see people routinely you can watch for changes and adapt to those changes. A key change we see as a dental profession is dementia; we can be one of first to recognise those changes in patients and become an early 'screen' and be able to say if something is different and look at how can we help."

That means dentists can adapt their approach to people who already have a dementia diagnosis, but also refer patients to other healthcare professionals for further help. There is also a recognition that dental practices can be stressful places to visit, so an understanding of how to respond to patients with dementia can help improve their experience.



213

Assessing the performance of a community-based memory clinic in detecting dementia among the elderly- a pilot study

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Hospital Kuala Lumpur, Kuala Lumpur, Malaysia

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Background and Aim: The issue of cognitive impairment has placed a high burden on Malaysia's healthcare system, as many were undiagnosed and treated late, leading to unwarranted complications for patients and caregivers. A pilot program was established in Malaysia, in which a community-based memory clinic was set up in a primary care setting to help improve the early detection of cognitive impairments among the elderly in the community. This presentation aims to assess the performance of the community-based memory clinic in playing the role of detecting cognitive impairments among the elderly.

Methodology: Data was gathered from 2020 until 2021. A total of 12 patients were referred by the primary clinic physician to be followed up in the memory clinic during the data collection period. The cognitive status of the patients referred was assessed by a multidisciplinary team, led by visiting geriatricians, using established dementia screening tools. The diagnosis was also supported through laboratory and radiological findings.

Results: Up to 58.3% (n=7) of the patients referred were detected to have cognitive impairment issues. Among those who had cognitive impairment issues, 2 (28.6%) had mild cognitive impairment, 2 (28.6%) had vascular dementia, 2(28.6%) had Alzheimer's dementia, and 1 (14.3%) had mixed dementia.

Discussion and conclusion: The community-based memory clinic has shown to be promising in detecting cognitive impairments among the elderly. In the future, the expansion of this program can be considered to mitigate the issue of late detection and undiagnosed cognitive impairments among the elderly in the community.

215

A triangulated study on non-pharmacological management of Alzheimer's disease in Mauritius

Dr Geeta Devi Dorkhy
Association Alzheimer Mauritius, Port Louis, Mauritius

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Mauritius faces a demographic change and a rise in population of senior people, of 7.5% above 65 years. Currently 14,000 people with Alzheimer's disease (AD), show very modest improvements with pharmacological therapies.

Aim: The main study aims at the outcomes of NPT in terms of cognitive power and functional states in the NPT of AD. Secondly, to find the quality of life of the participants in view of NPT and finally, to have correlation of data.

Method: Participants were recruited from Alzheimer's Association Mauritius who have been on NPT. Mixed studies using MMSE, ADI and IADL pre-validated questionnaires in quantitative study. Qualitative data was audio-recorded using a smartphone and interacting with the participant using a set of questions addressing their level of activities, leisure time spending and assessment of MMSE. Triangulation of studies in quantitative study in terms of cognitive and functional states and thematic analysis in qualitative studies thus finding meaning in qualitative data.

Result: Quantitative data (n=42) analysis showed a statistical decline in higher function (IADL) with respect to decreasing cognition. 7 main themes, such as "like music", "family", "dependency", in qualitative study (n=20). Mixed study results showed 6 out of 7 main themes matched with cognitive states in AD as well as functional states in AD.

Conclusion: NPT is an effective tool in the management of AD in Mauritius. The long-term effects with integrated NPT interventions, is of eminent need.



216

'Late-life brain health architecture: leveraging convergence science principles'

Mrs Fiona Walsh[1,2], **Mr Greg Walsh**[1,2], Dr Walter Dawson[3,4,5], Dr Harris Eyre[6,7,8,9,10]

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Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

A convergence science (transdisciplinary science) approach is needed to develop novel clinical solutions in late-life brain health and we highlighted the role of architecture in a letter to the editor of **The American Journal of Geriatric Psychiatry Volume 28, Issue 11**, November 2020, Pages 1221-1223. *The Multiple examples of innovation through convergence can be found at the intersection of engineering, science and architecture – from developing surgical suites that mitigate infection to designing paediatric wards to improve healing and safety. In both instances, there was a knowledge gap in the importance of the built environment in enabling better health outcomes. An increasingly aged population and the number of people living with dementia demand we bridge divergent disciplines – this time between late-life medicine, brain health, neuroscience, and architecture, to allow people to function in spite of cognitive and sensory deficits.*

217

The lived experience of decision making of people living with dementia and family caregivers in Thailand.

Dr Natthawut Suriya
Srimahasarakham Nursing College, Mahasarakham, Thailand

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: The prevalence of dementia in Thailand is rising. the number is expected to reach approximately 1.2 million in 2030 (ADI 2014).Being diagnosed with dementia does not automatically imply that people lack all decision-making capacity, however, so they should be included when making everyday decisions that affect them. Such decisions provide a great opportunity for people with dementia to maintain their autonomy and express their preferences.

Aim: To investigate the experiences of people living with dementia and their family caregivers

Method: A qualitative approach applying Interpretive Phenomenology Analysis (IPA) was adopted. Eight dyads (i.e. eight people living with dementia and their primary family caregivers) were purposively recruited through the primary care clinic at Mahasarakham Hospital, Thailand.Each interview was digitally recorded, and the data from the interviews and observations were analysed in their original language using Nvivo.

The findings: the value of familial responsibility reinforces the expectation of filial care from children. This obligation is embodied in the cultural norm of filial piety, and it plays a role in avoiding conflict and maintaining a good, harmonious relationship between children and their elderly parents. Caregivers seemed to take over decisions about difficult tasks, because safety always trumps autonomy.Providing the opportunity to be involved in decision making can foster a positive attitude in people with dementia.

Conclusion: Filial piety is a core value when caring for a parent living with dementia, so this also informs their decisions. People living with dementia also expect their children to take responsibility for supporting them



218

Portable multisensory toolkit to engage people living with dementia

Miss Esther Olorunda, Prof Rachel McCrindle

University of Reading, Reading, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

A major manifestation of dementia, especially in its advanced stages is the exhibition of passive behaviour. Many people living with dementia spend their days unoccupied and under-stimulated which can be detrimental to their well-being and quality of life. The use of non-pharmacological interventions such as multisensory rooms have been shown to have great benefits in engaging people living with dementia. However, multisensory rooms have some shortcomings such as their high cost of implementation and lack of portability.

AMuSED is an Active Multi-Sensory Environment for people living with Dementia. It is an exciting and innovative non-pharmacological intervention for providing engagement, stimulation and social interaction to people living with dementia to mitigate the behavioural and psychological symptoms of the condition such as apathy and agitation.

AMuSED combines the concept of multisensory rooms with activities and incorporates the use of multimedia, sound, taste, and tactile stimulation through a set of themed elements, activities, and reminiscence tools to keep people engaged. It is affordable, portable, adaptable to fit the severity of a person's dementia and personalisable to their interests. A range of themed AMuSED boxes such as seaside, entertainment, movie, countryside, and life have been developed to fit different needs and provide variety.

This intervention was developed in Reading, United Kingdom and co-created with experts in the dementia field. It has been evaluated in various care facilities across Reading and the Berkshire area and has been incorporated into the dementia chatty café at the Museum of English Rural Life (MERL).

219

How should we provide support for double carers who simultaneously care for and raise children of people with dementia?

Prof HIROFUMI WATANABE
Musashino University Faculty of Human Sciences, Tokyo, Japan

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Objective: To clarify the difficulties and factors of double carers: carers who simultaneously care for and raise children of people with dementia, and to examine the support they need. Double care is a term coined by Soma and Yamashita (2012). In a narrow sense, it refers to the condition in which one person has to perform both childcare and nursing care at the same time, mainly alone.

Method: Interviews were conducted with double caregivers selected by snowball sampling. The survey was conducted between October 2020 and January 2021. This survey was conducted with the approval of the ethical review of Musashino University's Institute of Human Sciences.

Results: 17 cases were collected. Discussion: As a result of the qualitative analysis of the collected cases, the most burdensome period was when the worsening of BPSD (behavioral and psychological symptoms of dementia) became apparent, and when troubles with children during childbirth and childcare (e.g., non-attendance at school) and other burdensome care occurred. This was due to the fact that the nursing homes, hospitals, and childcare support organizations involved were not providing support in fields other than their own. It is necessary for the agencies involved in the support to go beyond their own areas of expertise and share risks and how to avoid them with the double caregivers in advance, to improve their coping skills, and to support them in spreading the burden involved in care.This research has been performed as a special study fund of Musashino University.



220

An Online Health Management of Cognitive Impairment Population Education Program for subjective cognitive decline older adults: A Mixed-Methods Approach.

Prof Junyu Zhao
Fujian Medical University, Fuzhou, China

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Background: Cognitive Impairment is a common public health concern amongaging society, and the dysfunctional situation among the older population is serious in mainland China. Educational and therapeutic programs delivered online were used more often in Western countries, and accessible programs in China are limited, especially for cognitive health management among older adults. Objective:This study aimed to (1) providecognitive health-related knowledge and self-exercisesstrategies, (2) help participants reducestressand improvecognitive-related emotional well-being, and (3) explore participants' learning performance and the acceptability of the onlinecognitive healtheducation program.

Methods: 42 older adults (mean age, 65.58 years) with subjective cognitive decline within past 1 year attended a 6-weeks Online educational program that included basic knowledge of cognitive impairment, pharmacological and nonpharmacological treatments. All participants rated the program as highly acceptable and therapeutic (mean score 5, on a scale of 1 to 5). Group discussions and interviews with participants further demonstrated high satisfaction and acceptability of the program format, setting, process, and structure.

Results: After completing the educational program, more than half of the participants showed acceptance of and satisfaction with the program, and they were willing to recommend the program to others.

Conclusions: Our findings highlight the significant potential of this online education program in the treatment of cognitive health management.

221

Psychiatric and cognitive signs and symptoms in idiopathic normal pressure hydrocephalus (iNPH): a systematic review and meta-analysis

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aims: To conduct a systematic review and meta-analysis of the psychiatric and cognitive signs and symptoms in people with probable or possible idiopathic normal pressure hydrocephalus (iNPH) and estimate their prevalence in order to increase identification and differentiation of a potentially reversible cause of dementia from other dementias.

Methods: We will search PUBMED/MEDLINE, Embase, Cochrane, PsycINFO and CINAHL from inception to search date, without language or study type restriction, including only peer-reviewed publications. We will use the Newcastle-Ottawa Scale (NOS) tool to assess study quality. Key descriptive data extracted will include author, year, country, setting, participant number, age, sex, study design, diagnostic criteria, classification of iNPH, timing of assessment, follow-up time, comparison group, number of cases, response rate. Outcome data will include number of symptoms or signs, proportion with cognitive deficits, domains of cognitive deficits, how features were measured, whether treated. Statistical analysis to calculate pooled point estimates for signs and symptoms will depend on what data are available. Odds ratios or relative risks will be calculated when comparator groups are available. Mean scores for cognitive tests will be reported and effect sizes will be calculated if comparator groups are available. We will use the I^2 statistic to assess heterogeneity and if appropriate we will use random effect models for meta-analysis. We will provide a narrative synthesis of findings.

Results: Results will be presented.

Conclusions: We hypothesise that iNPH will be associated with undiagnosed reversible dementia and psychiatric and cognitive abnormalities which will help guide future diagnosis and management.



222

Improve Dementia Friendliness by Virtual Reality Experience

Mrs NAI-YU LIN, Dr CHIEN-LIANG LIU

Taipei City Hospital, Taipei, Taiwan

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Purpose: Improve people to use the right way to communicate and interact with people with dementia.

Method: Use Virtual Reality (VR) positive and negative videos as teaching materials to simulate the problems that may occur in the daily life of people with dementia. Which makes people more friendly and empathetic to sympathize with dementia patients and caregivers, and able to correctly use the dementia interaction and communication skills slogan" STE2P", pioneered by the Dementia Center of TAIPEI CITY HOSPITAL. It's ``smile, thanks, eye contact, embrace the moment, patience" dementia interaction and communication skills, effectively promoting people's dementia understanding of dementia and improving public literacy of dementia.

This VR video was shot in a first-person perspective, when people experience the difficult situation of patients with dementia, the people around them interact with them in an inappropriate way of interaction. if I am a person with dementia, how do I view this way of interaction?

Result: We organized six VR experience events in twelve administrative districts of Taipei City. A total of 303 people participated. 92.7% of people think that VR experience can improve their dementia awareness, and their satisfaction with overall activities is 91.5%.

This film is the pioneering VR film shot from the perspective of a person with dementia in Taiwan.

223

Establish Dementia-friendly Wards

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Background: In Taiwan, more than 290,000 people has been suffered from dementia. People with dementia are highly frequent users of hospitalization resources. As study shows that 20% to 25% dementia patients are over 70-year-old; 47% of them are over 90-year-old. Current general ward is not the ideal environment for dementia patient. Therefore, we are looking forward to building a dementia-friendly ward for these patients through integrating a interprofesstional team.

Methods: Steps for establishing dementia-friendly wards:

Step 1: Establish a interprofessional team for dementia patient, including neurologist, rehabilitation physician, nurse practitioners , speech therapist, occupational therapy, physical therapist, dietitian, pharmacist, case managers of dementia , well-trained volunteers.

Step 2: Education to nursing staff and nursing assistant for dementia care concept.

Step 3: Conduct dementia ward activities, which is letting dementia patients participate in daily activities during hospitalization, providing support and care skills to family members and caregivers.

Step 4: Space reconstruction: The multi-function activity room and consultation room are comfortable spaces for dementia patients and their families for daily activities.

Step 5: Develop standard operating procedures related to dementia care, including standard operating procedure for determination of dementia during hospitalization, dementia nutrition assessment, etc.

Results: 1. More than 400 dementia patients and their families has participated in dementia ward activities

2. 100% satisfaction for joining dementia ward activities

3. 99% satisfaction for activity spaces

4. 100% satisfaction for volunteers who assisting the activities

5. Overall 27 Dementia Care Standard Operating Procedures are developed.



224

Creating a Collaborative Centre

Mrs Alison Jones
Carers Trust North Wales, Colwyn Bay, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Importance of peer supporting and living well with dementia

Abstract

In 2016 we were commissioned to deliver a post diagnostic dementia support service across the six counties of North Wales to individuals living with Dementia and their unpaid carers.

One consistent message we heard from the individuals and families we have supported is that people living with dementia wanted their own Centre, where everything and anything regarding their diagnosis and dementia journey can be dealt with, a one stop shop for dementia care in a non-healthcare setting.

In collaboration with individuals living with dementia and their unpaid carers, we opened a North Wales Dementia Centre in June 2021, and in just five months over 800 people have walked through our doors. The Centre is funded by our own charitable funds and donations and offers social groups for individuals with dementia and their carers to attend together, carers' breaks where the person with dementia spends the day at the Centre, and drop in facilities where people can receive information and advice. We are fully co-productive with our users and our long-term plans involve offering short –term overnight respite; providing low level health interventions; offering benefits advice and support with completing forms; providing advocacy services, hosting bathing, hairdressing and chiropody services. We hope the benefits of the Centre will include reduced hospital admissions, reduced reliance on Social Care services, and will help to prevent carers reaching crisis point thereby keeping families together at home for longer.

We have recently been recognised at the Senedd as a 'best practice model' for the future.

225

Assessing quality of life in advanced dementia with the Quality of Life in Late-stage Dementia (QUALID) scale.

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Background: There has yet been a well-validated scale to assess the quality of life (QoL) in advanced dementia in Singapore. We sought to establish the psychometric properties of QUALID for assessing the QoL in patients with advanced dementia who live at home.

Methods: Data from 215 subjects[mean age±SD83.6±8.2years]in the "Panel study Investigating Status of Cognitively impaired Elderly in Singapore" were included.Principal component analysis (PCA) with varimax rotation was applied to assess the factor structure. Construct validity was performed by correlating QUALID with Bedford Alzheimer Nursing-Severity Scale (BAN-S) and Cohen-Mansfield Agitation Inventory (CMAI).

Results: The median of QUALID score was 22 (interquartile range 17-27). QUALID showed acceptable internal consistency overall (Crohnbach's α=0.77). PCA identified two factors accounting for 53.2% of the variance. The first factor was 'Emotion' (items were: facial expression of discomfort, appears physically uncomfortable, verbalization implying discomfort, being irritable and aggressive, appears calm, appears sad, cries, facial expression of discomfort). The second factor was 'Well-Being' (items were: smiles, enjoys eating, enjoys touching/being touched, enjoys social interaction). QUALID moderately and modestly correlated with CMAI (ρ=0.463, P <0.01) and BAN-S (ρ=0.305, P <0.01).

Conclusion: The QUALID has adequate reliability as well as construct and factor validity for assessing patients with advanced dementia in Singapore. It sets the stage for QUALID as a useful outcome measure in clinical care and research in this group of patients.



226

Dementia representations and well-being among people living with dementia and care partners in Great Britain

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aims: People experiencing an illness make sense of it in different ways, called 'illness representations'. We explored how people living with dementia and care partners make sense of the condition, and whether this is linked with well-being.

Methods: We talked to people living with dementia and developed a structured interview based on what they told us. We used this with 1,109 people living with dementia and 1,264 care partners in the British IDEAL cohort.

Results: We found that people living with dementia held one of 5 'dementia representations'. Some saw their condition as a disease with a medical name such as Alzheimer's (11%), some saw it as a disease but did not use a medical term for it (50%), some saw it as part of normal ageing (10%), some were unsure about it (22%), and some said they had no difficulties (7%). People who used a medical term tended to be younger and do better on cognitive tests. However, people who saw their difficulties as part of ageing, were unsure, or thought they had no difficulties scored higher for well-being and were less likely to be depressed. Care partners who viewed the condition as part of normal ageing or were unsure, and who thought something could be done to control its effects, scored higher for well-being and were less stressed.

Conclusions: This raises questions about what kinds of 'dementia representation' are helpful, whether some 'dementia representations' are harmful, and how to enable people to develop a helpful 'dementia representation'.

227

tide's Training programmes for health & social care professionals

Mrs Linda Gill, **Mr Micheál McLaughlin**

tide, Liverpool, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

tide – together in dementia everyday

tide offers training programmes for Health & Social Care professionals and family & friends carers.

We offer carer led, co-produced tailored training for the health & social care sector, aiming to improve the quality of life for people with dementia. We have a range of training modules aimed at supporting the best level of care possible for those with dementia, focusing on the following topics;

Knowing Me Pro

- 3D's - Dementia, Delirium and Depression
- Relationship-Based, Person-Centred Care
- Purposeful Activity
- Responding to Distress
- Adapting the Living Environment

Life Story Work

Professionals learn how Life Story Work can be a valuable tool in providing relationship-based and person-centred care and support.

- An in-depth Introduction and Carer's Story
- The Principles; Concerns, Consent, Confidentiality and the Outcomes
- Ideas for Getting Started, Practical Tips and Techniques.

Distressed Behaviour

- Terminology and Communication
- Cause of Distress
- Personalised Approaches to Assessment
- Strategies and Practical Approaches

During our presentation, you will learn more about our training programmes and how they are helping professionals in the community, clinical and residential care settings deliver even higher levels of person-centred approaches to those with dementia in their care.



We also will share with you how we support family & friends carers. We do this through a range of webinars commissioned by organisations for their staff who are also carers, informing them about dementia and specific issues which affect their role as a carer.

228

tide's Carer Development Programme

Mrs Eleanor Margaret Connelly[1], Mrs Linda Gill[2], **Mr Michael McLaughlin**[1]

[1]tide, Glasgow, United Kingdom. [2]tide, Liverpool, United Kingdom

Topic

Support for dementia carers: Education and training for informal carers

Abstract

tide – together in dementia everyday, is the voice, friend and future of all dementia carers, including family and friends, past or present. We are here for carers by supporting, listening, training and creating change.

Unpaid dementia carers do the hardest job in the world. Our training helps ensure they have the skills and knowledge to keep going, even in the toughest of times.

We work with carers and former carers; to create, design and develop content for our Carer Development Programme.

Our Carer Development Programme is a series of online workshops looking at everyday aspects of life as a carer.

Training sessions cover subjects carers have said they would like more support with:

- Emotional Wellbeing
- Ask, Negotiate, Advocate
- Living Grief and Bereavement
- Moving Forward into Residential Care
- Setting up Local Groups
- Influencing as a Group
- Presenting to Influence

Our training sessions are great opportunities for carers to learn more about their caring role, gain knowledge, skills, confidence and empowerment to help them create real change for all carers.

Following training sessions, carers also have the opportunity to spend time with other carers, with whom they might not have had the chance to meet face to face; this allows them to build a support network of their own and benefit from shared experiences and knowledge.

We ensure carers have the confidence to request the help and support they need, ensure their voices are heard and recognised by professionals for their Lived Experience.



229

Effects of Humanitude Training for Formal Caregivers of Persons Living with Dementia in the Hospital on Burnout, Empathy and Attitude towards Dementia

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aims - It is not uncommon for formal caregivers of persons living with dementia (PWDs) to experience burnout and job dissatisfaction. Humanitude is a relationship-centred and compassionate care approach that focuses on the communication between PWDs and formal caregivers. This study investigates the effects of Humanitude training on formal caregivers' burnout, empathy and attitude towards dementia.

- **Methods: Design:** Single arm pre-post implementation study
- **Setting**: Acute care hospital
- **Participants**: 137 formal caregivers (doctors, nurses and rehabilitation therapists)
- **Intervention**: Humanitude course was conducted over four consecutive days by a certified Humanitude trainer. The training includes the theoretical foundations of Humanitude and hands-on practice with in-depth analyses of the methods used by the formal caregivers to optimise care for PWDs.
- **Measurements**: Abbreviated Maslach Burnout Inventory (aMBI), Jefferson Scale of Empathy (JSE) and Dementia Attitudes Scale (DAS).

Results: Formal caregivers had lower aMBI score after Humanitude training (15.44 ± 7.66) compared to before Humanitude training (17.61 ± 8.053), a statistically significant decrease of 2.175 (95% CI, -3.095 to -1.255), $t(136) = -4.677$, $p < .001$. Humanitude training also elicited a statistically significant median increase in total JSE score from before training (110) to after training (120), $z = 6.995$, $p < .001$, and in total DAS score from before training (60) to after training (67), $z = 7.977$, $p < .001$ and DAS, $z = 7.977$, $p < .001$.

Conclusion: Humanitude training for formal caregivers reduces burnout, enhances empathy and improves attitudes towards dementia. This can potentially improve care for PWDs in the hospital.

230

Novel brain PET device for early onset Alzheimer diagnostic

Dr Jannis Fischer, Dr Max Ludwig Ahnen, Dr Stefan Bircher

Positrigo, Zurich, Switzerland

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Introduction: Dementia is a major problem in our aging societies, affecting around 50 million people worldwide and causing costs of nearly 1 trillion USD per year. Early diagnosis of Alzheimer's disease (AD) which accounts for 60% - 80% of patients with dementia is crucial and positron emission tomography (PET) is considered an important diagnostic modality. However, current scanners are whole body, expensive devices with limited availability resulting in more than 75% of people with AD to remain undiagnosed. We describe a dedicated brain PET scanner which is small and affordable with the goal to make PET more widely accessible.

NeuroLF – a dedicated brain PET device

NeuroLF is based on BPET which is an ultra-compact fully integrated brain PET system. The device consists of a detector head which can be moved and positioned to fit each patient and a comfortable chair to allow for high patient comfort. The device is movable to allow for various clinical settings. In a recent in-vivo study, data of 10 subjects injected with [18F]-FDG or [18F]-FET were acquired immediately after a clinical PET/CT scan on a 5-ring LYSO-based commercial reference PET (rPET) scanner. The results of this usability study are promising and support the use of a dedicated brain PET device for AD diagnostic.

Conclusion: NeuroLF is a brain PET device which is smaller and more affordable compared to full body scanners making it a valuable diagnostic tool in AD diagnostic.



231

Worry and rumination's association with cognitive health and physical health in older adults at risk of dementia

Ms Rachel M Morse[1], Ms Freya Koutsoubelis[1], Mr Tim Whitfield[1], Ms Harriet Demnitz-King[1], Mr Valentin Ourry[2], Dr Joshua Stott[3], Dr Anne Chocat[2], Ms Eglantine Ferrand Devouge[2], Dr Zuzana Walker[1], Dr Geraldine Poisnel[2], Dr Olga Klimecki[4], Dr Fabienne Collette[5], Dr Gaël Chételat[2], Dr Julie Gonneaud[2], Dr Natalie L Marchant[1]

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Worry and rumination are putative determinants of cognitive and physical health in older adults. This study aimed to establish whether worry and rumination are related to subjective perception and/or objective measures of health in older adults with subjective cognitive decline, a population at increased risk of dementia.

Method: Baseline data from141 participants from the SCD-Well RCT were used(91 female; Mage=72.7 years). Rumination and worry were measured using the Ruminative Response Scalebrooding subscale and the Penn State Worry Questionnaire, respectively. Subjective physical health was assessed using a physical quality of life measure (WHOQoL-Bref subscale), and objective physical health via modified versions of the Framingham Risk Score and Charlson Comorbidity Index. Subjective and objective cognition were assessed using the Cognitive Difficulties Scale and a modified Preclinical Alzheimer's Cognitive Composite, respectively. Linear regressions, adjusted for education, age, and sex, were conducted.

Results: Worry and rumination were negatively associated with subjective physical (worry: β=-0.10, p=0.005; rumination: β=-0.49, p=0.002) and cognitive (worry: β=-0.01, p=0.047; rumination: β=-0.09, p=0.007) health. No associations were observed between worry or rumination and objective physical or cognitive health.

Conclusions: Worry and rumination are common cognitive processes associated with subjective but not objective physical and cognitive health in older adults at risk of dementia. Declining subjective health can predict subsequent declines in objective health (cognitively and physically). Interventions reducing worry and rumination may thus promote both subjective and objective physical and cognitive health. Additional research is needed to determine whether these relationships are causal or associative.

232

Resilience building for family care-givers

Mrs Lynda Hutton
University of Stirling, Stirling, United Kingdom

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Dementia is a global concern, and with no cure as yet, how can we best support those living with dementia?

The Dementia Services Development Centre (DSDC) has developed evidence based dementia education to help support care-givers with practical hints and tips. Promoting well-being through a bio-psycho-social model of care that can help preserve personhood and acknowledge the importance of psychological and social wellbeing of the person. Developing interventions and strategies of support in their caring role and building resilience to help cope and maintain or improve quality of life for both the person and themselves.

For post diagnostic support (pds) to be effective we need to give more consideration to how we best support family care-givers, and education for families is vital for pds to be effective. Understanding the impact dementia has on the person and how it interrupts the way in which the brain works can help care-givers understand why a person may present in a certain way, and to consider the impact of dementia from the perspective of the person.

Developed as face to face educational workshops in 2017, our delivery method had to change due to Covid 19, to ensure continued support for families. The delivery model now lends itself to blended learning, with the incorporation of online delivery, promoting flexibility, cost effectiveness and wide reaching capabilities which could also lend itself to being multilingual.

Methods used for the workshops were both quantitative and qualitative.

An independent evaluation of the project will be available by March 2022.



233

From Carer to Cared for

Miss Marguerite Keating
The Irish Dementia Working Group, The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: Marguerite Keating is 58 and lives in Tipperary in Ireland. In 2019 Marguerite was diagnosed with young onset Alzheimer's disease. Marguerite is a member of the Irish Dementia Working Group (an advocacy group of people living with dementia)

Marguerite is a warm and caring person and spent much of her life working with people with disabilities. Marguerite's mother was born with polio and she says that gave her an insight in to supporting a person with a disability and the caring role.

Content: Marguerite used to work as a professional carer. When she received her diagnosis of young onset Alzheimer's disease, she felt she had to stop working. Marguerite has found the acceptance of no longer being the carer and allowing people to care for her has been the hardest part of her journey.

However, Marguerite is a resilient, passionate young woman who would like people to know how she has managed to stay positive and live a meaningful life. During the last three years Marguerite has discovered that positive mental health and well being has been the foundation of her success.

Marguerite realised her life was not over and when those around her tried to take the reins she found her resilience, used her strength, and stayed in control of her life. Marguerite has learned every moment is precious.

Marguerite would like to share her story, give people hope and help people realise that there can be 'Pocketsof fantasticness with Alzheimers'

234

A study of planning and design principles for the dementia unit care in residential long-term care facilities in Taiwan

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Residential long-term care facilities are an indispensable service in dementia care. A good living environment can help dementia patients maintain a certain quality of life. The focus of this study is to construct a practical design with proper planning principles in Taiwan.

In this study, inductive and focus group method are adopted for the environment of dementia unit care in residential long-term care facilities. First, research team studied several foreign cases and interviews 20 experts in related fields to sum up the critical level of residential facilities,18 experts and scholars are invited to carry out the focus group discussion and summarized the planning and design guidelines.

The research results show that the environments of dementia care unit should take the following principles into consideration: 1) Provide objects to identify the date and time; 2) Provide furniture with a sense of life; 3) Provide night floor lighting; 4) Provide monitoring point of entrances and living areas; 5) Provide group interaction area; 6) Provide walking path accompanied by relatives or friends; 7) Design must respect local culture; 8) Provide a place for healthy exercise.

In a word, the environmental features should be carefully planned for patients with dementia. By providing objects and furniture in each area, environment can urge them attending diverse activities. Also, the residential long-term facilities and the dementia care unit can be effectively supported in local lives.



235

Virtual consultations for memory clinic appointments – Breaking down barriers or creating them?

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Midlands Partnership Foundation Trust, West Midlands, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aims: The move towards virtual consultations has been accelerated due to the COVID-19 pandemic; however, the acceptability of this form of consulting to our population of older adults with cognitive impairment is unknown. This research aims to:

1. Explore the views of service users and their carers with regards to video consultations for memory assessments and reviews.
2. Identify any obstacles encountered during cognitive testing.
3. Propose a series of recommendations based on our findings to improve the accessibility and acceptability of video consultations to our study population.

Methods: Following a review of the existing literature, we created a 10-item questionnaire covering a wide range of aspects relating to the experience of virtual consultations. This questionnaire was disseminated to those individuals who had received a memory appointment (either a new assessment or follow-up) via a video consultation with the memory team over the past 12 months.

Results: The information gathered from the returned questionnaires will be analysed using both quantitative and qualitative methods.

Conclusions: This project will increase our understanding of how this novel way of consulting is perceived by service users and their carers. We acknowledge there will be unique challenges faced by those with cognitive impairment. By identifying these, we hope to discover ways in which this consultation medium can be adapted to better suit their needs.

236

Environmental scan of community-based programs for older adults in rural memory clinic communities and surrounding areas.

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University of Saskatchewan, Saskatoon, Canada

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Aims: In collaboration with primary health care teams in southeast Saskatchewan, rural memory clinics (RMCs) evolved in four geographical areas. This environmental scan focuses on local, community-based programs in these areas that RMC patients and families might use. Our goal is to identify and describe existing programs and gaps, create inventories/maps, and track changes over time.

Methods: The scan will be conducted at two time-points over 3 years using a multi-method qualitative design including focus groups with health care providers and managers, a review of secondary sources, and a systematic internet search. To date, the first time-point is complete, data were analyzed using content analysis, and results are presented. Recruitment is underway to interview people living with dementia (PLWD) and carers residing near RMCs.

Results: Thirty-seven services were identified, categorized into seven service types, and mapped by location. Most were Social/Leisure Activities (n=14), then General Support/Referrals (n=7), Transportation (n=7), Information/Education (n=4), Respite (n=2), Home/Personal Care (n=2), and Safety (n=1). Most involved no fees, referral by self or other, and a range of service provider education/training. Fourteen services (across 4 types) were offered remotely. There was a lack of in-person dementia-specific services.

Conclusions: Findings show a range of available services. This is a key step to creating service inventories/maps and tracking changes. Moving forward, the perspective of PLWD and family carers will deepen our understanding of their experiences with services/gaps. Findings may inform service delivery, future interventions, and improve participation in local programs.



237

Implementing User Friendly Technology to Maintain Relationships

Mr David Moore[1], Ms Anne-Sophie de Dreuille[2]

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

During COVID19, the restriction of families, friends and visitors was having detrimental effects on care home residents' mental health.Care professionals reported a risein residents showing or reporting signs of distress. However, keeping in touch via technology such as zoom or skype had mixed results, some residents struggled with telephone calls from families/ friends.

As a result, the dementia lead of MHA,the largest charity care provider for older people in the UK,decided to implement Famileo in all their schemes. It allows residents to receive steady news from their family on a paper format.Having something physical means it's tangible and residents can pick it up and reread it at any time.Each family upload content on the Famileo app. Once a week, these messages are turned into a personalised paper which is printed at the care home and distributed to the resident.

This tool is bringing families affected by dementia a great deal of comfort. Residents receiving family news this way have reported feeling valued and it has given them a sense of purpose which increased their wellbeing. Seeing old photos, snaps of life, babies, familiar places… contributes to a natural reminiscence therapy as it triggers the memory of residents. When they receive their newspaper they just light up.

The French company's product is used across Europe and North America by occupational therapists, dementia therapists, care home professionals; and is counting 160000 families using it to keep connected and memories alive.

238

Incidence of reported memory concern and cognitive decline in UK primary care and risk of developing dementia.

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University College London, London, United Kingdom

Topic

Dementia research and innovation: Epidemiology

Abstract

Aim: To investigate time trends in the incidence rate of recorded memory concerns (MC) and cognitive decline (CD) in a UK older population presenting to primary care with no prior diagnosis of dementia and determine their risk of developing dementia.

Methods: We included individuals aged 65-99 years who contributed to the IQVIA medical research database from 1st January 2009 to 31st December 2018. We reported crude incidence rates for MC (study population n=1,310,838) and CD (n=1,348,796). We conducted a Fine-Grey sub-distribution hazard model with competing risk of death to estimate the risk of developing dementia using complete case analysis.

Results: We identified55,941 patients (4.3%) with a record of incident MC; rates were fairly stable over the study decade. We identified 14,869 people (1.1%) with a record of incident CD, and these rates increased from 1.29/1,000 PYAR (95%CI 1.21 to 1.38) in 2009 to 3.49/1,000 PYAR (95%CI 3.30 to 3.68) in 2018. Within 3 years of follow up from the first record of MC, 45.5% of individuals received a dementia diagnosis, while people with a CD record, 51.7% received a dementia diagnosis.

Conclusion: Incidence rates of MC and CD estimated from routinely collected primary care data are lower than reported community surveys, suggesting that a minority of people who experience memory loss consult their GP about it. Our findings indicate that those who do report concerns to primary care, especially women, people from older age groups and more deprived areas, are at a higher risk for developing dementia.



239

How far can we adapt iSupport? Preliminary results from the cultural adaptation of an intervention for carers of people living with dementia in southern Switzerland.

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Institute of Public Health, Università della Svizzera Italiana, Lugano, Switzerland

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aims: iSupportis amodular, training and supportdigital health intervention designed by the World Health Organizationforcaregivers of peoplelivingwith dementia.Evidence is limited on how to culturally adapt and tailor online interventions to caregivers' needs.Our aimwastodesign a process foriSupportadaptationin southern Switzerland,toidentify andprevent possible barriers in using and acceptingthe intervention.

Method: We used acommunity basedparticipatoryapproachandmixed methodsto translate andadaptiSupport.WeestablishedalocalCommunity Advisory Board(CAB;N=11)ofinformal caregivers,and relevantstakeholderstochecksemantic and conceptualequivalenceofiSupport,using aLikert scale(1=revision needed/4=no revision needed)andopen comments.Further, we conductedsix focus groups with both formal (N=9) and informal(N=13)caregivers andusedaninductive thematic analysistoexplore the acceptability ofiSupportbased on localcaregiving knowledge,attitudesand practices.

Results: CABmemberssuggested content, language, and structural changesand agreed on thecultural appropriateness ofiSupport(mean=3.14). Focus groups confirmed an overall positive evalutation of the program andidentified potential improvements and facilitators for iSupport uptake and use,including additional contents, aless patronizingpedagogical approach, better account for the variability of caregivers'experiencesand contextualfactors.

Conclusions: Community based participatory approachesare indispensable to locally adapt iSupport,andto identifyuptake and usebarriers.Both the methods andresultsof our studyhave implicationsforiSupportimplementations worldwide.

240

Neuroticism is associated with higher levels of plasma neurofilament light (NfL) in healthy older adults.

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Topic

Dementia risk reduction: Risk factors

Abstract

Aim: The personality trait neuroticism (i.e., proneness to distress) is an established risk factor for Alzheimer's disease and related dementias. The underlying neuropathological correlates, however, remain unclear. The current study aimed to examine the association between neuroticism and blood plasma levels of neurofilament light chain (NfL; a putative biomarker of neurodegeneration) in healthy older adults.

Methods: Baseline data from 133 cognitively unimpaired older adults (Mage= 69 years; 62% female) enrolled in the Age-Well clinical trial was utilised. Neuroticism and other personality traits (i.e., openness to experience, conscientiousness, extraversion and agreeableness) were assessed via the Big Five Inventory, and blood samples taken for the quantification of blood plasma NfL levels using a Meso Scale Discovery assay. Linear regressions, adjusted for age and sex, were conducted to assess the associations between each personality trait and NfL.

Results: Higher levels of neuroticism were positively associated with plasma NfL levels after adjusting for age and sex (beta = 6.18 [95% CI: 0.46 – 11.90], *P* = 0.034). No associations were observed with the other personality traits and NfL.

Conclusion: This study advances knowledge on the association between neuroticism and underlying dementia-related neuropathology. Neuroticism may contribute to neurodegeneration; however, further research is required to determine the causal relationship.



241

Design for compound long-term care facility in Tainan County

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National Cheng Kung University, Tainan County, Taiwan

Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

Taiwan is an aged society from 2018, and Tainan County ranks second in the six capitals in terms of aging. The establishment of long-term care services and facilities in various regions has become extremely important, but there are still resources to be deployed in rural areas.

We investigated the long-term care needs of Yujing District in Tainan County and designed a composite long-term care facility. The first floor is a daytime service base, and 4 beds are set up to provide night care services. In order to strengthen the interaction between the demented elderly and the community, we opened up outdoor spaces and part of the first-floor space for community use, and set up a convenient storewith health care information stationand community rehabilitation center on the first floor. Also due to the impact of the covid-19 epidemic, in order to enhance the interaction between the elderly and their families, a video room was set up on the first floor, and a home treatment center was set up to provide in-home healthy services for the elderly in the community. The second floor is a unit-type dementia group home for 9 people, which provides living for elderly dementia with CDR 2 score and above. The shared space adopts an open design and a return corridor for residents to use, and a variety of activities are arranged. This design will provide more resources for the local aging of the elderly in Tainan.

242

(Re)connecting family and friends with people living with dementia

Ms Julia LE BRUN BILLANT, Ms Anne Sophie DE DREUILLE

Famileo, Saint-Malo, France

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Dementia is a challenge, every day, both for people living with it and for their loved ones.Keeping in touch via technology such as zoom or skype can be confusing, some residents struggle with phone calls from families and friends.

That is why, Famileo developed a solution to ease and enrich communication for people living with dementia. They receive steady news from their family on a paper format. Having something physical means it's tangible and residents can pick it up and reread it at any time. Each family upload content on the Famileo app. Once a week, these messages are turned into a personalized paper which is printed at the care home and distributed to the resident.

This tool brings families affected by dementia a great deal of comfort. Residents receiving their gazette have reported feeling valued and it has given them a sense of purpose, increasing their wellbeing. Seeing old photos, snaps of life, familiar places… triggers their memories: *"One resident, has a lot of trouble recognizing her children and many relatives. When she receives her Gazette, it is the absolute highlight of her day. She will point to each photo and state, "oh, oh, oh, I know you!" She will rub her fingers over all the photos saying, "this is my family." This is one of the reasons I love Famileo."*

Famileo is used across Europe and North America by occupational therapists, dementia therapists, care home professionals; and counts 160 000 families using it to keep memories alive.



243

Innovation in the outdoor visitor economy for living well with dementia

Dr Steve Owen, Dr Stephan Price, Dr Katie Ledingham. Presenting on behalf of the ENLIVEN team, led by Professor Linda Clare at the University of Exeter.

University of Exeter, Exeter, United Kingdom

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Getting out and about in nature is good for us. It helps us stay healthy and active, stimulates our brains, keeps us in contact with other people, and brings pleasure and joy to our lives. While the benefits of spending time in nature are well documented, people living with dementia say there are things that get in the way and stop them enjoying nature as much as they would like. There also remains little evidence surrounding which nature activities generate the greatest types of benefits and under what conditions. In this presentation, we present initial findings from ENLIVEN – an interdisciplinary project working with people with dementia, businesses and activity providers to co-create new services, experiences and innovations to increase accessibility and connectedness to nature. The project is funded under the UK Research and Innovation's Healthy Ageing Challenge. We discuss insights from our initial scoping of key issues and perspectives, highlighting the value of bringing together multiple stakeholders with people living with dementia to co-develop innovations to help create meaningful experiences and encounters with nature-based outdoor spaces at a national level.

244

Dementia-friendly research: Using ethnographic observations to explore the lived experience of people living with dementia

Dr Monica Leverton[1], Dr Alexandra Burton[2], Ms Jules Beresford-Dent[3], Dr Penny Rapaport[2], Prof Jill Manthorpe[1], Prof Claudia Cooper[2]

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

People living with dementia are the experts on their experience, yet they are often not included in research that informs their support and everyday practice. Ethnographic methods are a useful research tool to remove barriers to inclusion of people living with dementia in research. This work draws from 100 hours of ethnographic observations of home care for people living with dementia to help capture the reality of care as it is experienced by those involved. Observations enabled a deeper understanding beyond the scope of interview data to capture care and support provided in the private realm of the home. The experience of conducting ethnography in situations of potential intimacy will be discussed, alongside the challenges faced when observing a workforce that may be fearful of criticism. The process of consenting, reflexivity and ethical considerations will be shared to promote the use of ethnographic observations as a way of gaining meaningful understandings of care experiences of people living with dementia and the working practice of the home care workforce.



245

How can the MyCognitionPRO holistic digital health platform for monitoring and preventing cognitive decline be sucessfully implemented into the real-world context of people experiencing cognitive decline?

Miss Anna Sandford-Janes[1,2], Mr Claudio Marinelli[3], Prof Jackie Campbell[1], Prof Jacqueline Parkes[1]

[1]The University of Northampton, Northampton, United Kingdom. [2]Beingwell Ltd, Sheffield, United Kingdom. [3]Beingwell Ltd., Sheffield, United Kingdom

Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

MyCognitionPRO is a CE-marked, digital health platform offered as a subscription product by Beingwell Ltd, designed to help users manage their cognitive health. The KTP project between the University of Northampton and company is a staged plan to ensure the effective launch of a usable, evidence-based version of the platform, tailored to monitoring and preventing cognitive decline. A review of past literature has evidenced the mechanisms of action within the MyCognitionPRO platform and justifies its therapeutic use for cognitive decline. Several real-world trials have investigated the effectiveness of the platform in the context of people experiencing cognitive decline. The results indicated high rates of non-adoption and non-adherence in target users and several barriers with usability, accessibility, clarity and perceived usefulness of the applications. The project is now conducting an in-depth, mixed methods feasibility trial with older people (50+) experiencing a range of early-stage cognitive decline as well as their carers. Quantitative data (e.g. app engagement and performance data) and qualitative data (e.g. observation of user-experience and interviews) will be used as measures. Subsequent analysis will model factors that predict poor engagement as well as reporting the characteristics of subpopulations for which the MyCognitionPRO platform works best. Results will be synthesised into a user-centred product roadmap, providing recommendations for app developments, further user trials, coproduction and efficacy research. This evidence-generation strategy is necessary in order to deploy MyCognitionPRO as a digital tool that meets user needs, achieves regulatory approval and implements smoothly into markets to have a real impact in society.

246

Adaptation of an e-health intervention 'iSupport' for carers of people living with rarer dementias: Preliminary findings

Miss Bethan Naunton Morgan[1], Prof Gill Windle[1], Dr Carolien Lamers[1,2]

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

People caring for those with dementia face many challenges including emotional, physical, social, and financial difficulties. These can be amplified for those caring for someone with rare forms of dementia since most support services are developed for people diagnosed with more common types of dementia like Alzheimer and Vascular Dementia. These services are often not set up to support people with rare dementias and their carers.

'iSupport' is an online psychoeducation and skills development intervention created by the World Health Organisation to help support carers of people with dementia. Working with members of the Rare Dementia Support charity (RDS) we will use co-design methods to adapt iSupport for carers of those who have been diagnosed with a rare dementia. We will be recruiting informal carers of people with a rare dementia and professional members of the RDS.

This project will run in two phases. Phase 1 (adapting iSupport) will use co-design methods to involve informal carers and professional members of the RDS. Preliminary results from phase 1 will include the participants suggested changes ranked in order of perceived importance. Phase 2 (feasibility of iSupport) will investigate whether the adapted version of iSupport is appropriate for further testing and how this might be done. Phase 2 will include a range of pre/ post intervention measures and system usability data from the iSupport host to assess the feasibility and acceptability of the adapted version of iSupport.



248

Development of Dual Aβ-Tau Vaccines for the Treatment and Prevention of Alzheimer's Disease

Ms Robin Barbour, Dr Abderrahman Elmaarouf, Dr Michael Holden, Ms LeeAnn Louie, Ms Heather Prill, Dr Michael Skov, Dr Stephen Tam, Dr Clara Tourino, Dr Brian Campbell, Dr Gene Kinney, Dr Wagner Zago

Prothena Biosciences, Inc., South San Francisco, USA

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Introduction: Alzheimer's disease (AD) is characterized by two pathological hallmarks: Aβ plaques and tau tangles. Several Aβ pathology-targeting antibodies have exhibited signs of slowing cognitive decline in AD, while antibodies and vaccines against either Aβ or tau are in earlier clinical development stages. Since Aβ and tau may act synergistically in the cause and/or progression of disease, targeting both may lead to better efficacy towards AD treatment and prevention. Prothena developed two dual Aβ-tau vaccines for AD, targeting clearance of pathogenic Aβ and inhibition of tau neuronal cell-to-cell transmission.

Methods: Aβ-tau immunogen constructs were evaluated in multiple species. Sera from animals were assessed for high and balanced titers, immunoreactivity against pathological Aβ and tau, and binding avidity to aggregates of Aβ and tau. *In vitro* models of Aβ phagocytosis, Aβ neuronal toxicity, and tau cellular uptake were developed and utilized to evaluate sera from immunized animals.

Results: Prothena's dual vaccines generated robust and balanced immunogenic responses against Aβ and tau proteins in multiple animal species. Immunized sera was shown to bind Aβ plaques and tau tangles in human AD brain sections at titers expected to be achieved in the CNS *in vivo*. Immunized sera inhibited the binding of soluble Aβ aggregates to cultured hippocampal neurons. *In vitro* models demonstrated the sera induced phagocytosis of Aβ aggregates and blocked tau binding to heparin, a model of cellular uptake.

Conclusion: Prothena's dualAβ-tau vaccines may lead to disease modifying treatment and/or prevention of AD with improved efficacy over monotherapies.



249

Microtubule Binding Region (Mtbr)-Specific Antibody PRX005 Prevents Pathological Tau Progression via Blockade of Neuronal Internalization

Dr Philip J. Dolan, Dr Stephen Tam, Dr Tarlochan Nijjar, Dr Michael Holden, Dr Clara Tourino, Dr Abderrahman Elmaarouf, Ms Lauri Li, Ms Heather Prill, Dr Wagner Zago

Prothena Biosciences, Inc., South San Francisco, USA

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: Cell-to-cell transmission of pathogenic tau species has been proposed as the principal mechanism for the propagation of tau pathology across brain regions in Alzheimer's disease (AD). In order to develop targeted therapeutics that may delay pathological progression in AD by impacting this prion-like mechanism, an unbiased epitope strategy was used to define critical regions of tau involved in neuronal uptake and to assess antibodies targeting regions throughout tau in multiple *in vitro* and *in vivo* assays.

Methods: Antibody binding profiles were assessed by surface plasmon resonance, Western blotting, ELISA, and immunohistochemistry. Inhibition of tau internalization and neurotoxicity was tested in B103 cells and mouse primary cortical neurons, respectively. Seedingand passive administration studies were performed in tau transgenic mice.

Results: A large antibody panel was created, consisting of antibodies with high affinity to tau irrespective of aggregation state. *In vitro* assessment of this panel identified antibodies targeting the MTBR region of tau as more effectively blocking tau internalization and toxicity than antibodies binding other regions of tau. Upon further examination, one of these antibodies, mPRX005 (the murine precursor of PRX005), demonstrated significant inhibition of tau seeding *in vitro* and *in vivo*, and slowed pathological progression in a tau transgenic mouse model.

Conclusions: Antibodies spanning the full-length tau molecule were tested for neutralization activity in a variety of *in vitro* models, with activity confirmed *in vivo*. MTBR-binding antibody mPRX005 displayed consistent potency across a range of neutralization and efficacy assays, supporting further investigation as a clinical candidate.



250

The WW-FINGERS-SARS-CoV-2 initiative: effects of the COVID-19 Pandemic on Lifestyle and Psychosocial factors relevant to Brain Health

Dr Francesca Mangialasche[1], Dr Ana Sabsil López Rocha[1], Dr Jenni Lehtisalo[2], Prof Alina Solomon[3], Prof Lefkos Middleton[4], Dr Charlotta Thunborg[1], Dr Nicholas Levak[1], Dr Celeste Loots[4], Prof Tiia Ngandu[2], Prof Miia Kivipelto[1]

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aims: To assesshow the SARS-CoV-2 (COVID-19) pandemic has affected factors related to mental and physical health of populations at-risk of dementia, within the World-Wide FINGERS (WW-FINGERS, https://wwfingers.com) global network of multidomain trials for dementia risk reduction and prevention

Methods: The WW-FINGERS-SARS-CoV-2 survey was developed to assess direct and indirect effects of the COVID-19 pandemic. The questionnaire measureschanges in lifestyle factors (e.g., diet, physical activity), management of chronic noncommunicable diseases (e.g., diabetes, hypertension), and psycho-socialfactors -including depressive symptoms, sleep disorders, social isolation- that are relevant to cognition. Both a pen-and-paper and a digital version of the survey have been developed in several languages. The digital version is supported through REDCap (Research Electronic Data Capture), which is used also for harmonized data collection.

Results: 30countries are participating in the survey. As for November 2021, data have been collected from 19 countries, with 22000+ participants. Local adaptations and piloting were done to optimize implementation in clinical-based and population-based settings. Participants are in the at-risk spectrum for dementia: from normal cognition to pre-dementia cognitive symptoms. An updated report of the survey status will be presented.

Conclusions: The WW-FINGERS-SARS-CoV2 survey is a joint global action of the WW-FINGERS network which can inform better care of older adults in the context of a pandemic. The survey is also a valuable tool for pre-screening of participants for prevention trials, and results can inform adaptions to ensure successful recruitment and adherence in forthcoming multidomain trials for dementia prevention in older adults.

251

Knowledge of Dementia Risk Reduction: a new instrument to measure knowledge of dementia prevention

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Wicking Dementia Research and Education Centre, University of Tasmania, Hobart, Australia

Topic

Dementia risk reduction: Public health campaigning

Abstract

Aims: The study aim was to develop a contemporary, validated measure of knowledge of dementia prevention and lifestyle strategies to mitigate risk. Such an instrument will allow understanding of community risk reduction knowledge and can inform education and behavioural interventions to reduce dementia prevalence.

Method: We developed the three-part Knowledge of Dementia Risk Reduction survey (KoDeRR). Literature review informed the first part which assesses general dementia prevention knowledge. We analysed individual items, correlations and internal consistency. The second and third sections determine the capacity of participants to recall and recognise specific dementia risk factors, and recognise common misconceptions. The instrument was administered to 3334 participants of a large-scale, long-term public health cohort study. Discrimination between groups was examined by comparing results between participants with and without previous dementia risk education.

Results: The final instrument contains 28 items. Internal consistency of part 1 was moderate (Cronbach's alpha= 0.77). One part 1 item was discarded due to poor item skew and discrimination. Nearly 80% of participants understood that dementia risk can be modified, though participants recognised nearly four times as many modifiable risk factors as they recalled. Misconceptions were poorly understood.

Conclusion: The instrument assesses the ability of individuals to recall and recognise risk factors and to appraise common misconceptions about dementia risk, along with their general knowledge about dementia prevention. It allows an understanding of the extent to which individuals comprehend that personal risk can be reduced through behavioural change, and the success of risk reduction education campaigns.



252

Air Travel and Passengers Living with Cognitive Impairment or Dementia

Miss Valentina Primossi[1], **Dr Michael Mulvey**[1], Dr Linda Garcia[1], Miss Heather Cowie[2], Dr Paulette Guitard[1], Dr Burak Kantarci[1], Dr Ravi Malhotra[1], Dr Kiran Rabheru[1], Dr Mark Salter[1]

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

The LIFE Research Institute at the University of Ottawa is currently investigating how to create a strategy that will shape the best dementia-friendly air travel experience for persons living with cognitive impairment or dementia, their companions, in-cabin crew, and other passengers. This research aims to investigate the barriers and gaps within the current situation, to then appropriately enhance the air travel services for this clientele. The profile of today's travellers is changing, and clearly, this is the time to act and develop a plan.

To date, while important steps have been taken globally regarding persons living with cognitive impairment or dementia, there still is a lack of research in this field. Although airlines do not plan consumer protection legislation, air services are starting to plan for the projected increase in elderly travellers and responding to dedicated rights and consumer protection legislation and policy. We will conduct fieldwork using a netnographic approach to study consumer conversations in social media, uncovering people's extensive and detailed views during their travel plans.

Crucially, this timely and multi-disciplinary project will guide towards an improvement of lives giving policy-makers and industry informed alternatives and presenting individuals or groups information about how to identify and fight for their rights. Lastly, we expect this will help address the challenges facing the transport industries in the post-COVID19 era. The international framework is one of the main components of this research, and presenting at this conference could be an excellent opportunity to enlarge the global network in this field.

254

A multidomain intervention for dementia risk reduction in Australian primary care settings: The HAPPI MIND Trial

Dr Gopisankar Mohanannair Geethadevi[1], Dr Amanda Cross[1], Prof Parker Magin[2], Prof Amanda Baker[2], Prof Billie Bonevski[2], Dr Stephanie Ward[3], Prof Ajay Mahal[4], Prof Vincent Versace[5], Prof Simon Bell[1], Prof Kevin Mc Namara[6], Dr Sharleen O'Reilly[7], Dr Andrea Hernan[5], Dr Dennis Thomas[2], Prof Elizabeth Manias[5], Prof Kaarin Anstey[3], Dr Marlien Varnfield[8], Dr Rajiv Jayasena[8], Prof Rohan Elliott[9], Mrs Denise van den Bosch[1], Dr Johnson George[1]

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aim: To evaluate the effectiveness of a multi-domain intervention-HAPPI MIND (Holistic Approach in Primary care for PreventIng Memory Impairment aNd Dementia) for assessing dementia risk and reducing dementia risk factors in middle-aged adults in the primary care setting.

Methods: HAPPI MIND is a pragmatic single-blind cluster randomised controlled trial, targeting community-dwelling adults aged 45–65 years with at least two potential risk factors for dementia: hypertension, dyslipidaemia, diabetes mellitus, obesity, smoking, excessive alcohol consumption, physical inactivity, poor diet, depression, social isolation and lack of cognitive activity. Clinics (17 per trial arm) will be randomised to HAPPI MIND or minimal intervention. Participants (N=510) will be recruited and followed up for 3 years. Practice nurses will be trained in motivational interview skills to deliver the HAPPI MIND intervention under GP supervision. The intervention comprises, i) quarterly face-to-face or phone-based meetings between participants and practice nurses, ii) personalised risk reduction action plans, and iii) referrals for targeted additional activities, as needed in 1st year and tailored mobile phone-based risk reduction support for 3 years. The minimal intervention participants will receive dementia risk screening, brief intervention and referral for treatment if needed. The primary outcome is the change in dementia risk at 12 months, measured using the Australian National University Alzheimer's Disease Risk Index (ANU-ADRI). The study also involves economic evaluation of the HAPPI MIND model of care. Implications:Findings fromHAPPI MIND will inform the feasibility, efficacy, and acceptability of a multi-domain intervention targeting dementia risk reduction among middle-aged adults.



255

Trends in a blood pressure trajectories in people presenting to primary care and their risk of developing dementia.

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aim: To investigate the trajectories of systolic and diastolic blood pressure over time (calendar time and age) recorded in primary healthcare. Secondly, to examine how these trajectories may be associated with risk of developing dementia.

Methods: A retrospective cohort study withindividuals who contributed to data within IQVIA medical research data from 1st January 2003 to 31st December 2018 and aged 50-99 years were be included. A study 10% random subsample of n=361,929 people was identified with 4,489,677 blood pressure measurements. A Joint Latent Growth mixed model (JLCMM) was used to identify different blood pressure trajectories subgroups (latent classes) and then run a survival analysis to examine the risk of developing dementia within the different blood pressure trajectory groups.

Results: The study is ongoing, and results will be presented at conference.

Conclusion: Potential results could provide a greater understanding into the association between mid-to-late life blood pressure trajectories and dementia risk in people presenting to primary care.

256

Enhancing the dementia care workforce's ability to provide high-quality care: Exploring dementia care students' reasons for participation in education and translation of education into practice

Dr Emma Lea[1], Dr Claire Eccleston[1], Dr Melissa Abela[2]

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aims: It is vital that aged care staff can provide skilled, informed care to meet the needs of people living with dementia, yet there are gaps in staff dementia knowledge. It is important to explore workforce participation in dementia education and the impact of this education on understanding and agency to improve care quality.

Method: This case study of the Wicking Centre's online Dementia Care Program, undertaken by students across Australia typically working in residential, home or community care, involves tracking students over three years. Data are being collected primarily via online surveys, administered at multiple time points, on the impact of studying the Diploma and Bachelor of Dementia Care on dementia knowledge, attitudes, care practices and career pathways.

Results: To date, 101 participants have consented to take part in the study. Baseline and first follow-up results have been collected with 61% of participants indicating their main reason for study is to improve the lives of people with dementia. Qualitative (open-ended response) data show students recognise they require education so they can more appropriately address the needs of people living with dementia.

Conclusion: Students recognise the need for education, demonstrating its potential to effect change in aged care. How education is used to change care practices, advocate for broader care improvements, and provide the opportunity to move into different roles and career pathways are considerations for the aged care sector if it is to build and reshape its workforce to be more innovative and highly skilled in care delivery.



257

Five essential tips, STE^{2}P, for dementia-friendly communication

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Good communication in daily routine is very crucial for people living with dementia. Comparing with the public, people living with dementia need more eye contact and body language during communication. Most importantly, the listener needs to be patient and give them sufficient time to respond or express their thoughts before they respond.

According to above mentioned principles of good communication, our team created the communication tips of STE^{2}P, Smile, Thanks, Eye contact, Embracing the moment, and Patience.

Our team incorporated the STE^{2}P in different fields of training program in Taipei City, such as in hospital, junior high school, National Palace Museum, National Taiwan Library, bus and taxi drivers, art and culture centers, bank, and communities. We gave the training through different kinds of material such as leaflet, manual, 2D video, VR video, workshops, and face to face communication with people living with dementia.

In the training course, the five tips had the sequence from a happy smile, thankful thought, and eye contact to generate embracing the moment and patience. The trainee stated the gap between general adult and people living with dementia were very negligible when using the STE2P tips. People living with dementia said the trainee were so friendly with bright smile. The caregivers experienced the respect and empathy from trainee.

To sum up, making good use of five communication tips of STE^{2}P, Smile, Thanks, Eye contact, Embracing the moment, and Patience are the key principle to generate good communication with someone living with dementia.

258

WhatMatters – A mobile application to support person-centered care for people with dementia in care settings

Mrs Ellen Yi Peng Guo[1], Ms Candy Tran[1], Dr Mariko Sakamoto[1], Prof Lillian Hung[2], Mrs Garima Sood[3], Miss Eva Skole[3], Dr Jim Mann[4]

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Introduction: The purpose of our study is to provide comfort through digital resources (e.g., music and visual materials) for patients/residents with dementia in hospitals and long-term care. By working with users (patients/residents, families, and staff) and using a co-design approach, we are developing a mobile app prototype called "WhatMatters" – a digital solution to equip staff with a useful tool for delivering person-centered care in hospitals and long-term care homes.

Methods: We have conducted a series of virtual co-design workshops with acute and long-term care staff (n=10), clinical experts (n=3), residents (n=3), and patient and family partners (n=7) to understand: (a) what "comfort" means, (b) how care needs are communicated and provided for, and (c) how a mobile app may be used to support psychosocial needs of people living with dementia in hospital and long-term care settings.

Results: Thematic analysis has identified three themes to inform the development of the mobile app, WhatMatters: (a) familiarity brings comfort, (b) sharing of information between staff and families allows for continuity of care and person-centered care, and (c) accessible and curated content can evoke memories and create a comforting space.

Conclusion: It is feasible and necessary to work with users (including patient and family partners) and relevant stakeholders to co-design a mobile app, a useful tool to support the delivery of person-centered care in hospitals and long-term care.



259

Development of various Low-Tech memory aids and interventions to prevent BPSD by Middle-Tech devices

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

For a person with impaired visual acuity, or gait disturbance, we encourage them to live an independent life by having them use a pair of glasses, or a wheelchair. Thus, we should also support the life of patients with MCI or dementia by using memory aids (Assistive Technology; AT). Although non-electronic Low-Tech ATs such as special diaries, calendars, message boards and wearable notepads are indispensable for supporting people with MCI/dementia, they have been mostly overlooked and rarely implemented. Thus, I created various new Low-Tech ATs.

In most of the widely accepted textbooks, reflective attitudes, or redirection techniques have been recommended for dementia caring. However, they do not always work depending upon the situations and the caregiver's character. The essence of MCI/dementia symptoms is information impairment (Yasuda, 2022) and that "The Strategy of Providing Information in Advance"using Assistive Technologies (ATs) is critical. In applying this strategy, I succeeded in solving some BPSD such as anger, getting lost, and asking repetitive questions by using electronic "Middle-Tech" devises or interventions, such as a Sonny IC recorder, Voice guidance, reminiscent photo videos and a conversation system with anime-agents.

As a variety of ATs and interventions for supporting the people with MCI/ dementia have become available, they has been classified into Low-, Middle-, and High-Tech ATs. I will introduce these ATs at the conference. See Kiyoshi Yasuda (2022)"Rehabilitation for MCI and Dementia: Using Assistive Technology to support Daily Activities" for detail information.

260

A multidisciplinary approach on assisting dementia caregiver in Indonesia: community based participatory research and flashcard

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Introduction

Although challenging, dementia research in the midst of a pandemic is vital. There is a need for an effective, practical, and comprehensive guideline for dementia caregivers. Therefore, we conducted Indonesia-the Netherlands multidisciplinary research to create a dementia caregiver's flashcard involving neurologist, general practitioner, physiotherapist, nurse, and psychologist.

Methods: Five Community-Based Participatory Research using nominal group discussions involving experts and one Focus Group Discussion involving dementia caregivers in Indonesia were conducted. The photovoice approach was used in the FGD session to assist the discussion based on depictions of participants' problems in daily care. All processes were done digitally. A comprehensive literature study was done to add evidence-based practice in the flashcard further.

Results: Dementia and social project experts were involved in the nominal group discussions, and six caregivers participated in the FGD. The caregivers shared their challenges and needs for a comprehensive source of information. The photovoice approach helped them in telling their own perspectives. Other issues and several proposed solutions were also discussed.

Conclusion: Our experience opens up more innovation in research in the midst of the pandemic. Readily available digital platforms allow us to reach out to more people, especially people with dementia and their caregivers. As a result, a comprehensive and practical flashcard was made without ever meeting in person. We hope this collaboration will help close the gap of dementia care in developed and developing countries. Further research to test the effectiveness of the flashcard is needed.



261

Implementing small-scale living environments to promote the participation in meaningful activities for people living with dementia

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

People living with dementia and residing in traditional residential care homes (RCH) can face challenges in the accomplishment of meaningful occupations. Small-scale approaches help maintain their occupational engagement by adapting the physical environment, daily schedule, and care approach to their life story.

Aims: This study aims to adapt small-scale approaches to Quebec's context to facilitate their implementation within RCH for people living with dementia.

Methods: Qualitative interviews with key players from Quebec, and worldwide (n=7) documented the facilitators, barriers, and areas for improvement in their experience in implementing small-scale approaches. Two focus group discussions (n=12; persons living with dementia, caregivers, care team members and managers from Quebec RCH) explored the applicability and acceptability of small-scale approaches, then suggested adaptations to identify winning conditions for their implementation.

Results: Facilitators include the acceptability of the approaches by care team members, managers, and families as well as the support of key players who have implemented similar environments. Barriers include the norms of traditional institutions and the practitioners' culture of practice. Collaboration during the implementation process, with intersectoral experts (architects, decision-makers) as well as with families, is an area for improvement. The suggested adaptations concern secured access for citizens to businesses inside the RCH and the addition of trainings for all practitioners for sustainable change.

Conclusions: Learning from the key players' rich experience in the implementation of small-scale approaches can lead the way for innovators from all fields wanting to create positive changes for people living with dementia and residing in current RCH.

262

A Longitudinal Study of Namaste Care in a Residential Care Facility in Singapore: Benefits for Persons Living with Advanced Dementia

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Apex Harmony Lodge, Singapore, Singapore

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Aim: Namaste Care has been implemented in Apex Harmony Lodge, a residential care facility in Singapore, for 1.5 years. Our main objective was to understand the benefits of Namaste Care by examining longitudinal data on psychosocial outcomes, physical health and cognition. Our secondary objective was to identify potential gender differences in outcomes.

Method: Participants include 37 residents (21 female, 16 male) who attended weekly Namaste Care for 1 to 1.5 years. Data were extracted from routine assessments conducted twice yearly, namely International Resident Assessment Instrument (InterRAI), Bradford Well-Being Profile (WBP), and Severe Impairment Rating Scale (SIRS). Psychosocial outcomes include aggression, depression, and social engagement from InterRAI, and well-being measured by WBP. Physical health indicators include pain and BMI from InterRAI, and cognition was measured by SIRS. Data analysis was conducted via paired samples t-test and one-way analysis of variance.

Result: Significant improvements in symptoms of depression and social engagement were documented. While there was significant improvement in cognition at 4-months follow up, significant decline in cognition was observed at 1-year follow up. No significant changes were documented for other outcome measures. Significant gender differences were only noted in well-being and cognition, where females experienced better outcomes than males.

Conclusion: Overall, our findings show support for Namaste Care in reducing symptoms of depression and improving social engagement. Although improvements in well-being were not documented, it is encouraging that well-being was maintained despite long-term cognitive decline. Further works are underway to explore how Namaste Care can be enhanced to generate more benefits.



263

Reminiscence with Soundscapes for Persons Living with Dementia: Participants with Limited Verbal Speech Benefit from Group Sessions

Ms Tay Shi Ying, Ms Hana Sabido Concepcion

Apex Harmony Lodge, Singapore, Singapore

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Aims: This pilot program involved CRDL, an interactive instrument, as therapeutic intervention for persons living with advanced dementia by integrating multisensory stimulation and reminiscence. We were interested in comparing its effect on mood and engagement, (a) between participants with verbal speech and limited verbal speech; (b) between individual and group settings.

Method: The pilot involved 6 persons living with advanced dementia from a long-term care facility in Singapore, comprising of 3 persons with verbal speech and 3 persons with limited verbal speech. The program was held weekly over a period of 10 weeks, consisting of 5 individual and 5 group sessions. Observational data was collected using Menorah Park Engagement Scale which measures positive and/or negative mood and engagement.

Result: Participants with verbal speech maintained the maximum level of positive engagement and no negative engagement across both settings. Participants with limited verbal speech demonstrated greater positive engagement in group sessions attributed to increased constructive engagement. Greater positive mood was observed in individual sessions for participants with verbal speech and group sessions for participants with limited verbal speech. Negative mood was not observed in all sessions.

Conclusion: Overall, positive effects on mood and engagement were observed which shows support for CRDL as an instrument for therapeutic intervention. Interestingly, group sessions were more beneficial for participants with limited verbal speech which contrasts common practice of one-to-one facilitation for this profile. This study appeals to researchers and practitioners to challenge the notion that one-to-one facilitation should be promoted for those with lower functioning.



264

An innovative training mode - Online course for caregivers of PLwD

Dr Dana Peer, Mrs Hadas Bar-El Fremder

EMDA, Kfar-Saba, Israel

Topic

Support for dementia carers: Education and training for informal carers

Abstract

In recent years there has been a boom of online training courses. Many of these target layperson audiences interested in acquiring skills and abilities. Academic institutions also joined this trend, and were embracing online training as a legitimate and effective learning mode even before the disruption of face-to-face learning due to COVID19.

The COVID19 pandemic and the ensuing lockdowns and regulations in response have focused a spotlight on the advantages and versatility of online courses. In light of these, EMDA, the Israeli Alzheimer's Association, produced an online course about dementia. This course is an important learning tool for caregivers of persons living with dementia, as well as for professional health care providers supporting these caregivers.

The online course is constructed of a series of short clips (5-6 minutes) addressing various relevant issues. The course starts with general information, and then delves into specific issues concerning caregivers: adapting the physical environment, effective communication, coping with behavioral changes, palliative care, taking care of the caregivers themselves, and more. All the clips have subtitles, and EMDA is in the process translating the course into more languages to support the multicultural society in Israel.

The feedback from caregivers who have used the course has been positive, and they appreciate the ease of watching and re-watching relevant clips addressing the changing nature of dementia caregiving as they find necessary. A large HMO has also purchased the course and it is now part of the training for all their healthcare professionals.



265

Dementia-friendly changes to acute and sub-acute wards at Fiona Stanley Fremantle Hospitals Group in Perth, Australia

Ms Jane Hopkins, **Ms Katharine Earl**

Fiona Stanley, Fremantle Hospitals Group, Perth, Australia

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Due to their unfamiliar, busy and stressful nature, hospitals can be challenging for some patients, particularly those with a cognitive impairment (CI). For a person with a CI (especially dementia and/or delirium), the hospital experience may be impacted by a reduced ability to understand and adapt to the new setting, resulting in it being a difficult and disorientating experience.

With a commitment to bettersupport patients with a Clacross the Fiona Stanley Fremantle Hospitals Group (FSFHG), dementia-friendly design principles were implemented to enhance independence, improve wayfinding and better mitigate against the risk of falls. As a result of a successful business case, dementia-friendly changes were implemented in three acute wards at Fiona Stanley Hospital with minimal impact on the clinical operations. The sub-acute neurology rehabilitation unit at Fremantle Hospital also underwent significant environmental improvements as part of a larger hospital development project. These improvements were made in line with the ward being relocated to another area within the hospital.

This presentation will provide a project summary and evaluation of the two projects identifying key strengths, stakeholders and barriers to achieving the environmental design changes within acute and sub-acute wards. This will include before and after photos and highlighting the changes, a comparison between the two projects regarding the scope for change and introduce plans for future dementia-friendly changes across FSFHG.



266

"Custom Made"- The Israeli Multi-Cultural Process for Improving Dementia Care in Minority Groups

Mrs Hadas Bar-El Fremder, Mrs Daphna Golan-Shemesh, Mrs Debi Lahav

EMDA, Kfar-Saba, Israel

Topic

Dementia awareness and friendliness: Diverse populations – inclusion, equality, cultural issues

Abstract

Israel is a multi-cultural country. Our goals in EMDA – Israel Alzheimer's Association, are to promote awareness and improve the quality of care for PWD's and their caregivers, with special emphasis on minority groups (the Arab and Bedouin communities, Jewish immigrants from Ethiopia and the ultra-orthodox Jewish stream).

The purpose is to understand the process of developing "custom made" culturally appropriate tools.

The first step is to learn about the customs, values, beliefs, and social structure in each community. We learn from family members in the community about their challenges and use their assistance as mediators.

We make contact with local professionals, religious and community leaders to help form collaboration with the community, and organize steering committees and Dementia awareness events with the municipality, local health and welfare services.

Support groups started in communities run by social workers from the same minority. We translated and culturally adapted brochures, online course of dementia care, and activity kits for PWD's.

Our current challenges are entering closed traditional communities where there is little information about dementia. We hired a Bedouin social worker to work with the Bedouin communities. We are focusing on women who are the main caregivers. The ministry of health is supporting a joint project with EMDA for the Muslim population.

It is important to create a relationship of honor and respect with the minority communities. In the presentation we will also address the challenges we had to face during COVID-19, the rural aspects and more that will be done until 06/2022.



267

Identification of key pathways and core genes associated with Alzheimer disease using a transcriptomics approach

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Alzheimer's disease (AD) is a neurodegenerative disorder, which preferentially affects individuals over 60 years of age with steadily increasing risk in older ages. The prevalence of AD in the general population increases from about 1% in persons younger than 65 years to about 40% in nonagenarians. Accessible evidence suggests the role of certain abnormally expressed genes in AD. Thus, the study was designed to understand the associated dysregulated pathways and underlying genes responsible for the occurrence and development of AD using bioinformatics analysis. The gene expression profile of GSE5281 with 161 samples, including 87 Alzheimer's samples and 74 normal samples was downloaded from NCBI, GEO. The DEGs were identified using the affy package in R software. The KEGG pathways of the DEGs were analyzed using cluster Profiler, the Bio conductor. Cytoscape was utilized to construct a protein interaction network and analyze the interaction of the candidate DEGs encoding proteins. 2159 dysregulated genes were obtained of which 906 were up-regulated and 1253 were down-regulated genes. DEGs were involved in the intracellular part, Phosphoprotein, Acetylation, mitochondrion organization, and microtubule-associated complex. The PPI and module analysis revealed GAPDH, HSP90AB1, GFAP, GRIN1, IGF1, ATP5C1, DYNC1H1, PSMA1, CCT5, and PSMA3 as the hub genes. The identified hub genes and pathways can be used to understand the clear molecular mechanism to define the molecular targets and diagnostic biomarkers for the treatment of Alzheimer's.

268

Discovery of natural small molecules as selective GSK-3β inhibitors, a disease-modifying strategy for Alzheimer's Disease: structure-based virtual screening and preliminary biological evaluation

Ms Sukanya Sukanya, Mr Bhanwar Singh Choudhary, Dr Ruchi Malik

Central University of Rajasthan, Ajmer, India

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: Alzheimer's Disease (AD) is an irreversible, intensifying, neurodegenerative, multi-factorial disorder, one of the most typical forms of dementia. Neurofibriallary tangles (NFTS) and senile plaques are neuropathological indicators of Alzheimer's Disease. Overactivity of Glycogen synthase kinase-3β (GSK-3β) leads to increased tau (microtubule-associated protein) phosphorylation, destabilizing microtubules and resulting in the formation of neurofibrilary tangles. This overactivity of GSK-3β also results in senile plaques formation and deposition, triggering inflammatory responses, making GSK-3β an attractive target for AD.

Method: Structure-based virtual screening was performed to identify novel scaffold of GSK3β inhibitors using Chembridge natural compounds library. The methodology involves the selection of GSK3β structure (PDB ID: 5F94) from the protein data bank, protein preparation and receptor grid generation, ligand preparation, and XP Glide structure-based virtual screening. 10 hits were identified based on interaction, binding energy, and dock score. The identified hits were investigated for *in-vitro*kinase inhibitory activity against GSK-3β and other disease-related kinases. ATP-competition assay was performed for determining the mechanism of action.

Results: Here, we have reported compounds 7014692, 5468327, and 7248520 with IC50 of 8.16μM, 7.79μM, and 2.61 μM against GSK-3β, and the compounds emerged as selective GSK-3β inhibitors.

Conclusion: The encouraging results of our work led to the discovery of natural, potent, and selective GSK-3β inhibitors. These selective natural inhibitors can be the potential lead candidate for AD treatment.



269

Mid-life Hearing Impairment As Risk Factor For Dementia In People Aged ≥70 Years (HIRD). A Population-Based Prospective Cohort Study: The HUNT Study, Norway

Mr Christian Myrstad[1,2], Dr Bo Lars Engdahl[3], Prof Gil Livingston[4,5], Dr Sergi Costafreda[4,5], Dr Bjørn Heine Strand[3,1,6], Prof Geir Selbæk[1,7,8]

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Topic

Dementia risk reduction: Risk factors

Abstract

Introduction: Early risk factor modification of dementia is crucial. Hearing impairment (HI) in mid-life is a risk factor for dementia that is prevalent and potent. The present study has a bigger sample size and a longer follow-up than previous studies. We aimed to study the association between objectively determined HI in mid-life and dementia in late-life.

Methods: Participants aged ≥70 years in the fourth wave of the Nord-Trøndelag Health Study (2017-2019), who had audiometry in the second wave (1995-1997), were assessed for dementia. We based diagnostic assessment of cognitive impairment on cognitive tests, functional capacity and an interview with next of kin by research nurses. Clinical experts diagnosed dementia according to the Diagnostic and Statistical Manual of Mental Disorders 5 criteria. This abstract reports logistic regression with adjustment for age to assess the association between a hearing threshold level >25 dB and dementia.

Results: Out of 6,952 included individuals (mean age at follow-up 77.9 years, 55% women), 1,003 (14%) had HI at baseline, and 975 (14%) had dementia 22-24 years later. HI was associated with an increased risk of dementia, odds ratio 1.4 (95% confidence interval 1.1-1.6).

Conclusion:HI in mid-life was associated with an increased long-term risk of dementia in older adults. This support previous research suggesting that hearing loss might result in cognitive decline through reduced cognitive stimulation.

270

Testing an evidence-based post-diagnostic dementia care model in primary care: preliminary findings from the PriDem feasibility and implementation study

Dr Sarah Griffiths[1], Mrs Emily Moran Spencer[1], Prof Kate Walters[1], Ms Jane Wilcock[1], Ms Claire Bamford[2], Dr Greta Brunskill[2], Dr Alison Wheatley[2], Prof Louise Robinson[2], Prof Greta Rait[1]

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Aims: The UK PriDem research programme aims to develop and test primary care led models of post-diagnostic dementia care. An evidence-based, person-centred intervention was co-developed with key stakeholders. We aim to test the feasibility of the intervention in a 12-month multi-site feasibility and implementation.

Method: Settings and recruitment. Up to 80 People living with dementia and 66 care partners will be recruited across the Southeast and Northeast of England from up to 4 Primary Care Networks.

Intervention: The intervention has three components: building capacity by supporting non-specialists to deliver dementia care and support; improving local systems for delivery of evidence based, post diagnostic support, and enhancing care by creating bespoke care plans to optimise dementia care reviews. The intervention is supported by a Clinical Dementia Expert (CDE). CDEs in the Southeast and Northeast of England will be trained and supervised.

Outcomes: We will:

- Measure feasibility and acceptability outcomes (e.g., recruitment, retention, questionnaire completion rates)
- Collect quality of life, wellbeing, and service use data at 0, 4 and 12 months
- Conduct an electronic records audit, for the presence/absence of a personalised care plan (0 and 12 months)
- Undertake multi-methods process evaluation (including interviews and observations) to describe factors influencing implementation of the intervention in practice

Results/Conclusions: Findings from the feasibility will be presented: successes/challenges of recruitment, outcome measures, and operationalising and conducting the baseline audit. Preliminary implementation findings will be shared.



271

Is dementia research being delayed due to a lack of support for early career stage researchers?

Mr Adam M Smith[1,2], Dr Elizabeth Shaaban[3], Dr Sara Laureen Bartels[4,5], Dr Lindsay A Welikovitch[6,7], Mr Wagner S Brum[8,9]

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Attracting, supporting, and retaining dementia researchers is essential to advance basic science, treatments, care, and prevention of dementia. Early career researchers (ECRs) are the workforce that drives the engine of discovery.

The Alzheimer's Association International Society to Advance Alzheimer's Research and Treatment (ISTAART) Professional Interest Area to Elevate Early Career Researchers (PEERS) and University College London conducted a worldwide survey of ECRs to understand what attracted them to the field, the challenges they face, and what they thought about their career. The survey received 584 responses from 43 countries, working across all areas of discovery, from basic science, to care, psychology and the arts. The survey revealed that while 75% of respondents found a career in dementia research rewarding and enjoyable, 64% worry about their future career in dementia research, 20% stated that they were actively considering leaving the field, and a further 32% might leave. Respondents indicated that the main barriers to career progression were lack of funding, job availability and security, and difficulty maintaining work-life-balance.

The challenges faced by these ECRs are regularly raised by ECRs across all fields of research. However, little has been done to address the challenges, particularly in relation to career bottlenecks, short-term contracts, and funding. The World Health Organization has highlighted Dementia as a major a major global health crisis, and to ensure there is continued advancement of dementia research, it is critical that policy makers, research funders, and health institutions improve their support for ECRs.

272

Psychosocial interventions for persons living with dementia: a guide to improve knowledge, understanding and implementation.

Dr Jean-Bernard Mabire, Mrs Christine Tabuenca

Fondation Médéric Alzheimer, Paris, France

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Psychosocial interventions are essential and effective for persons living with dementia. There is a real demand from professionals to know more about these interventions in order to better tailor them to the needs of persons living with dementia. The Foundation Médéric Alzheimer proposes a guide to improve knowledge, understanding and implementation of psychosocial interventions.

This guide was developed in three steps: selection of interventions; writing of the chapters and chapters' popularisation for persons living with dementia and family caregivers.

Interventions were selected based on scientific evidence of their effectiveness: adapted physical activity; animal assisted interventions; art therapy; cognitive rehabilitation; cognitive stimulation therapy; dance-based interventions; horticultural therapy; multisensory stimulation; music therapy; and reminiscence therapy. For each intervention, an expert wrote a chapter according to a model: presentation, theoretical background, scientific evaluation, implementation and practical advice. Chapters have been reviewed by another expert of the intervention and by professionals or academics in the field of dementia. The guide provides summary tables based on the symptoms for which interventions have been shown to have effects. The chapters have been popularised into factsheets with the contribution from persons living with dementia and family caregivers to provide them suitable information on the interventions available.

This guide is the result of collaborative and participatory work between professionals, academics, persons living with dementia and family caregivers. It is not a substitute for the training required to provide these interventions but provides theoretical and practical knowledge to better implement them.



273

Reviewing the impact 'Join Dementia Research' a United Kingdom digital trial recruitment platform

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Topic

Information systems for dementia: Registries

Abstract

The discoveries that result from the undertaking of dementia research rely upon researchers finding appropriate people to participate. Studies have exacting requirements e.g. age, location, health status and a dementia related disease which is at exactly the right stage. The difficulty in finding willing and appropriate people can result in discoveries being delayed, and increasing the costs of study delivery.

To address these issues, the UK Government funded the National Institute for Health Research to create 'Join Dementia Research' (JDR). Using innovative matching technology, JDR provides volunteers with an opt-in, secure way of registering interest in dementia studies and allows researchers to access matched volunteers across the united Kingdom.

As of October 2021, JDR has 50,331 registered volunteers, and 1,682 trained research users at 304 sites and recruited to 365 studies. This represents 55,354 recruitment instances and over 33,000 people becoming enrolled in one or more studies as a result of their participation in the register.

A 2020 survey of participants demonstrated the further value of the service with 62% stating that the service had made it easier to take part in research. Furthermore 70% of the respondents confirmed JDR had increased their awareness of what research is taking place.

JDR has helped address disparities in public participation in dementia research and reduced the risks of studies failing through recruitment challenges. Lessons learned in the United Kingdom could be used to support a concerted and strategic effort to broaden the use of such services in other parts of the world.

274

Culture change for dementia - A coalition led response to raising awareness of dementia and inspiring stakeholders to create dementia inclusive communities

Ms Fiona Foley[1], Ms Elaine Sloan[2], **Mr Matthew Gibb**[3]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Dementia: Understand Together in Communities is a national programme supporting and inspiring people to create dementia inclusive communities where people living with dementia and their supporters are respected, supported and connected.

The campaign included TV and radio advertisements to increase awareness and understanding of dementia (2016-2018). As a next phase an innovative social movement model is bringing about a dementia culture change in local communities. Supported by a coalition of partners from public, private & voluntary sectors and local champions, the core focus is on inclusion, engagement and making community resources enabling, ensuring that a diagnosis does not exclude a person because of stigma or socially, physically disabling environments.

As part of the campaign, dementia public attitudes surveys (N=1,000+) in 2016 (baseline), 2018 and 2021 gauged public understanding of dementia, perceptions of people with dementia and insights into help seeking behaviour.

- 68% would treat a person with dementia as they would treat anyone (56% in 2016)
- 67% would accept a person with dementia as a close friend (56% in 2016)
- 92% believe people with dementia have the right to be active citizens
- 84% believe businesses can do things to make their services accessible
- 91% agree that receiving an early diagnosis is good as it allows an opportunity to make decisions about care (78% in 2018)

The collaborative approach, transferability of campaign's messages and call for actions is proving successful. The campaign will further embed dementia in the workplans of key strategic partners and inspire and support sustainable local change initiatives.



275

Pilot studies on designing the built environment to honour the rights of people living with dementia under the UN Convention on the rights of persons with disabilities, articles 9 & 19

Mrs Fiona Walsh[1,2], **Mrs Fiona Foley**[3], Mr Greg Walsh[1,2]

[1]Global Brain Health Institute, Dublin, Ireland. [2]DDS Architects Ltd, London, United Kingdom. [3]Health Service Executive, Dublin, Ireland

Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

In Ireland, Dementia: Understand Together in Communities is a national programme inspiring people to create dementia inclusive communities where people living with dementia and their supporters are respected, supported and connected.

Supported by a coalition of partners from public, private & voluntary sectors and local champions, the campaign's innovative social movement model is bringing about a dementia culture change in local communities. It focuses on 6 key actions people can take, one of which is "Making our spaces and amenities accessible".

To design and build environments that are accessible and support people with dementia to stay connected, we must understand how the environment can affect a person who may experience physical, sensory and/or cognitive difficulties.

Dementia can make people more sensitive to their environment. They can become disorientated, lost, feel agitated or stressed if the environment can't compensate for their needs. This can result in feelings of exclusion, loss of confidence, withdrawal and isolation. When people find an environment too challenging to navigate, they will withdraw from it.

Partnering with Global Brain Health Institute fellows and local stakeholders, we conducted professional walkability/ inclusive design audits, that were supplemented to account for cognitive and sensory impairments, as well as Inclusive Design Workshops for town planners, architects and accessibility officers in pilot communities. The campaign is using these findings to inform stakeholders on the environment's impact on a person's health and well-being, and to provide practical guidance and supports for those responsible of making spaces and amenities inclusive.

276

Dementia Attitudes Monitor Wave 2: Tracking UK attitudes to dementia and research

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: In 2018, Alzheimer's Research UK launched the Dementia Attitudes Monitor, an in-depth analysis of the UK's attitudes towards dementia and research. Wave 2 in 2021 tracked changes in attitudes with the aim of shaping public dialogue around dementia.

Method: Wave 2 in 2021 was conducted by Ipsos MORI on behalf of Alzheimer's Research UK. It surveyed a nationally representative quota sample of 2,259 UK adults aged 18+ using a telephone omnibus, including 387 adults from an ethnic minority background.

Results: Compared to Wave 1, Wave 2 shows growing public understanding of dementia. More people in 2021 recognise that dementia is not an inevitable part of getting older (68%) and that it is a cause death (62%). Despite a drop in diagnosis rates during the pandemic, 89% would likely seek a formal diagnosis if they had dementia concerns. There continues to be strong public appetite for risk information and pre-symptomatic detection of disease using a range of diagnostic tools. Willingness to engage in dementia research is at an all-time high (69%), following a year of mass participation in COVID-19 research. Sadly, awareness of dementia risk and risk factors remains incredibly low.

Conclusion: The pandemic undoubtedly shaped public attitudes to dementia in 2021. Despite rising understanding and strong appetite for engagement, there must be national focus on dementia risk reduction messaging, as well as targeted information to key underserved groups. The Dementia Attitudes Monitor is an essential tool for informing ongoing charity and government efforts to tackle dementia.



277

Engaging Carers Of People with Dementia to Influence and Develop Policy, Practice and Legislation.

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[1]tide (together in dementia everyday), Liverpool, United Kingdom. [2]tide(together in dementia everyday), Liverpool, United Kingdom

Topic

Dementia as a public health priority: Engaging people with dementia and carers in policy

Abstract

tide is a UK wide network connecting carers and former carers of people with dementia to create real change together.

Whether it's making changes locally or influencing at a national level to create policy change; We support carers to make their voices heard.

Recently tide members have:

- Shaped legislation - Anne's Law is currently under consultation in Scotland to deliver it in primary legislation, to ensure that people who live in adult care homes have the right to see and spend time with the people who are important to them – this started with a care home petition lodged by Natasha Hamilton (tide carer)
- Worked with the Welsh Ambulance Service to improve awareness of dementia carers for ambulance staff to give insight into carers experiences of supporting loved ones living with dementia
- Been involved in a pilot project shaping GP's of the future by using their lived experiences to teach medical students about the struggles of life as an unpaid carer of a loved one with dementia
- Been involved with an EHRC inquiry into how unpaid carers can challenge local council decisions about Social Care and support.

We believe that carers and former carers have the experience and knowledge to improve health and social care and policy development throughout the UK.

We do this by working with carers to upskill them through our free Carer Development sessions to give them the confidence to speak up and speak out; to help create real change.

278

Hands-on Dementia: Reflexology Techniques as a Tool for the Caregivers of Persons Living with Dementia

Ms Oran Einhorn Aviv, Mr Jeffrey Lieder

Savion Senior Day Care Center, Kfar Saba, Israel

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background/Objectives: Most foreign live-in caregivers in Israel do not receive formal training to work with persons with dementia prior to their arrival, nor do they receive adequate support and training during their employment. This pilot program was created to offer instruction in hand reflexology as a tool for caregivers to assist in reducing anxiety experienced by their employers living with dementia.

Method: Four pilot programs were conducted at the Savion Senior Day Care Center in Kfar Saba, Israel. The caregivers learned how to work hand reflex points during 10 weekly, 1-hour classes. The course was held at the Center while the seniors participated in activities.

Results: Caregivers reported that when they applied hand reflexology, their employer exhibited reduced anxiety, improved sleep patterns, and created a better relationship between themselves and the older person. In addition, caregivers shared that the course itself improved their own self-esteem and offered them educational resources as well as moral support.

Conclusions: Hand reflexology may serve as an alternative or complement to other methods to enhance the quality of life for both persons living with dementia and their caregivers. In addition, such training will provide caregivers with skills and support they need in the daily management of behavioral and emotional challenges of their work. A broader research base is needed, however, to provide not only definitive evidence about the benefits for both persons living with dementia and the caregivers, but also its adaptability to senior day care centers world-wide.



279

Stabilise, Energise, Realise: a long term plan for social care

Mr James White[1], Mr Richard Sloggett[2], **Ms Fiona Carragher**[1]

[1]Alzheimer's Society, London, United Kingdom. [2]Future Health, London, United Kingdom

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

In September 2021, we launched a new report, 'Stabilise, Energise, Realise: a long term plan for social care,' produced jointly with Richard Sloggett of Future Health. The report lays out a long-term social care plan for Government across three phases – **stabilise**, **energise**, and **realise**, and builds on our #CureTheCareSystem campaign.

It's undeniable that the Covid-19 pandemic had a devastating impact on people affected by dementia, along with others, and it's vital that its legacy is a properly reformed social care system. The Stabilise, Energise, Realise report deliberately takes a positive, constructive approach which acknowledges the challenges the sector has faced, while also working from the position that meaningful change is possible and within reach over the next decade.

This perspective is backed up by 30 recommendations across seven key areas: funding, workforce, public engagement and information, quality, integration, carers, and new technology and investment. As well as drawing upon experts from the sector, the report was written following interviews with people affected by dementia, and advocates a focus on delivering personalised care that offers choice and control and that's tailored to people's wants and needs, beginning with the simple question 'what matters to you?'

The stepped plan proposed in the report makes suggestions about how social care itself can be reformed, meaning it's an especially important influencing tool as we move forward from the Government's recent announcements on the funding of health and social care and the introduction of a new health and social care levy.

280

Association between cognitive impairment and falls in older patients: a systematic review

Dr Victoire Leroy[1], Dr Valérie Martinet[2], Dr Christel Dentel[3], Dr Hélène Durand[4], Mr David Mockler[5], Dr Yaohua Chen[6,7]

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

INTRODUCTION

Dementia is a well-established risk factor for falls. However, the association between cognitive impairment without dementia and falls remains to be elucidated. In 2012, Muir *et al.* have shown association between global measures of cognition, executive functions and falls in a systematic review. More data have been published since then, particularly in patients with Mild Cognitive Impairment (MCI).

Thus, the aim of this review is to update the link between falls and cognitive impairment.

Methods: From 5 electronic databases, we selected articles published between Jan 2011 and Jun 2021. Inclusion criteria were observational studies, persons aged 65 or more, having a cognitive assessment and having falls as the main outcome. Four researchers independently selected articles and assessed the quality of the selected articles. Conflits were solved by another researcher. Quality was assessed using STROBE checklists.

Results: From 4346 articles initially retrieved, we selected 41 eligible studies, including 11 in defined persons living with MCI. Among them, only 5 (45%) found a significant association between falls and MCI. In populations with an unclearly defined cognitive status, 11 out of 20 (55%) studies found a significant association between cognitive decline and falls.

Methods used were highly heterogeneous, particularly in the method of collecting falls, the diagnosis of cognitive decline or mild cognitive impairment, and the cognitive assessment.

Conclusion: Association between cognitive impairment and falls met discrepant **Results:** Further studies are needed to better characterize the association, define the most predictive variable, and to generate recommendations to prevent falls in this population.



281

Mandate equal financial professional protection for seniors as juniors campaign

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

Ontario, Canada, teachers are mandated by law, and by their professional teachers' code of ethics, to report their vulnerable at-risk young students, juniors. Similar legislation for all professionals who are in contact with older people, seniors, must now be mandated.

This is particularly important in the financial professions, for which there are over 208 worldwide designations. Professional codes of ethics and professional dementia awareness training are not sufficient to protected vulnerable seniors, specifically, undiagnosed vulnerable seniors. We need country-specific and international senior professional protection legislation.

We must raise the awareness to lead the creation of legislation to protect seniors as effectively as juniors are protected. Since senior women are often not as well versed as senior men in financial matters, this is also a gender issue in financial matters.

282

It is often possible to enable those living in the later stages of Dementia to talk when many no longer consider that conversation is either understandable or possible

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Topic

Dementia awareness and friendliness: Language challenges and how to overcome them

Abstract

Those living with dementia can forget words, as word sounds separate from their meanings or be unaware they are not making sense.

There are 5 main ways to enable speech: Music, Singing, Laughter, Convergent, Parallel

Musical awareness and enjoyment remain until the end. releasing positive emotion

bringing back memories. enabling activities to be be carried out more successfully.

Music improves cognitive function enabling speech. stimulating the right side of the brain

They can come alive. Singing stimulates the left side so work well together. After singing some can read aloud and even speak for a while.

Laughter stimulates the production of chemicals in the brain making us feel good. After a good laugh, many can tell stories from their past with ease.

Convergent If someone with dementia is talking in 'word salads', refect back the emotions used repeating any word sthat makes sense, It takes considerable time but they can then speak several perfectly understandable sentences.

Parallel Someone not communicating by words may have 'frozen inside' perhaps anxious or being asked a factual Q, so turning away from them to talk about something nearby can release them remembering with them can enable them to join in If stuck on a particular phrase, continue talking to them as if they are making sense as they might not realise that they are 'stuck'.



283

Use remote multi-component training programs to improve the dementia care competence of foreign care workers

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Objectives: The purpose of this study was to examine the effectiveness of the remote multi-component training program to improve the competence of foreign care workers to care for person living with dementia in Taiwan

Method: This study was divided into two phases. In phase 1, questionnaire surveys and qualitative interviews were adopted at the dementia care center to understand the training needs for foreign care workers. In phase 2, the training programs were implemented and evaluated.

Results: A total of 21 foreign care workers and family members participated. In Phase 1, the results showed the foreign caregivers were faced with the following care problems: (a) lack of dementia care information, (b) insufficient real-time two-way language communication platform, (c) lack of guidance tools for daily care, and (d) insufficient ability to cope with behavioural problems. In Phase 2, develop and provide remote multi-component training programs, including: the establishment of line groups, teaching translation app operation, using daily life communication diagram card, video learning and BPSD handling tips. The post-test data was collected at 1 month after the training program administered. The results of this study showed that the implementation of the training program can effectively improve the dementia care competences of foreign care workers.

Conclusions: Our study showed that the remote multi-component training programs were effective in improving the quality of care for foreign care workers in other countries, especially during the period affected by the COVID pandemic.

285

#demenzraum – an easy-access online initiative to inform carers and people with dementia

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Information and advice for those affected with dementia, caring relatives and all interested parties; Initiative against the stigmatization of dementia. The most important goal is to educate, remove taboos and de-stigmatize dementia. This should be achieved through information, advice and networking among viewers. Different aspects and facets of the topic of dementia should be dealt with, as well as self-help and support offers for those affected and their environment should be explained. Through the cooperation and the presentation of other institutions as well as the inviting of different (famous) guests, the format and the associated topic of dementia should appeal to an even broader audience. As a simple online format, the inhibition threshold to deal with the topic in this way should be reduced. On the one hand, there is the opportunity to actively participate in the live events and to ask questions; on the other hand, the option of reviewing the events on YouTube ensures a certain anonymity and independence of time. The broadcast takes place live online every 2nd Wednesday per month. Each program has a different focus, for example those affected with dementia such as Helga Rohra are guests and tell about their lives, experts such as Naomi Feil and authors as well as Promenz as a self-help group provide information on all aspects of dementia. Questions can be asked live. Then the broadcast is posted online on youtube and questions can still be brought in via e-mail (demenzraum@kwp.at) (episodes viewed 300-500 times / shared on social media)



286

The Preferences of Older Self-funders in Navigating Community Social Care (the PRESENCE study)

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Older people living at home who pay privately for social care ('self-funders') face significant challenges in finding and choosing their care. All self-funders (and their families) should get help with this care navigation, especially as most people receiving home care have dementia or some kind of cognitive impairment. However, lots of older self-funders are left to 'go it alone', making some very important decisions that they have not considered before, often at quite a troubling time of their lives, leading to poorer outcomes. This study examined the preferences of older self-funders and informal carers for support in navigating community social care and the different approaches taken when making decisions. To understand what people most value a discrete choice experiment (DCE) survey was completed by 182 participants. In-depth qualitative interviews(n=37) were undertaken to examine how they made decisions when choosing care. Early findings show people valued information about the quality of care provided by an organisation but they also wanted help to think things through, so they could make use of information more easily. Importantly, people were prepared to pay for help in 'navigating' the system, rather than being left to 'go it alone'. Not all people looked for care in the same way and they had different preferences when choosing care. The final stage of this study will be a series of action planning workshop (with key national and local stakeholders) that will specify mechanisms for achieving impact to improve the experience of older self-funders when navigating their care.

287

Dementia in North Macedonia- current state of affairs in the management of dementia by the healthcare system

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Topic

Dementia as a public health priority: Healthcare system readiness

Abstract

As an upper-middle-income country, for North Macedonia dementia is becoming a rising health priority. In the previous years, there are improvements in the diagnostic process and the technologies used, but the post-diagnostic support and management of dementia remain challenging. This overview aimed to investigate the current state of dementia in North Macedonia.

We used data from the E-health system, The State Statistical Office, and the Health Insurance Fund to create this overview.

The data collected from the E-health system shows that in 2019 there were 17 367 people diagnosed with dementia. Most of the patients are women (64%) and diagnosed with Alzheimer's-related dementia (88.3%). The average age of the patients is 78.6 years. The diagnostic procedures for dementia have improved in the past four years with the introduction of liquid biomarkers (SPEC and CSF) in two Outpatient clinics. The main treatments of dementia in Macedonia are still pharmacological. Patients are usually prescribed donepezil or memantine. According to the Health Insurance Fund, in 2019, only about 35% of the people diagnosed with Alzheimer's disease were taking donepezil. Information on memantine is unavailable, as it can only be bought privately.

This overview shows that there is a significant problem of underdiagnosis of dementia in North Macedonia based on the comparison between the current and expected number of diagnosed people for the size of the population. Additionally, it raises a question about the availability of the prescribed medical treatments for dementia patients and proposes directions for further investigations.



288

My journey in returning to sport

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Topic

Dementia risk reduction: Dementia and sport

Abstract

In line with current research that identifies the involvement in Physical Activity as a key component in the rehabilitation of those who have been diagnosed with Dementia, this abstract aims to provide insight into the benefits of a personalised training program that has enabled myself, who was recently diagnosed with Younger Onset Alzheimer's Disease, to return to sport. Namely, Masters Swimming and Masters Surf Lifesaving, at a local, State, National and International level.

Additionally, to making a number of lifestyle changes, such as eating healthy, losing weight, and following a regular strength, flexibility, and fitness program, this abstract specifically refers to the inclusion of selected neurological rich exercises that are designed to improve your balance, reflex actions and coordination. Referred to as NCTP (Neuro-Cognitive Training Program) by my exercise physiologists, it is hoped that these exercises have over the past 18 months, allowed my brain to rewire itself (neuroplasticity), thereby allowing neuro-connective adaptations to form between my sensory and motor neurones. Resulting in a more co-ordinated sequence of movements which will enhance my performance. This will be evident not only in better times being recorded for each of the events that I am currently participating in but it will also *'build my capacity'* to participate in a wider range of events throughout 2022.

It is hoped that my performance results will shed light on the application of these neurological rich exercises as a means of addressing some of the balance and coordination issues that arise as this disease progresses.

289

Clinical and Imagistic Aspects in Young Onset Dementia

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Topic

Dementia research and innovation: Young onset dementia

Abstract

Aims: Dementia in young individuals can be difficult to diagnose since the symptoms and investigations are frequently nonspecific. A direct result of this is that people with young onset dementia are more likely to be misdiagnosed. The primary goal of this study was to emphasize the importance of brain imaging in the first evaluation of patients with subjective cognitive decline.

Method: This cohort study was conducted at The Memory Center Bucharest. A total of 110 individuals aged between 45 and 65 years old, who presented to our tertiary care system were included. During their admission, an evaluation of the cognitive status and brain CT scan were performed.

Results: Neuroimaging is required for the examination of individuals up to 65 years of age with subjective cognitive decline, since solo psychometric evaluation is inadequately sensitive at the stage (80.9% of participants achieved a MMSE score>24). There is a negative correlation between the degree of brain atrophy detected by CT scan and the MMSE score ($p<0.001$, $r=-0.530$). Furthermore, cerebral atrophy is related to a variety of risk factors, including hypertension ($p=0.003$), diabetes ($p=0.44$), history of mental disorders ($p<0.001$), and alcohol use disorder ($p=0.004$). There are significant changes at neuroimaging level, cerebral atrophy having been associated with ventricular dilatation (17.3%), asymmetric atrophy (11%) and leukoaraiosis (9.1%).

Conclusion: Neuroimaging proves to be an indispensable tool in the process of diagnosing young onset dementia. The onset of the neurodegenerative process requires the corroboration of the results of psychometric cognitive evaluation tests with those of structural neuroimaging.



290

Increasing social engagement through community involvement

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Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Social awareness, isolation and reduced opportunities for social engagement are well documented as key factors that need to be addressed in the rehabilitation of people who are living with dementia. This abstract aims to identify positive aspects of two novel initiatives that have not only promoted social engagement and helped reduce social isolation, but they have also raised community awareness about dementia.

The first initiative involves the novel idea of a wearing a 'Hello t-shirt' which invites people to say hello to each other as they cross paths while walking along the coastal walkway that connects South Curl Curl beach to Freshwater headland. By incorporating my own mental health and well-being on the sleeve of the t-shirt, I also hope to raise community awareness about dementia. As one of my passions is swimming, the second initiative involves a fundraising event where participants will spend the day travelling throughout the Northern beaches and swimming one lap of the 14 rock pools that are located in this area.

As a person who experienced a loss in confidence and the ability to socialise with people, the benefits of both initiatives have been enormous. Not only has it encouraged me to get out in the community, by meeting and making many new friends, but I now feel that my eyes, mind, and heart have been re-opened to all the other wonderful things that are happening around me. More importantly, I am helping to build a community where everyone is valued and treated equally.

291

The Power of remaining Positive

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Personally, I found my diagnosis of Alzheimer's disease to be devastating, as it left me confused and uncertain of my future. With no cure on the horizon, I lost hope and became apathetic in how I viewed life. However, after a chance trip to Japan, I realised that I needed to create a new life, based on new dreams and new goals. This abstract aims to describe my journey in creating a multi-modal approach that not only helps me to manage my health and well-being, but more importantly, it gives me hope for a better quality of life in the future.

Symbolically, I choose the Tree of Life to represent my approach as I wanted to show that the four dimensions in our lives (Body, Mind, Heart and Soul) are all interconnected by the same core theme – the need to remain positive through our thoughts and actions (positivity). Based on my own circumstances, I then created 'leaves of positivity' for each of these dimensions. These leaves represent the daily actions that I have undertaken and the changes that I have made to my lifestyle. When joined together, they form my Tree of Awakening your Positivity (TAP).

After two years, I believe the success of this approach, is evident not only in my positive outlook on life but more importantly on the quality of life that I am currently experiencing. For this reason, I believe my approach would be beneficial to many others who have a similar diagnosis to mine.



292

The position of informal dementia caregivers in North Macedonia: experiences with the healthcare system, needs and subjective experiences of the caregiving role

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

This study aimed to describe the characteristics, experiences, and needs of informal dementia caregivers in North Macedonia. The data was collected in August 2021 through an online questionnaire.

The questionnaire consisted of four sections: demographic questions, The short version of the Zaritt Burden Interview, Questions about the experiences with the healthcare systems in a Likert scale format and a multiple-choice question about caregiver's needs. Sixty caregivers answered the questionnaire.

The data showed that most of the participants are women, from Generation X, employed and caring for a parent. The majority of the participants (72%) have a care partner but still dedicate many hours in the care of their relative with dementia and experience moderately high levels of psychological burden (M= 27.23). Regarding the experiences with the healthcare system, there are divided opinions on the efficacy of the diagnostic process. The participants are generally dissatisfied with the quantity of information on management and support given upon diagnosis and the availability of the healthcare institutions. Among the caregiver's needs, as most prominent ones surfaced the need for daycare centres, training for informal caregivers and professional consultations.

These results illustrate the gaps in the systematic management of dementia in North Macedonia from diagnosis to post-diagnostic support and how they reflect on the informal caregivers. As dementia becomes a pressing healthcare priority, especially in low- and middle-income countries, there is a need for a comprehensive management system to support both patients and family members.

293

ACTnow - Increasing cognitive reserve to treat mild cognitive impairment using concurrent computerised cognitive training and non-invasive neurostimulation

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Alzheimer's Disease (AD) is a major contributor to the rapidly growing dementia crisis that threatens to economically undermine the healthcare system. Mild cognitive impairment (MCI) is a crucial transitional stage with a 15-20% conversation rate into early-stage AD (Petersen et al., 1999) and ultimately progresses into dementia. It could, therefore, hold great value to the dementia crisis if MCI was effectively managed, alas, MCI is often overlooked.

The project aims to develop and test prototypes for an efficacious treatment in MCI in the form of digital therapeutics medical device, called ACTnow. It aims to boost cognitive reserve (CR), a fluid quality that mediates one's ability to cope with AD pathology. ACTnow is a software product and works by synergistically combining two promising therapeutic technologies, namely, a personalised computerised cognitive training (ACT) and transcranial direct current stimulation (tDCS). ACT is delivered in the form of interactive videogames on tablets and smartphones and activates the frontoparietal areas, which are associated with CR. Concurrently, the user will receive tDCS stimulation over the same neuronal network, the protocol of which is built in in the ACTnow software and can be used with available and mobile tDCS devices (hardware). The benefit of combining ACT and tDCS is that tDCS could upregulate brain circuitry neuroplasticity, and can thus augment the ACT outcome and enhance the overall intervention effect on CR.

The aim is for ACTnow to become the state-of-the-art non-invasive intervention to slow down the progression from MCI to AD and to improve symptoms.



294

Dementia- the blind spot of societies and healthcare systems: a qualitative study

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Dementia is a condition that can easily fit in the Social Model of disability as it is surrounded by a lot of stigma and false beliefs that penetrate deeply into societal structures. Additionally, there is a lack of social and systematic support that would allow people affected to live a life of the highest quality. Healthcare and social care institutions are not always competent to respond to the needs and demands of the people affected.

The aim of this study was to gain a better insight into the position of dementia within the social structures and the healthcare system. Nine semi-structured interviews were conducted with informal caregivers coming from different countries from July-September 2020. The data were analyzed using thematic inductive analysis out of which five main themes were derived.

The results show that families of people with dementia are not given enough relevant information to support them in coping with the condition. They feel that the responsible institutions are inert in responding to their demands, and there is a general mistrust in their competence to support people with dementia. There are high financial demands that are difficult to meet and on top of everything, caregivers are pressured by societal norms and expectations regarding their caregiving role.

It is of the highest importance to work on optimizing the 'social treatment' for conditions that are yet untreatable. This is a crucial step towards overcoming feelings of despair, hopelessness and fear upon diagnosis and building environments where people with dementia could thrive.

295

A parallel qualitative study of the RECage project (Respectful Caring of Agitated Elderly): preliminary data

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Background: The RECage Project, funded by the European Commission, has a threefold objective: a) to validate a clinical intervention (the Special Care Unit for BPSD, SCU-B) through a clinical trial; b) to adapt it and produce a consensus document; c) to promote the implementation and scaling up. The clinical trial is a multicentre, multicountry study. Since the centres, besides the common features, have also relevant peculiarities, we are running a qualitative analysis of the participating SCU-Bs and their context.

Method and Results:

1. Questionnaire about the SCU-B: the structure of the SCU-Bs is not homogeneous;: the number of beds varies from 5 to 23; the length of stay from 18 to 90 days. The specialist care is entrusted mainly to psychiatrists or geriatricians. Only in one country (France) there is a national web of SCU-Bs: in one country (Greece) there is no SCU-B; in the others the number varies a lot.
2. Focus groups: the goal is to provide context and needs analysis for each centre (SWOT analysis) involving healthcare professionals and stakeholders. The preliminary results of this analysis will be presented in form of a table with four components
3. Exploring the potential of social innovation and replicability: SCU-B can be considered socially innovative as it satisfies unmet social needs; replicability is fraught with economic problems.

Conclusion: This qualitative analysis showed the challenges and pitfalls related to SCU-Bs, building up the knowledge for a consensus model of care, which is crucial for future widespread implementation.



296

"I don't want things done to me, I want things done with me" – Engaging People Living with Dementia and Unpaid Carers in Responding to the Scottish Government's National Care Service Consultation.

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Topic

Dementia as a public health priority: Engaging people with dementia and carers in policy

Abstract

Debates range across Europe on the most effective means of organising social care, with a major tension existing between local and centralised models. Scotland's proposed National Care Service is one example of the latter. The extent to which these proposals will deliver services founded on human rights, personalisation and a preventative approach to social care are highly contested, with concerns raised that the voices of those with lived experience of social care will be lost in political posturing from vested interests.

This paper shares findings from direct engagement with people living with dementia, unpaid family carers, and civil society representatives about the NCS proposals. A mix of methods were deployed to maximise engagement including five online engagement sessions (two for people living with dementia, two for unpaid carers and an open session including third sector organisations), an online survey, and a twitter 'takeover.' Findings were written up and formed the basis for an organisational response to the proposals as well as a tool for influencing within the debate.

This approach to engagement generated a wealth of insights, allowing people living with dementia and unpaid carers to communicate their voices directly with policy and decision makers in the Scottish political sphere. In this paper we share some of the lessons learned, including spotlighting creative engagement undertaken at the first conference run by, for and about people living with dementia. We also highlight key recommendations for those seeking to conduct similar research with a view to influencing policy and practice.

297

Health care utilization among dementia care clinic attendees in the last three years of life

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aims: Little is known about patterns of health care utilization among dementia clinic attendees. The existing literature often does not recognize that patient contact with dementia clinics varies widely, from those attending just once, e.g. for confirmation of a diagnosis, to those attending regularly to access a range of treatment and support services.In this study, we examine probability and predictors of emergency department (ED) visits and inpatient hospitalizations in the last three years of life among dementia clinic attendees.

Methods: We conducted a detailed chart review of 396 patients seen at least once at a dementia clinic between 2012-2017, who were deceased by 2019.Ordered logistic regression and postestimation predicted probabilities calculations were used to examine whether demographic characteristics, frequency of dementia clinic contact, dementia subtype, hospice use, and driving time to the clinic predicted the probability of ED visits and inpatient hospitalizations in the last three years of life.

Results: Our results suggest that proximity to the dementia clinic and hospice use are key factors impacting late-life health care utilization. We find higher hospitalizations among those with dementia diagnoses with primary motor symptoms. Importantly, findings suggest that more frequent dementia clinic attendance may be associated with reduced ED utilization in the last three years of life.

Conclusion: The potential dose-response relationship between dementia clinic visit frequency and health care utilization merits further examination and arguably supports a more nuanced approach to assessing dementia clinic contact in future studies, capturing quantity and quality of contact.



298

The value of occupational therapy (OT) in memory assessment services – An evaluation of an innovative OT service to provide assessment, therapy and valued outcomes for people living with dementia.

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Purpose: Develop the first OT dedicated provision in Wales within Memory Assessment Services (MAS), aligned with Dementia Action Plan Wales objectives.

Ensure collaboration with people living with dementia and their care-partners, from concept, design and throughout delivery.

Seek lasting impact by sharing knowledge/evidence in working partnerships across Wales and beyond, creating an OT MAS provision blueprint.

Plan: Provide individual occupational profiles and occupational performance baselines to inform diagnosis (pre-diagnostic) and deliver early stage dementia OT intervention programmes (post-diagnostic).

Design intervention programmes to improve function and maintenance of skills by embedding meaningful strategies into individual routines, creatively exploring the use of digital technologies.

Evaluate service provision using the Australian Occupational Therapy Outcome Measure (AusTOMs).

Outcomes: Service evaluation demonstrates evidence of significant positive changes in everyday occupational performance for people living with dementia.

Evaluation at 3, 6 and 12 months indicates that despite the progressive nature of dementia, maintenance of skills aligned with the person's own therapy goals has been achieved.

Conclusion: OT intervention programmes were initially offered post-diagnostically. However, pre-diagnostic assessment identified OT intervention earlier in an individual's journey through MAS better supported consolidation of memory strategies and functional skills.

Providing OT intervention pre-diagnostically particularly supports the 'responsive' theme in the newly developed All Wales Dementia Standards, ensuring individuals have access to OT at the right place and right time to meet their functional goals when identified.

OT pre-diagnostic intervention will form part of the ongoing MAS model.

Publishing AusTOMs findings and evaluating OT intervention programmes are planned.

299

Tango for older people with dementia: a multicenter, prospective, observational study

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Introduction: Symptoms of dementia are a major cause of loss of independence in regards to carrying out activities of daily living (ADL). The most characteristic signs of the disease are memory and cognitive impairments. However, balance and gait disturbances are very often present, and they worsen the patient's overall condition. Therefore, the quality of life (QoL) is severely affected. These symptoms can be addressed through non-pharmacological interventions. Increasing research shows the effectiveness of dance and music in alleviating symptoms of various diseases.

Aims: to determine the effects of a tango dance intervention for older people with dementia living in nursing homes, with regards to physical performance, ADL, and QoL.

Methods: a multicenter, prospective, observational study with assessment at 0, 12 and 24 weeks. The duration of the tango dance intervention was 60min and was carried out weekly over six months. To assess the physical performances we used the Short Physical Performance Battery, the Katz Index was used to assess the independence to carry out ADL, and the QoL was assessed using the QoL-Alzheimer Disease scale.

This protocol was approved for the Research Ethics Committees of the University of Bourgogne.

Results: this multicenter study includes 20 facilities and around 200 participants. The first results of this research will be available from January 2022. For the conference in June 2022 we will have the results and a complete analysis of them.



300

'Dementia in India 2020' report- challenges and facilitators

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Alzheimer's Disease International recommends that every country has a national dementia plan and emphasises the work by non-governmental organisations serving as a case statement to persuade governments. Dementia in India 2020 is such a background document by the Alzheimer's and Related Disorders Society of India - Cochin and Kottayam chapters, with academic support from Kerala University of Health Sciences.

Purpose: In this paper we discuss the framework for successful completion of this work, highlighting the facilitators and challenges. The learnings from this project can be useful for any similar future work especially in resource-scarce settings, as a background document for development of a national dementia plan.

Project Plan: A core group meeting discussed the direction of the document and a stakeholders meeting focused on the challenges and priorities of dementia care in India. A multiple author document inviting experts to contribute on their areas of experience and expertise was planned.

Outcome: Dementia in India 2020 is probably the most comprehensive work on Dementia from India with fourteen chapters including current epidemiology, care costs, medical and non-medical treatment, rehabilitation, caregiver support and digital interventions. It alsoprovides a framework for developing a national dementia strategy in India. https://dementiacarenotes.in/dcnfiles/Dementia-in-India-2020.pdf

Conclusion: The challenges included ensuring user friendly language and accessible formats to stakeholders, balancing research evidence and clinical experience and involving care partners and people with lived experience of dementia in all stages of the work. The strategies used when undertaking such a massive project with minimal costs will be discussed.

301

Urban planning and design for dementia friendly communities: Perspectives of municipal staff in British Columbia, Canada

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Municipal dementia-friendly community (DFC) action plans in British Columbia (BC), Canada acknowledge the importance of the physical environment and spell out actions under this domain that are within the purview of City departments, such as planning, design, engineering, transportation, parks, and community services. However, it is unclear how these action plans influence urban planning and design practice. Therefore, we aim to understand the needs, challenges, and solutions to address local municipalities' priorities for a dementia-friendly physical environment. Semi-structured interviews were conducted with 15 municipal staff from different departments in four BC municipalities with DFC action plans launched in the last five years. Participants reported a range of systemic challenges to adopting the DFC lens in urban planning and design related to inadequacies in 1) awareness about dementia and training of municipal staff, 2) implementation and follow-up strategy, and 3) regional and provincial standards and guidelines for accessibility and wayfinding. Participants also indicated the value of research identifying best practices and exemplars, and integrated knowledge translation to facilitate dementia-friendly planning and design. Innovative methods of consultation and engagement, such as community walkabouts have proven useful to enable municipal staff to interact with people with dementia and their care partners while surveying the outdoors to identify key challenges and action areas. Participants indicated that with appropriate resources, advocacy, and buy-in to address DFC priorities in planning and design, a collaborative and user-engaged approach could be adopted to meaningfully involve people with dementia and their carers in the design process.



302

Cognitive functioning of unaffected first-degree relatives of individuals with late-onset Alzheimer's disease: A meta-analysis

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Topic

Dementia risk reduction: Risk factors

Abstract

Background: The associations between family history oflate-onset Alzheimer's disease (LOAD) and cognitive decline remain unclear. In this quantitative review, we provide the first meta-analysis on the cognitive profile of unaffected first-degree blood relatives of LOAD-affected individuals compared to controls without a family history of LOAD.

Methods: A systematic literature search was conducted in PsycINFO, PubMed /MEDLINE, and Scopus up to November 2020. Structural equation modeling controlled for non-independent effect sizes.

Results: Thirty-four studies enabled us to estimate 218 effect sizes across several cognitive domains. Overall, first-degree relatives (n = 4,086; mean age = 57.35) showed significantly inferior cognitive performance (g = -0.16, 95% CI [-0.25, -0.08], p < .001) compared to controls (n = 2,388; mean age = 58.43). Specifically, controls outperformed first-degree relatives in language, visuospatial and verbal long-term memory, executive functions, verbal short-term memory, and verbal IQ. Furthermore, cognitivetest type was significantly associated with between-group differences, andAPOE ε4 carriership amongst the first-degree relatives was associated with more significant cognitive dysfunction.

Conclusions: The current findings provide strong support for mild but robust cognitive dysfunction in first-degree relatives of LOAD-affected individuals that appears to be moderated by cognitive domain, cognitive test type, and APOE ε4.



303

Cultivating normality and upholding dignity in home care services for people with dementia

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Topic

Dementia diagnosis, treatment, care and support: Dementia and dignity

Abstract

Aim: The aim of this study was to learn about the nature of home care services for people with dementia from the perspective of the home care workers. Of special interest were the beliefs, values, ideals, and ambitions that guided the home care workers' practice.

Method: The study applied an ethnographic approach. Data consisted of written materials and audio recorded reflections that were collected during a project aiming to improve the use of evidenced knowledge in home care services for people with dementia. Thirty-four home care workers and four facilitators (also authors) participated. The data was interpreted parallel to the data collection, applying a constant comparative approach.

Preliminary Results: The home care workers emphasised dignity, doing good, and supporting normality as central motives for the care. This was expressed in examples concerning the persons they cared for. Dignity concerned for example maintaining oral health and serving appropriate food, according to the persons' wishes and cultural traditions. Doing good was expressed in stories about going over and beyond the call of duty to support well-being in the persons cared for. Dignity and normality were interrelated. The staff described striving to uphold normality in the everyday life of the cared for persons, to preserve their dignity.

Conclusion: The study provided in-depth knowledge about the moral reasoning and motives held by the home care workers specialised in care of people with dementia. The findings can inform quality improvement in home care for people with dementia and form a basis for future research.



304

Cost-effectiveness of the digital platform "support, monitoring and reminder technology for mild dementia" (SMART4MD) for people with mild cognitive impairment and their informal caregivers in Sweden and Spain

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Background: The aim of this study is to estimate the cost-effectiveness of a smartphone application (SMART4MD) designed specifically for persons with mildcognitive impairment (PwMCI) to improve or maintain quality of life.Some important features of the app include reminders (e.g., medication, healthcare appointments), cognitive support (e.g., cognitive-stimulating games and photographs), and an optional function where health information can be shared with family andinformal caregivers (e.g., day-to-day health status, specific health problems and quality of life).692 dyads (intervention=347 and control=345) from Sweden and Spain participated in this 18-month trial.

Methods: The cost-effectiveness analysis is performed from the health care provider perspective. The cost data include intervention cost as well as inpatient-, outpatient-, and primary care cost, which are derived from administrative registers.Quality-adjusted life years is the primary outcome measure for PwMCI and informal caregivers. Secondary outcome measures are Quality of Life-Alzheimer's Disease for PwMCI and Zarit Burden Interview for informal caregivers.The results are presented as incremental cost-effectiveness ratio. The 95% confidence interval around the ICER is estimated using 5000 non-parametric bootstraps.

Results: Preliminary results suggest that the cost of the intervention is not statistically significantly higher than standard care.The effectiveness analysis is still ongoing. However, indications are, based on short-run data from the Swedish site, that the intervention is effective for informal caregivers but not for PwMCI.

Conclusions: Early preliminary analyses of the cost-effectiveness of the SMART4MD app are inconclusive but this may change in the ongoing work of analyzing the full data.

305

Tetrahydropyrimidine-5-carboxamides as selective and ATP-Competitive GSK-3β inhibitors: a disease-modifying strategy for Alzheimer's Disease

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: Alzheimer's Disease (AD) is one of the significant diseases of the aging population and affects Central Nervous System dominantly. Overactivity of Glycogen synthase kinase-3β (GSK-3β) causes tau's hyperphosphorylation, leading to microtubule destabilization, neurofibrillary tangles formation, senile plaque formation/deposition, which are the major hallmarks of AD, hence making GSK-3β an attractive target for AD.Although GSK-3βis an attractive target for AD, there is no single GSK-3βinhibitor in clinical trials for AD. Therefore, the development of GSK-3β inhibitors is a prompting challenge and is the need of the hour for AD treatment by disease-modifying approach.

Method: In the current study, 50 derivatives of tetrahydropyrimidine-5-carboxamide were synthesized and investigated for *in-vitro*kinase inhibitory activity against GSK-3β and other related kinases. Molecular modeling studies were performed on the synthesized compounds to get an insight into the protein-ligand interaction. ATP-competition assay was performed for determining the mechanism of action of synthesized molecules.

Results: Here we report the synthesis of 50 compounds with good to excellent yields. Synthesized compounds showed promising results; compound RM-SU-J-124 showed IC50 of 6.06 μM against GSK-3β and showed selectivity over other related kinases. Kinetic experiments revealed that compounds were inhibiting GSK-3β in an ATP-competitive manner.

Conclusion: We successfully identified tetrahydropyrimidine-5-carboxamide derivatives as selective and ATP-Competitive GSK-3β inhibitors. These results will encourage the exploration of tetrahydropyrimidine-5-carboxamide as valuable drug lead for the treatment of AD.



306

Examining the health and social care needs of older people living with dementia in Bangladesh

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Context: Older people (60 years and over) in Bangladesh account for approximately 8% of the population and this proportion is projected to increase to 21.9 % by 2050. Moreover, dementia prevalence in Bangladesh is estimated to be between 4% and 19%. International literature reports that people living with dementia have a range of unmet needs (physical, psychosocial, and spiritual) and experience a decreased quality of life.However, most of this research is conducted in high-income countries and there is a paucity of evidence on the needs of people living with dementia in Bangladesh.

Objective: To examine knowledge of dementia and the health and social care needs of older people living with dementia in Bangladesh as reported by their family carers.

Methods: This research adopts a mixed-methods design. Family carers of people living with dementia in Bangladesh were administered surveys (Camberwell Assessment of Needs of Elderly, and Dementia Knowledge Assessment Scale) and participated in in-depth interviews to explore the met and unmet needs of individuals with dementia.

Results: The study will examine both the met and unmet needs of older people living with dementia in Bangladesh as perceived by their family carers. Our findings will also explore to which extent the carers consider that current health and social needs are being met for people with dementia.

Conclusion: Understanding the needs of people living with dementia will help strengthen the health and social care delivery arrangements for this group of people in Bangladesh.

307

Global projection study to 2060: serious health-related suffering from dementia

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aims: To project the burden of serious health-related suffering (SHS) associated with death from dementia to 2060, by World Bank income region, age and gender.

Methods: Global population-based projections of the future burden of SHS as defined by the Lancet Commission on Palliative Care and Pain Relief, combining WHO mortality projections (2016-2060) with prevalence estimates of physical and psychological symptoms requiring palliative care, among people dying from dementia.

Results: By 2060, an estimated 7.2 million people will die from dementia (compared to 2.0 million in 2016). Of these, 5.8 million (80%) will experience SHS due to physical and psychological symptoms requiring palliative care (compared to 1.6 million in 2016). The majority of these deaths occurred in low- and middle-income countries in 2016 (64%, 1 million) and will increase further until 2060 (70%, 4 million). Globally, 93% of the individuals dying from dementia with SHS occurred at ages of 70 years and over in 2016, increasing to 97% in 2060. Women account for most of the burden of SHS from dementia (65%, both in 2016 and 2060). However, in high-income countries, the number of men affected is expected to increase more than women until 2060 (362% vs. 280% increase).

Conclusions: The burden of SHS from dementia will almost four-fold from 2016 to 2060, with the fastest rises in low- and middle-income countries, those aged 70 and over and men in high-income countries. Policies and care models targeting palliative care in dementia are urgent.



308

Stigma and discrimination related to dementia in Brazil: Qualitative study

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aim: This study aimed to understand stigma in relation to people living with dementia in São Paulo, Brazil.

Methods: We used a critical narrative inquiry methodology informed by Link and Phelan's sociological theory of stigma. Data were collected through face-to-face semi-structured interviews (6 people living with dementia, 15 family carers) and online and face-to-face focus groups (8 healthcare providers, 15 members of the public). Findings: We noticed low levels of knowledge and awareness about dementia among all groups. Enacted stigma was expressed by healthcare providers and members of the public through secrecy and avoidance, negative attribution, and blame, and through reports of undefined and abusive care. Negative perceptions of people living with dementia were common and included being dangerous, time consuming, difficult to relate to, and abnormal. People living with dementia appeared to manage the negative views of dementia through minimising and normalising the condition, highlighting their ability to live an active life, and emphasising the positive impacts of dementia in their lives. Fear of negative reactions appeared to lead to selective disclosure of their diagnosis. Among family carers, stigmatising attitudes coincided with a strong willingness to protect the person cared for and to validate their caring experiences. However, this led to depersonalising and infantilising attitudes towards people living with dementia, underestimating their capacities, demanding 'obedience', and restricting the person's freedom.

Conclusion: There is an urgent need to reduce dementia-related stigma and to promote empathetic and compassionate attitudes towards people living with dementia among Brazilian population.

309

Reducing dementia-related stigma and discrimination amongst community health workers in Brazil: Protocol for a randomized controlled feasibility trial

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: Stigma and discrimination related to dementia are common. This is particularly important among healthcare workers,considering thedetrimental impact on the lives of those living with the condition and their families.

Aim: We will develop, implement, and evaluate the feasibility of a three-day (9 hours) group intervention to improve knowledge and attitudes and reduce the stigma and discrimination related to dementia among Community Health Workers (CHW) in Brazil.

Methods: This will be a controlled and randomized feasibility study conducted with 150 CHW from 20 Primary Care Units (PCU) located in São José dos Campos, São Paulo. The 20 PCU will be randomly allocated (1:1) in two parallel groups - experimental group (EG) or control group (CG). CHW from PCU allocated to EG will receive an intervention using audio-visual and printed materials seeking to increase knowledge, improve attitudes, as well as reduce stigma and discrimination in relation to people with dementia and their family carers. The CG will follow their usual routines. Assessments: Baseline measurements will be applied to both EG and CG and will include socio demographic data and questions on attitudes, knowledge and intended behaviours towards people living with dementia. At follow up (30 days), in addition to the same measures as in baseline, EG will receive questions on feasibility. A subgroup of the EG will participate in semi-structured interviews. Quantitative analyses will follow an "intention to treat" approach and the feasibility data will be analysed descriptively. Content analysis will be used to analyse the qualitative data.



310

Fear and Dementia

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Fear, it grips you when you get diagnosed, if you're lucky find your way through the fear, for most it's the fear of the unknown. They, like most of society, have been for years fed the images of people with dementia being totally disabled, not just cognitively but physically as well, images of people in wheelchairs, staring into space, drooling and needing full care.

This misinformation that was allowed to be displayed and promoted, is the worst thing that happened to dementia and all those living with the illness. It remained and by and far still is the image many imagine people conjure up in their minds when they think about someone living with dementia.

Upon diagnosis, those images dance through your mind, causing depression, anxiety and fear.

It causes us to hide, isolate, give up. It Takes away hope, purpose, self esteem

Fear is about others thinking that they know and understand more than those living with the illness.

Fear is about being subjected to what all those old outdated belief systems mean for me when I finally do reach the late stage.is the support of peers, others living with dementia, not care givers, family or friends but peers, they are the only ones who can grasp what and how you are feeling.

So Fear about Dementia actually isn't fear about Dementia, but the fear of the unwillingness for those who can drive change actually have the courage to do it.

311

Physiotherapist Roles, Perceptions, Level of Knowledge and Attitudes on Delivering Treatments for Older People with Dementia in Indonesia: A Cross-Sectional Study

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Objectives: The aims of the study were to i)explore the current practice, roles and perceptions of physiotherapists who treat older people with dementia in Indonesia, ii) identify the level of knowledge and attitudes about dementia among physiotherapists treating people with dementia in Indonesia.

Methods: This was a cross-sectional study in which registered physiotherapists in Indonesia were surveyed online using Qualtrics. Descriptive statistics and linear regressionwere used in this study. The Dementia Knowledge Assessment Scale (DKAS) was used to assess level of knowledge and attitudes about dementia. Qualitative data from the survey were analyzed using thematic content analysis.

Results: The online survey was sent to 6,327 physiotherapists who met the inclusion criteria and 1,061 (16.8%) returned the survey. Eight hundred and eighty-four (83.3%) respondents worked with older patients, and 632 (59.6%) worked with people with dementia. Average percentage of practice time spent treating older people with dementia was 35.9% and most common treatment provided for older people with dementia was exercise (88%).TheDKASmean score (SD) was 32.1 (±5.1)/50 indicating some limitations in dementia knowledge by respondents, and 62% of physiotherapists reported low levels of confidence in treating older people with dementia.

Conclusion: The relatively low dementia knowledge, and generally low confidence in treating people with dementia among Indonesian physiotherapists were important findings in this study. This study highlights opportunities for improvement in physiotherapist's knowledge and skills in this emerging area of practice in Indonesia.



312

Effects of an art-based intervention in older adults with mild cognitive impairment: a randomised controlled trial

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: Art-based interventions may delay cognitive decline and improve health-related outcomes in older adults with mild cognitive impairment (MCI).

Objective: To examine the effects of the Creative Expressive Arts-based Storytelling (CrEAS) program compared to active and waitlist controls on neurocognitive outcomes and other health-related assessments inolder peoplewith MCI.

Design: Three-arm parallel-group, randomised controlled design.

Participants: One-hundred and thirty-five adults with MCI (mean age: 70.93±6.91 years).

Methods: Participants were randomly assigned to the intervention (CrEAS, n=45), active control (n=45), or waitlist control (n=45) group. Interventions were applied once per week for 24 weeks. The primary outcome was global cognitive function; secondary outcomes were specific cognition domains (memory, executive function, language, and attention) and other health-related outcomes (anxiety, depression, and quality of life[QoL]). All variables were measured at baseline(T0), 24-weekfollow-up (T1) and 48-week follow-up (T2).

Results: Participants in the CrEAS group showed significantly higher global cognitive function (adjusted mean difference [MD]=-0.905, 95% confidence interval [CI] -1.748 to -0.062; *P*=0.038) and QoL (adjusted MD=-4.150, 95% CI -6.447 to -1.853; *P*=0.001) and lower depression symptoms (adjusted MD=2.902, 95% CI 0.699 to 5.104; *P*=0.011) post-intervention at the 24-week follow-up compared with the active control group.At 48-week follow-up, only the Auditory Verbal Learning Test Immediate recall score was significantly improved compared with the active control group (adjusted MD=-2.941, 95% CI -5.262 to -0.620;*P*=0.014).

Conclusions: Older adults with MCI who participated in the CrEAS program improved their neuropsychological outcomes and QoL and reduced their rate of cognitive deterioration.

313

My Life, My Goals: co-producing a self-help resource to support people with dementia to set and achieve their goals

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

My Life, My Goals is a self-help resource for people in the earlier stages of dementia. It was co-produced in 2021 with a team of people with dementia, building on research from the University of Exeter around cognitive rehabilitation (the GREAT programme). It is a dementia accessible resource full of ideas, stories, strategies and solutions to help people with dementia think about their goals and strategies and how to tackle them. This includes how to identify a goal, deciding on a goal, getting in a positive frame of mind (leaving stress behind), choosing the best method for working towards a goal and creating a plan. It is intended to give people with dementia hope. Hope that there are ways to manage difficulties. Hope that there are solutions to problems. Hope that you can lead a good life with dementia. The resource is currently being disseminated across the UK to reach people who are newly diagnosed with dementia. It has also been of interest to other countries, who have initiated their own translations of the resource.

Our presentation, with people with dementia, will describe the development of My Life, My Goals - how we became a team that talked, learned, shared, translated, wrote and designed this new post diagnostic resource. It will highlight some of the research around cognitive rehabilitation for people with dementia including some additional resources e.g.a short animation and e-learning modules for practitioners. We will describe our work as an example of good co-production practice.



314

Transitioning from institutionalised care to a person-centred approach: Perspectives from a long-term care facility for people living with dementia in Ireland

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Saint Joseph's Nursing Home, Shankill, Dublin, Ireland

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aim: There is a growing prevalence of people being diagnosed with dementia in Ireland.Some circumstances may dictate that it is more appropriate for people with dementia to live in a specialised long-term care facility rather than at home. Some studies suggest that home-like facilities and person-centred care is better received by staff in long-term care. Therefore, this study aimed to explore perspectives of the transition from an institutionalised model of care, to a person-centred approach in an Irish long-term care facility for people living with dementia.

Methods: This study implemented a qualitative design. Staff and family members of residents were recruited (n=25) from one specialised long-term care facility. Semi-structured interviews lasted approximately one hour, and results were analysed using thematic analysis.

Results: We describe themes on staff opinions on the person-centred care, perspectives on resident well-being, and family member experiences while their loved ones are in care.

Conclusions: The results of this study highlight the experiences of both staff and family members of residents living with dementia as they navigated the implementation of person-centred, emotion-focused care in a long-term care facility. Findings have implications for people living with dementia in long-term care, as well as other services looking to improve their care for people living with dementia.

315

Pattern of Utilization of Psychosocial Interventions for Persons with Dementia: A Retrospective Study from Tertiary Care Hospital, India

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background: Dementia is a term used for a group of symptoms that occur due to the death of brain cells. It is a clinical syndrome wherein deterioration happens in memory, thinking, behavior and ability to perform daily activities. It is a neurodegenerative condition and one of the significant causes of disability, dependency and shorter survival among older people worldwide. Psychosocial interventions play significant role in the management of persons with dementia.

Aim: To examine the pattern of utilization of psychosocial interventions for persons with dementia.

Methods: Thisstudy examined 54 persons with dementia who received psychosocial intervention from December 2019 – October 2021. All the persons with dementia who received psychosocial interventions in Out-Patient (OP) and In-Patient (IP) were considered for the study.

Results: The study population comprised 48% females and 52% males, 96.3% were married, and 3.70% were widows. The present study has a mixed population in the form of literates and illiterates who belonged to different socio-economic statuses. One-third of patients (29.6%) were dependent, 40.8% were independent, and 29.6% were partially independent on activities of daily living. The Psychosocial Interventions provided to persons with dementia are Breaking Bad News, educating the family members about illness, behavioral activation, patient safety measures, cognitive stimulation activities, palliative care and end of life care, addressing caregiver burden, disability certification, social welfare benefits, advance care planning and so.

Conclusion: The study elucidates the psychosocial interventions provided to persons with dementia. The psychosocial interventions provided were beneficial to the persons with dementia and their family members.



316

Understanding the Role of Technology Resources Based Intervention to Support Care Partners of Older Adults Living with Dementia

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aim: Approximately 15.7 million family care partners in the US alone support the needs of individuals living with a form or type of dementia. The impact of supporting someone with dementia can often impact social connectivity, social network, and social engagement leading to physical and psycho-social consequences including depression, anxiety, and lower quality of life. However, leveraging communication technology tools and interventions present promising opportunities to meet the needs of care partners. The aim of this research is to understand the current state of literature and help identify key themes and challenges related to the implementation of technology tools such as video-conferencing to support the social needs of care-partners.

Methods: This research applied PRISMA analysis principle to identify the existing literature on the application and implementation of communication technologies to meet the social needs of care-partners.

Results: The findings of our study indicate that communication technologies hold much potential in helping connect care-partners and provide increased resource accessibility. Across the current literature care partners often reported a positive affect towards the use of communication technology, improved knowledge, perceived social support, and mental health. However, only few studies have explored the use of video conferencing to support caregivers.

Conclusion: The implementation of communication technologies to provide social support can bridge the resource gap and facilitate opportunities for social connectivity. Involving the care-partners in communication technology development can help ensure that the unique needs and preferences of this group are met in order to most effectively support opportunities for meaningful social connections.

317

THE HUMAN BRAIN: THE TRUE ARCHITECTURE

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Introduction: Since Brodmann and Cajal, knowledge of the brain has not changed much, all due to the fact that classical research methods no longer give more.

Method: Adding information about the unconscious level of the mind, with the information available until now about the brain, with neurolinguistic programming, with electronic bases, and with quantum physics, I was able to design the new scientific clinical applied research (NSCAR) that allowed me to conceive the brain as a mixed, biological and electronic machine.

Results: Here we have the Brain Basic functional circuit, that generates the bit, the storage circuit, (memory), the divergent and convergent connections, expressed in these graphs here below. More explanation in the references.

Conclusions: The results of a scientific research work depend in the first place on the method used (Descartes) and on the volume of pertinent information that the researcher is able to accumulate.



318

DEMENTIA & DESIGN - A GLOBAL CHALLENGE, LOCAL RESPONSE: Creating Dementia-Friendly Communities: The Atria-ADFM Community Corner (AACC) in Malaysia - a pilot local corporate partnership initiative - first in Malaysia and the Asia Pacific region

Ms Jacqueline WM Wong
demensia Brunei, Bandar Seri Begawan, Brunei Darussalam. Dementia Alliance International, Ankeny, USA. CommonAge, London, United Kingdom

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Launched in September 2017, the AACC is a pilot DFC initiative aimed at:

- raising greater awareness of Alzheimer's Disease and dementia;
- providing information and support to the neighbourhood communities and vicinity.

The AACC opens daily from 11 am to 7 pm. All health talks, activities and information materials provided are free. From observations:

- 1. many seniors have some cognitive impairment and memory loss. AACC encourages them to seek early diagnosis.
- 2. awareness and understanding of dementia is low. Stigma and discrimination are major challenges.

3. plwd and their carers interacting with a broader community through:

1.- weekly health talks on Saturday afternoons

2.- elder yoga sessions on Sunday mornings

3.- carers sharing session, once a month.

4.- weekdays from 4-6 pm: Sudoku, jigsaw puzzles, art & crafts

4. AACC is reaching out to a wider population around the neighbourhood, and beyond. The public has started to approach to share their concerns, seek advice: where and how to get medical help, etc.

5. AACC is seeing results with:

- frequency of participants in weekly talks and activities
- daily enquiries
- sign-ups of volunteers
- sign-up of health specialists, practitioners, and more volunteering to provide health talks
- Atria tenants are offering their services to support

6. AACC encourages carers to participate in social interactions: sing-along and dance, carers sharing sessions, health & wellness talks.

7. AACC also plans activities for the wellbeing of the larger elderly, family and youth.

8. AACC organises awareness programmes for the multi-lingual community.

* Supported ADI in a proposal to IKEA from experience in establishing AACC.



319

The relationship between anxiety and amyloid-beta (Aβ)/tau in healthy older adults: A systematic review

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Topic

Dementia risk reduction: Risk factors

Abstract

AIMS: Anxiety has been identified as a risk factor and prodromal symptom of Alzheimer's disease. The underlying biological mechanism(s), however, are unknown. The aim of this study was to systematically review literature examining the relationship between anxiety and amyloid-beta (Aβ) and/or tau in healthy adults.

Methods: This review was performed according to PRISMA guidelines, registered on Prospero (#CRD42020189425), and conducted searches on 5 databases. Studies were eligible if they were peer reviewed original investigations that examined the relationship between anxiety and Aβ and/or tau in healthy adults. Studies that assessed anxiety via validated self-report questionnaires or according to established clinical criteria were eligible. Two independent researchers assessed study eligibility, extracted data and rated study quality.

Results: Twenty-five eligible studies were identified, of which 24 (96%) assessed the association between anxiety and Aβ. The majority (22 studies [92%]) reported no relationship between anxiety symptoms and Aβ. In 4 studies that also examined associations between anxiety and tau, none found a relationship. In one (4%) study that used a PET tracer which binds to both Aβ and tau, evidence of an association with anxiety symptoms was reported. Studies, however, were generally limited by their cross-sectional design and inclusion of only participants with subclinical levels of anxiety.

CONCLUSION: There was little evidence for associations between anxiety and either Aβ and tau. Future investigations should consider prospective longitudinal design, investigating the association between clinical levels of anxiety and Aβ and tau, and adjusting for key confounders (e.g., depressive symptoms).

320

Portraits of Care: A Multi-Country Study Exploring Support and Coping Strategies of Carers for People Living with Alzheimer's Disease During and After COVID-19

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Informal carers play a key role in supporting people living with Alzheimer's Disease (PLWA). Caring can be a rewarding role, but carers may face challenges including stress and loneliness. COVID-19 has severely impacted carers, with increased hours exacerbating loneliness, and restricting access to support services. Given this, it is important to build understanding of the experiences of carers, exploring these in countries with differing health and social care systems.

Methods: A mixed-methods design will be adopted to examine the care-giving experience during the pandemic in Brazil, South Africa, the United Kingdom, and the United States. In each country, approximately 150 carers are to be recruited to complete a 10-minute quantitative questionnaire to capture demographics and access and use of support services. Qualitative interviews with 8-10 carers per country will explore their experiences, using participant-generated photographs to reveal deeper thoughts and feelings. The interviews will be analysed thematically. The study is a collaboration between Roche and ADI with the University of Westminster in London, UK.

Results: The findings will provide an overview of who is caring for PLWA, how they access and use support, and the impact of COVID-19. They will also offer an in-depth understanding of the lived experience of being a carer during the pandemic in four countries, reflecting on changes and use of support networks (informal and formal) and coping strategies.

Conclusions: The conclusions will inform ways in which organisations can improve provision and support for carers for PLWA to better meet their needs.



321

"There is no excuse for lynching widows living with dementia to grab their land"

Mrs Sarah Wairimu Mbithi, Mrs Monica Njeri Kinyanjui

Women For Dementia Africa, Nairobi, Kenya

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

In Kenya, older women often get ostracized in the society by their kin for the sake of the land they hold. This local occurrence often affects women living with dementia.

Purpose: The increase in aging longevity in low and middle- income countries has seen an increase of the elderly and those living with dementia.

Dementia is usually dismissed as a part of normal ageing due to lack of proper diagnosis and awareness. Recently in Kenya, four elderly women living with dementia were lynched on allegation of being witches; such heinous incidences are not new in the country.

Action Plan: Women for Dementia Africa (WFDA) together with other civil societies drafted a statement that condoned the heinous behavior. It read in part, "Firmly urge the government of Kenya to ratify with speed and implement the AU Protocol on the African Charter on Human and People's Rights. The Charter provides for the protection of the property, land and inheritance rights of older women, Article 8, prohibits abuse from harmful traditional practices and specifically calls for measures to eliminate harmful traditional practices including witchcraft accusations which affect the welfare, health, life and dignity of older people particularly older women". The story saw a successful multidisciplinary approach involving different civil societies as highlighted by the media houses.

Solution: To demystify the conditions of dementia through critical mass awareness

Conclusion: Kenya should adopt WHO Global Dementia Action plan 2017-2025, it calls for a multidisciplinary approach involving all the society.

322

"Preserving dignity to the end"

Mrs Sarah Wairimu Mbithi, Mrs Monica Njeri Kinyanjui

Women for Demential Africa, Nairobi, Kenya

Topic

Dementia diagnosis, treatment, care and support: Dementia and dignity

Abstract

PURPOSE

Mapping done by NCD alliance Kenya and Women for dementia Africa in the low income households in Nairobi to find out how many undiagnosed people are living with NCDs.

Project Plan: Women for dementia Africa worked together with other community based organization. A door to door excise collecting data was undertaken.

A medical camp was organized with a multidisciplinary team of doctors, nurses, nutritionist, counselors, caregivers and social worker each playing their different roles. Those diagnosed with NCDs where treated and referred to a health facility.

Outcome:-

- Dementia is usually dismissed as part of normal aging
- There was lack of awareness, that means patients are suffering undiagnosed
- Unaffordability of meals, majority of the house hold had one meal a day
- Inadequate nutritious diet
- Unaffordability of adult diapers, use of other substitutes that are unhealthy and unsuitable
- Challenge of bed sores
- Women and girls provide substantial proportion of the informal care

Solution:

We identified 3 key needs for intervention:-

- Inadequate nutritious diet
- Unaffordable adult diapers
- Challenge of bed sores

We come up with a free "dignity care pack" comprising of a month's supply of adult diapers, petroleum jelly and 2Kgs nutritious porridge at a cost of KSh. 2000 (USD 20). We requested well wishes to give a donation through our social media platforms.

Conclusion: We are currently working among the informal settlements in Nairobi County and would like to go to other counties. Our quest is to preserve dignity to the end!



323

Translating research and experience: Co-producing the Living with Dementia Toolkit

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Catherine Charlwood, Rachael Litherland, our involvement group of people with dementia and carers – Allison, Chris, David, Jacqui, Jane, Julia, Keith, and Monica – on behalf of the IDEAL research programme

In November 2021, the IDEAL research programme launched the Living with Dementia Toolkit website. Primarily aimed at people with dementia and carers, the toolkit brings together the research findings from a large longitudinal cohort study of living with mild-to-moderate dementia in the community – IDEAL – and the lived experience of a dedicated group of people with dementia and carers.

The structure of the toolkit is based on the 'living well' map from IDEAL's research and centres around five themes: Stay safe and well, Stay connected, Keep a sense of purpose, Stay active and Stay positive. A variety of resources have been both gathered and created underneath these headings. As we worked with the involvement group, certain topics kept emerging across the breadth of the toolkit:

- the concept of 'risk' – people with dementia being enabled, not prevented, from doing things; carers being able to manage their anxieties
- the importance of having open and honest conversations – between people with dementia and carers, between a person with dementia and their wider social network

This paper discusses the learning journey of co-producing the toolkit, from conception and design, through to implementation, dissemination and reshaping based on feedback. With illustrative examples and hearing from the group involved in co-producing the toolkit, you'll hear about the manifold benefits of such collaborations.



324

"Championing" dementia care education in Canada: A collaboration with Scotland

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

With high rates of hospitalizations among persons living with dementia, it is vital they receive safe and appropriate care; yet hospitals are harmful environments for persons with dementia. Currently, Canada lacks comprehensive dementia education programs for acute healthcare providers. Scotland presently delivers a successful dementia education program, known as the *Scottish National Dementia Champions Programme*. This presentation shares the collaboration between Scottish experts and Canadian stakeholders to adapt the *Programme* for Canada.

Utilizing Hawkins and colleagues' (2017) framework for co-production of interventions, the team undertook an evidence review and stakeholder consultation. This included an environmental scan of Canadian dementia education for acute healthcare providers; key informant interviews; and a meeting with experts and stakeholders to establish program principles, priorities, outcomes, and pedagogical approaches that align with the values of dementia care in Canada.

The environmental scan revealed dementia education in Canada is piece-meal and often not specific to hospitals. Moreover, while some programs are grounded in person-centred care none address the education needed to lead change in policies and organizational cultures. Informant interviews highlighted the importance of communication, environmental deficiencies, and need for person/family-centred care in hospitals. These findings supported the meeting that resulted in adapting the *Programme*to the Canadian context.

The results of this collaborative work are being used to inform the next steps in Hawkins and colleagues' framework to pilot a Canadian dementia education program. Canada would benefit from a program that supports healthcare providers to be leaders and change agents to improve dementia care in hospitals.





325

Hoarding syndrome in Dementia – Case Report

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Topic

Dementia research and innovation: Other syndromes and dementia

Abstract

Ms M is a 69-year-old admitted after a fall at home, complicated by delirium and a community acquired pneumonia. Collateral history from family identified cognitive impairment for a year, with longer standing hoarding behavior. Occupational therapy input was obtained to assess function. The home visit identified significant clutter in the bedroom, without space for mobility. There were stacks of her belongings in the living room and medications scattered in many areas of the house. In the bathroom, the sink, bidet and side of the toilet were filled with items.

Hoarding is a persistent difficulty discarding or parting with possessions regardless of their actual value. It becomes pathological when accumulated possessions impacts the ability to use living areas of their house. In older adults, this causes problems with accessibility, falls, social isolation, medication mismanagement and poor sanitation. Hoarding tends to occur in the early and middle stages of dementia, particularly for those with premorbid hoarding tendencies. It tends to be a compensatory mechanism against the fear of losing memories, while items increase their self-security as their cognitive abilities deteriorate. As cognitive decline progresses, the hoarding becomes more disorganized and emotional outbursts occur with missing or losing items.

The Hoarding rating scale (HRS) or Clutter image rating scale (CIR) objectively quantifies the hoarding severity. Management requires a biopsychosocial and multidisciplinary approach. Decluttering can cause severe emotional upset, thus removing everything may not be appropriate. It is also important to establish therapeutic relationships with family to ease the acceptance of interventions.



326

Integrating the person living with Alzheimer's Disease (AD) and care partner perspective into AD clinical trial development

Ms Ruth Croney[1], Mr Jean Georges[2], Ms Léa-Isabelle Proulx[3], Ms Jannice Roeser[3]

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Topic

Dementia research and innovation: Clinical trials

Abstract

Aim: Participating in a clinical trial for Alzheimer's disease (AD) can be challenging for people living with AD (PLWA) and their care partners; understanding their needs can improve clinical trial experiences. The development of a community-accessible Clinical Trial Playbook that incorporates the needs of PLWA, their care partners, and AD patient organisations is critical to enhancing clinical trial design and conduct and improving outcomes.

Methods: Collaborating with PLWA and their care partners, as well as global and local AD patient organisations, Roche developed a playbook using key insights to inform the design and conduct of AD clinical trials, covering all stages of clinical trials and extending to post-trial considerations.

Results: Feedback from interviews and working groups revealed that understanding the PLWA journey and associated complexities, in addition to the crucial role care partners play, is critical to designing AD clinical trials that optimise outcomes and experiences for all by utilising a participant-focused approach. These insights formed distinct playbook chapters outlining the trial journey, which can guide organisations when designing clinical trials in AD.

Conclusions: The Clinical Trial Playbook was developed as a living document, that provides insights into the ecosystem of AD clinical trials. It outlines guidance and considerations into the needs of PLWA, care partners, and AD patient organisations to improve clinical trial design and outcomes. This project highlights the importance of an inclusive collaboration with the AD community and provides a resource that can be utilised mutually by the AD community and industry when developing AD clinical trials.



327

The issues involved in sustaining community-based groups and activities for people affected by dementia in the long term: The SCI-Dem realist review

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Aims: Community-based support for people with dementia and their care partners, such as groups and activities, can play an important part in post-diagnostic care. Typically delivered piecemeal in the UK by a variety of agencies with inconsistent funding, provision is fragmented and many such interventions struggle to continue after only a short start-up period. The SCI-Dem realist review investigated what can promote or hinder them in being able to sustain long-term.

Methods: Key sources of evidence were gathered using formal database searches and informal search

Methods: No restrictions were made on type of article or study design, but only data pertaining to ongoing, community-based interventions were included. Data were extracted, assessed, organised and synthesised to trace realist context-mechanism-outcome configurations as part an overall programme theory. Consultation with stakeholders involved with a variety of interventions in various roles informed this process.

Results: Ability to continually get and keep members, staff, volunteers, support of other services and organisations, and funding/income were found to be critical areas, with multiple mechanisms feeding into these, sensitive to context. Key factors included an emphasis on socialising and person-centredness; lowering stigma and logistical barriers; providing satisfaction, support and recognition for personnel; networking, raising awareness and sharing with other organisations, while avoiding conflict; and skilled financial planning and management. Challenges were especially acute for small-scale and rural groups.

Conclusions: This review presents a theoretical model of factors and mechanisms involved in the long term sustainability of community-based interventions, providing a framework for new primary research to test.

328

EARLY ENGAGEMENT WITH THE WIDER ALZHEIMER'S DISEASE COMMUNITY IN EARLY-PHASE CLINICAL TRIAL DESIGN: INSIGHTS FROM THE CARERING CAREGIVER COMMUNITY IN DESIGNING AN AD TRIAL

Ms Ruth Croney[1], Mr David Agnew[1], Ms Annamarie Vogt[2], Mr Fabien Alcaraz[2], Mr Hanno Svoboda[2], Mr Luka Kulic[2], Ms Léa-Isabelle Proulx[3]

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Topic

Dementia research and innovation: Clinical trials

Abstract

Aim: Care partners of people with Alzheimer's disease (AD) influence the decision to participate in a clinical trial. The CareRing initiative gathered care partner insights on: motivations for involvement in early phase clinical trials; care partners' role when loved ones participate in a trial; and holistic support that could minimize the impact of trial participation on daily life. Method:Six Roche employees, who are care partners for a person with AD, participated in two 60-minute interviews. These interviews discussed the draft protocol and technology behind a Phase IB/IIA AD trial in prodromal or mild-to-moderate AD (NCT04639050). Care partners provided input on the trial protocol and holistic support needed that could lessen the burden of clinical trial participation.

Results: Feedback suggested participants are motivated by helping others avoid their experiences, decreasing isolation, and accessing state-of-the-art care, testing, and neurology teams. Care partners' participation goes beyond study visits: they prepare participants for visits physically and mentally (e.g. detailing what visits will involve and providing emotional support), accompany them on visits, and help participants recover from their schedule changes. Care partners carry the psychological burden of providing continual reassurance and often being the sole person to answer participant's questions, particularly until they trust the study team. They also face challenges in taking time off and re-organizing appointments.

Conclusion: Guidance provided by care partners in the CareRing initiative helped adapt the design and holistic management of the AD trial and refine specialized support for both care partners and participants.



329

PEOPLE LIVING WITH ALZHEIMER'S DISEASE AND CARE PARTNER'S EXPERIENCE IN CLINICAL TRIALS IN EARLY STAGE (PRODROMAL AND MILD) ALZHEIMER'S DISEASE: QUALITATIVE SURVEY RATIONALE AND DESIGN

Dr Alberto Villarejo-Galende[1], Prof Christine D Pozniak[2], Prof Fiona McDougall[2], Dr Sheila Seleri Assunção[3], Mr Wael Abouelkheir[2], Ms Beverly Assman[3], Mr Rozanno Gonzales[3], Dr Oliver Peters[4], Dr David Watson[5]

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Topic

Dementia research and innovation: Clinical trials

Abstract

Aims: Patient/care partner experiences and perceptions about drug administration as well as the monitoring required during clinical trials may provide insights into real-world treatment experience, including patient outcomes and adherence to medication. These insights are increasingly important to researchers, clinicians, payers and regulators. A non-interventional, interview-based survey was recently initiated to obtain experiences from participants and care partners involved in 2 Phase III double-blind studies (GRADUATE 1 [NCT03444870]; GRADUATE 2 [NCT03443973]) and an open-label extension phase of these studies (POST-GRADUATE [NCT04374253]) for early (prodromal-to-mild dementia) Alzheimer's disease (AD). The primary aim of these surveys is to identify enablers and barriers to disease care and management which could then help to develop real-world strategies to support people living with AD and their care partners.

Methods: Participants in the GRADUATE studies and their care partners will each be asked to join a one-time, 60-minute semi-structured interview, up to 8 weeks after their final study visit or date of early withdrawal/discontinuation from a study. Advice from an expert advisory board and pilot interviews with persons living with AD and their care partners informed development of interview guides.

Results: Transcribed interviews will be analysed to identify common themes. Study is expected to finish in 2022.

Conclusions: In-depth interviews will help describe the clinical trial experiences of people living with AD and their care partners and aid the development of potential future support strategies.

330

Designing a Therapeutic, Dementia-Inclusive Nursery and Garden – Overcoming Challenges and Transforming during COVID-19

Dr May Yeok Koo, Ms Guat Teng Ong, Mr Khee Soon Tan, Ms Mui Siang Tan

Nanyang Polytechnic, Singapore, Singapore

Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Problem Statement: The original garden and nursery at a purpose-built Dementia Care Home was not elderly- and dementia inclusive. It lacked certain safety aspects, colour contrast, clear directions; was unengaging and did not promote residents' independence. Overall, it lacked a holistic therapeutic effect.

Innovation: Nanyang Polytechnic's School of Health and Social Sciences (SHSS) and School of Design and Media (SDM) adopted an interdisciplinary approach to address the problem – SHSS with our deep domain knowledge and expertise in dementia care and SDM with theirs in Visual Communications and Design. This resulted in the first therapeutic garden project in Singapore that focuses on an elderly- and dementia-inclusive design, adhering to the principles of Spatial Environment, Wayfinding, Accessibility and Safety, Lighting and Nature, Colour Contrast, Tranquil Environment, and Barriers/Challenges. We applied these principles, proposed and implemented some changes targeted at Sensory and Cognitive stimulation.

Impact on stakeholders:(1) Dementia awareness and capability development of SDM faculty in conceptualizing and designing an elderly- and dementia-inclusive garden. (2) Preparing SHSS and SDM students to be more future ready. (3) Facilitation of the Dementia Care Homein their Transformation Vision to further enhance their current garden and nursery.

Challenges: Commitment beyond current roles/responsibilities and finding a common time for the 1-year project. Students and SDM faculty were unfamiliar with dementia and the therapeutic requirements. Due to COVID-19, not all students could go for onsite visits and relied on team leaders to provide the pertinent information. The collaborative project work had to be via zoom.



331

How can online education better support family carers of people with dementia? a case study from an Irish NGO.

Mr Fergus Joseph Timmons
The Alzheimer Society of Ireland, Dublin, Ireland. Dublin City University, Dublin, Ireland

Topic

Support for dementia carers: Education and training for informal carers

Abstract

The Alzheimer Society of Ireland (ASI) has been providing education and training for family carers of people with dementia since 2009. Since 2015, ASI has been delivering these education and training programmes online via our Moodle Learning Management System. Following the COVID-19 outbreak in 2020, The ASI moved all its education and training provision for family carers online. However, can online education be an effective support for family carers of people with dementia? This presentation will describe The ASI's fully online Home Based Care-Home Based Education (HBC-HBE) course. We will present quantitative and qualitative results of our research exploring the views and experiences of family carers who took part in the HBC-HBE course. Among the questions to be addressed will be – how did participating in an online course support family carers? In what ways did family carers feel supported? What practical impact did this have on their caring situation? Which elements of their learning experience did they find most supportive? And what recommendations would they make to the course designers to improve their online learning experience? This presentation will be of interest to family carers, people with dementia, education and training providers particularly those using online or blended approaches, as well as funders and policy makers interested in the development of supportive online educational interventions.

332

Inhibition of the Activation of Microglia: A Potential therapeutic Strategy in preventing the Progression of Alzheimer's Disease.

Mr Benjamin Tèmídayo Adebisi
Osun State University, Nigeria, Osogbo, Nigeria

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aim: The review aimed at understanding the major driver of the progression of Alzheimer's Disease (AD), hence, elucidating the underlying pathogenesis might initiate a targeted therapeutic strategy to intercept the progression of the disease.

Methods: The basic approach is understanding the immunological response, initiated by the Microglia, resident in the brain, which is indicted in neuroinflammation and exacerbation of the symptoms of Alzheimer's Disease. This brings us to the knowledge of the links between the 'Trigger' and 'Pathology' in the diseases.

Results: Several Scientific evidences suggest neuroinflammation is a vital contributor to the development and progression of Dementia in Alzheimer's Diseases and several other Neurodegenerative Diseases.

The chemokines, cytokines, reactive oxygen species and other proinflammatory biomarkers produced by activated Microglia is responsible for axon-glia disruption and impaired neurovascular coupling leading to cerebral hypoperfusion, alongside aggregation on insoluble amyloid beta protein, which is the Hallmark of Alzheirmer's Disease.

The Sum total of these pathological processes is compromise of the Blood Brain Barrier, Oxidative Stress and Cerebral endothelial injury, which worsen the progression of Dementia in patients suffering from Alzheimer's Disease.

Conclusion: Invariably, arresting the activation of Microglia might be a targeted strategy in the interception of the chain reaction and this could slow down the progression of the disease and apparently, act as a Disease Modifying Therapy in patients.



333

Investigating the Relationship between Repetitive Negative Thinking and Sleep in Cognitively Intact Older Adults

Ms Lydia Munns[1,2], Ms Harriet Demnitz-King[1], Dr Clare Andre[3], Dr Stephane Rehel[3], Dr Valentin Ourry[3], Dr Pierre Champetier[3], Dr Gael Chetelat[3], Dr Geraldine Rauchs[3], Dr Natalie Marchant[1]

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Poor sleep and high levels of repetitive negative thinking (RNT; future-directed [i.e., worry] and past-directed [i.e., rumination] negative thoughts) have been associated with cognitive decline and dementia. This study aimed to explore the association between RNT levels and objective and subjective sleep measures in cognitively healthy older adults.

Methods: Baseline data from 134 community-dwelling older adults (mean age = 69; 62% female) enrolled in the Age-Well clinical trial were included. RNT (i.e., worry and rumination) was assessed via the Penn State Worry Questionnaire and Brooding sub-scale of the Rumination Response Scale, respectively. Sleep was measured objectively via polysomnography and subjectively via the Pittsburgh Sleep Quality Index.Associationsbetween RNT and objective and subjective sleep characteristics were assessed via a series of adjusted linear and logistics regressions. Covariates included age, sex, and the apnoea-hypopnea index.

Results: Higher levels of worry were associated with poorer subjective sleep quality (b=0.06, p=0.001), shorter objective sleep duration (b=-0.17, p=0.05) and poorer objectivesleep efficiency (b=-0.32, p<0.001). The latter was also associated with higher rumination levels (b=-0.26, p=0.002).No associations were observed with other objective or subjective sleep characteristics.

Discussion: These results suggest that among healthy older adults RNT (primarily worry), is associated with particular sleep characteristics that have been associated with increased dementia risk. Interventions aimed at reducing RNT levels may help promote better sleep, and thus reduce dementia risk. Further research to determine the causal relationship between RNT and sleep characteristics and the associations between these risk factors, however, is required.

334

"Implementing a new long-term residential care concept for people with dementia: a process evaluation reflecting its challenges."

Ms Suzanne Portegijs, Ms Sandra van Beek, Ms Lilian van Tuyl, Prof Cordula Wagner

Nivel, Utrecht, Netherlands

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

Aims: Dementia-friendly communities are important for the well-being and quality of life of people with dementia. Currently, scientific research on how these communities can be linked to institutionalized dementia care in nursing homes is lacking. Therefore, this case study follows a nursing home that opened their doors and developed a park and restaurant that is accessible for both the residents and people from the community. Consequently, the aim of this study is to gain insight into the process of implementing an innovative living concept for people with dementia within society, the subsequent barriers and facilitators, lessons learned and implications for implementation.

Method: A process evaluation was conducted using three focus groups with managing directors at different time points in the change process. Additionally, relevant policy documents were collected. Both are currently being analysed using the Theoretical Framework of Adaptive Implementation.

Preliminary results: Multiple factors influence the implementation of the innovative living concept, including: the social networks among the neighbourhood residents and their relationship with the residents and employees of the nursing home, the extent to which the concept is supported within the care organization, vision and commitment from leadership, administrative burden on municipal and regional level and disruptive events such as the COVID-19 pandemic.

Conclusion(s): This study provides a meaningful insight into the facilitators and barriers of implementing a new way of long-term living for people with dementia, which can be beneficial for other care organizations aiming to achieve change in the organization of long-term dementia care.



335

Caregivers' perception about the barriers, motivators, and facilitators to the participation of care recipients with neurocognitive disorder in a physical exercise program

Miss Flávia Borges Machado[1,2], Mr Duarte Barros[1,2], Prof Paula Silva[1,2], Mr Pedro Marques[3], **Prof Joana Carvalho**[1,2], Prof Oscar Ribeiro[3,4]

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Aims: To investigate the perspectives of caregivers about the barriers, motivators, and facilitators toward the participation of individuals diagnosed with neurocognitive disorder (NCD) in a physical exercise program.

Methods: Data from semi-structured interviews were analyzed following the Braun and Clarke's Thematic Analysis guidelines, under the socio-ecological framework.

Results: Twenty informal caregivers (N Male: 13; 67.5 ± 13.94 years old; age range: 37-86) of older adults diagnosed with NCD from the "Body & Brain" project. Two main barriers, 3 motivators, and 5 facilitators were identified. Care-receivers' unwillingness to take part of exercise sessions was identified as the main barrier for participation, aside from physical environment limitations. The advice and support given by health professionals, the potential physical and mental health benefits, and the care-receivers' need for specialized activities came out as main motivators. Lastly, the individuals' wellness and enjoyment for participating in the exercise sessions emerged as a crucial facilitator to the engagement in the program, along with benefits on general health, social connectedness, and routine. An overall positive evaluation of the physical exercise program characteristics was also highlighted.

Conclusions: Considering the dynamic and complex relationship between intrapersonal, interpersonal and community factors illustrated with this qualitative study, well-designed and specifically designed programs for individuals living with NCD should promote a welcoming environment, facilitating participants' well-being, enjoyment, and social interaction. Future exercise interventions targeting this population must consider the key-role health professionals play in recommending participation, and caregivers in promoting care-receivers motivation.

Funding: Fundação para a Ciência e a Tecnologia (FCT): "Body & Brain" Project [POCI-01-0145-FEDER-031808]; CIAFEL [FCT/UIDB/00617/2020]; ITR [LA/P/0064/2020]; Ph.D. Grants [SFRH/BD/136635/2018] to FM and [2020.05911.BD] to DB.

336

Encouraging physical activity in unpaid caregivers: the co-development of a novel personalised physical activity app 'CareFit'.

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Introduction: Family members and friends looking after a loved one with dementia are likely to face significant mental and physical health challenges: 81% of carers are not able to do as much physical activity as they would like to. The COVID-19 pandemic forced many to spend more time indoors due to shielding and lockdown restrictions. As we emerge from COVID-19- there is a need for accessible evidence-based tools to facilitate physical activity for all including those caring for a person with dementia.

Methods: We designed a smartphone/tablet app, "CareFit" through examining existing literature and guidelines (e.g. behavioural change models, U.K. Government physical activity guidelines). We co-designed the app by directly involving caregivers, health care professionals, and social care professionals. We conducted three co-design sessions involving participants from a variety of backgrounds. Each co-design session was followed by a development sprint.

Results: We successfully developed and tested a novel, evidence based android application based on the needs of caregivers to undertake physical activity. Participants identified different barriers and enablers to physical activity, such as a lack of time, recognition of existing activities, and concerns regarding safely undertaking physical activity. Our final application included educational, physical activity, and communication components.

Discussion: Here, we present the results of a novel project that integrates key physical activity information into an accessible smartphone app. After establishing the acceptability, feasibility and usability of the app, we are currently exploring how to integrate a high-fidelity version of the app within health and social care pathways.



337

Little Black Boxes - Human Connections in the middle of Chaos

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Findings from The New Zealand Social Report show that 10% of New Zealanders aged 65-74, and 13% of those aged over 75 feel lonely all, most, or some of the time. The reports also show young people aged 10 -16 experiencing loneliness more often than those aged 17 +. Loneliness and Social Isolation increases are detrimental to health and anyone can be lonely, but it is clear that older people over and young people are most at risk in Aotearoa.

On the 25th March 2020, New Zealand entered a Level four coronavirus lockdown, known to be one of the strictest regulations around the world in order to prevent what could have potentially been a wave of human devastation for our country.

In the middle of the lockdown PhD Carlene Newall was seeking for a collaborative project between HighJinx Youth Company and diverse New Zealanders in response to their unique experiences through the Covid-19 response. Summerset Diversional and Recreational Therapists came across her proposal and welcomed the idea of hosting a group of young members of HighJinx Youth Company on weekly 1-1 Zoom conversations with seniors living in care in a Summerset Care Centre in Nelson to collect the feelings and experiences that both groups were having during the lockdown.

Little did we know that what started as a simple project ended up facilitating meaningful participation and expression, and act as a means to enhance a sense of connection and counter the loneliness felt by young and old during lockdown.

338

End-of-life preferences in the face of dementia: findings from a survey of US adults over 50.

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Purpose: The current state of advance directives in the United States allows only limited options to people facing a diagnosis of dementia. Existing options focus on choices involving the final stages of dementia, e.g. refusing feeding tubes when one can no longer swallow. Our question was whether these choices responded to the concerns of many Americans. Our hypothesis was that a substantial number might wish their lives to end at earlier stages.

Plan: We sampled 1050 people over the age of 50 in the United States. 58% of respondents had experienced loved ones living with dementia. Participants were divided into two groups (n=525). Group One responded to a vignette about four people who experience fatal heart attacks at different stages of their life with dementia. Group Two imagined that they were writing a document directing a health care proxy about when to accept or refuse antibiotics for pneumonia, should they be in a state of dementia.

Outcomes: The majority of Group One respondents (56%) would prefer a life trajectory in which they had a final heart attack while still in the first stage of dementia. The majority of Group Two (57%) would choose to refuse antibiotics for a fatal pneumonia sometime in the first or second stage of dementia.

Conclusion: Advance directives and end-of-life strategies that focus only on the final stage(s) of dementia fail to reflect the concerns of a majority of Americans over 50.



339

A randomised controlled trial of the effects of an e-health intervention 'iSupport' for reducing distress of dementia carers.

Dr Kieren J Egan[1], Prof Paul Brocklehurst[2], Dr Zo Hoare[2], Dr Patricia Masterson-Algar[2], Ms Gwenllian Hughes[2], Dr Joshua Stott[3], Prof Aimee Spector[3], Prof Rhiannon Tudor Edwards[2], Mrs Joyce Gray[4], Mr Tim Banks[5], Prof Gill Windle[2]

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Studies have shown that carers are more stressed, depressed, and have lower levels of subjective well-being, physical health, and self-efficacy than non-carers. Dementia carers have expressed a need for relevant information and knowledge, support with activities of daily living; behavioural and psychological symptoms; and their own physical and mental health.

'iSupport' is an evidence-informed online training and support programme for dementia carers designed to help provide high quality care and take care of themselves, developed by the WHO. This multi-centre, pragmatic, single-blinded, two-arm randomised controlled trial (with a nested internal pilot) will evaluate the effectiveness of 'iSupport' in reducing: carer distress using the 12-item Zarit Burden Interview (ZBI) and; symptoms of depression using the Centre for Epidemiological Studies of Depression Scale (CES-D10). Secondary outcomes will assess changes in anxiety, resilience, competence, relationship quality and dementia knowledge.

350 participants will be recruited across Wales, Scotland and England. To reflect the 'real world' application of 'iSupport', participants randomised to the intervention arm will be given access to the 'iSupport' platform for six months, while the comparison group will receive Alzheimer's Society based dementia information. Assessments will be completed at baseline, 3 months and 6 months via internet-based calls.

Primary analysis will be conducted on an intention to treat (ITT) basis, blinded to treatment allocation. The primary assessment for effectiveness will be adjusted estimates of the ZBI scores and CES-D10 scores between the two groups assessed at 6 months. A mixed-methods process and health economic evaluations will take place alongside the trial.



340

Development of an app to provide a digital platform to record "My Life's Journey"

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Reminiscence therapy is a popular psychosocial intervention that involves discussion of past events and experiences, using tangible prompts to evoke memories or stimulate conversation, and has been used as a means to reduce loneliness, anxiety and agitation.

The app has been developed by someone with dementia for people living with dementia and is available free. This presentation will discuss the application of this digital facilitated reminiscence and life storybook. Many people have enjoyed the opportunity to narrate, compose and produce their own life storybook using the numerous paper-based programs available, but few of these are in a digital format. Paper based systems tend to be one dimensional and can become quite cumbersome if additional information is needed to be added, amended, or deleted over time.

With new technology, the life storybook can be created on a computer, tablet or mobile phone, with the use of text, photographs, pictures, audio, videos and music. Through visual reminiscence, paired with music, the app helps people with dementia and their families preserve yesterday's memories. The app provides prompts that help to draw out long term memories include hearing stories from one's early life, looking through old family photos, and listening to music from one's youth.

The app was developed toempower people with dementia to tell their story. To provide respect and autonomy for the individual to control and direct the content of their story however they choose and to create the opportunity to reconnect and leave a legacy.



341

Effect of clinical communication skill training for physicians in geriatric medicine with video analysis by artificial intelligence

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Background: Despite many physicians experiencing difficulties to communicate with dementia patients, there are few opportunities in pre-and-post graduate training.

Objectives: To evaluate the educational effect of communication skill training for dementia to physicians in geriatric medicine.

Method: Single arm pre-post study. Physicians in geriatric medicine received weekly 1-hour online lectures and once a week bedside training with the instructor of multimodal care communication methodology: Humanitude for 4 weeks. Before and after the training, participants performed a physical examination on a simulated patient. Their clinical performances were recorded by first-person cameras of participants and simulated patients, and third-person cameras. The participants' eye movement was recorded by an eye-tracker. The videos were evaluated by computing analysis with artificial intelligence in the elements of communication modes; eye contact, verbal communication, and touch interaction.

Result: 16 physicians enrolled in the study. The quantity of communication during the examination before and after the training were eye contact; 6.2%, 25.3% ($p<0.001$), verbal communication; 38.1%, 50.4% ($p<0.001$), and touch interaction; 39.2%,47.9% ($p<0.05$), respectively. The multimodal communication index which is defined by more than two simultaneous interactions during the physical examination was increased from 15.6 before the training and 41.9 after ($p<0.001$).

Conclusion: The clinical communication skill training for physicians in geriatric medicine analyzed by artificial intelligence is effective to improve the quantity of communication.

342

Rehabilitation: a new occupational therapy pathway of diagnostic support

Ms Elaine Hunter[1], Dr Claire Craig[2], Ms Helen Fisher[2], Ms Alison McKean[1], Ms Ashleigh Gray[3]

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Dementia is a complex, multifaceted condition that individuals and their families frequently navigate alongside other health needs. However, in spite of a growing evidence base showing the value of multi-disciplinary rehabilitation programmes for people with dementia, individuals are not routinely offered these services. This is unlike other chronic neurological conditions for which rehabilitation is more accepted in the clinical pathway.

Calls are increasingly coming from the academic, AHP leader and dementia community to challenge this lack of access to rehabilitation. Indeed, Dementia Alliance International have argued that access to rehabilitation is a human right under the convention on the Rights of Persons with Disabilities.

This poster describes the development of an emerging occupational therapy model of service delivery in Scotland (Alzheimer Scotland 2017, 2020). Adopting the WHO definition of rehabilitation as a holistic approach to chronic disease management, a model will be shared that has taken evidence based occupational therapy interventions for individuals' post-diagnosis to create an integrated model of occupational-therapy led support which meets the needs of individuals living with dementia where they are at. This includes receiving rehabilitation in the persons home (McKean et al 2021), in the community (Craig et al 2021), face-to-face, on-line or a hybrid of these elements. The importance of interconnectivity of each aspect of the rehabilitation approaches will be shared, with a focus on core principles which creates a sense of seamlessness and cohesion.

The poster shares initial learning and plans for future development, sharing the transferability to an international audience.



343

Connecting People, Connecting Support. Transforming the allied health professionals contribution to rehabilitation and diagnostic support for people living with dementia and their families

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Background: Connecting People, Connecting Support (Alzheimer Scotland 2017, 2020) is an evidence based allied health professional (AHP) dementia policy that outlines how AHPs can support people living with dementia and their families with 4 ambitions to transform practice. The poster will share how this policy fulfils a commitment in Scotland's National Dementia Strategies (2017, 2021)

Method: The poster will share an implementation model to integrate national policy to local practice sharing

- An integrated improvement approach utilising relational approaches and technical approaches
- Use of social media to raise awareness of the AHP role in dementia
- Digital solutions to AHP rehabilitation in dementia incorporating co-designed use of animation and films
- An innovative tiered approach to access AHPs through universal, targeted and individual rehabilitation
- Outline how the work of AHP supports Alzheimer Scotland's strategic direction
- Importance of national and local AHP leadership to support changes in current and future practice.

Conclusion: Connecting people, connecting support is the first policy of its kind in the UK however the key messages will be of interest to an international audience who are looking to integrate rehabilitation in their services models. Lessons learnt in working with allied health professionals to deliver national policy and what this can mean for people living with dementia and their families will be shared. The poster will conclude that services are much more effective when they are coordinated, integrated and working in tandem with people living with dementia and calls for a multidisciplinary, multi-sectoral approach in which AHPs play a unique part

344

Translating science into breakthroughs: the future of late-stage dementia clinical trials in the UK

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Topic

Dementia research and innovation: Clinical trials

Abstract

Background: Clinical trials are vital to the development of new treatments but there are a number of challenges hampering the delivery of dementia trials. While investment has been increased in basic research of dementia over the last decade in the UK, action is now needed to drive improvements in later stage clinical research, particularly given recent progress in the development of disease modifying treatments.

Methods: Data was compiled on the number of applications and registered trials in Europe and US. Further stakeholder engagement was undertaken to understand the drivers behind the differences and suggest initiatives that could be developed to make the UK a world leader.

Results: While the UK led in the number of Phase I and II trials, both Spain and Germany registered more Phase III trials and the USA registered almost four times the number of Phase III/IV trials than the UK. In dementia, the UK registered the second most trials, behind Spain. Challenges identified included identifying trial participants with an accurate diagnosis, efficiency of delivery and blocks to embedding dementia research into clinical care.

Conclusion: Data suggests the UK has a strong presence in clinical trials but government action is needed if the UK is to increase its leadership in dementia research. This report outlines recommendations which would enable the UK to maximise its potential in dementia clinical trials, including the creation of a network of high performing clinical trial sites in the UK and more access to molecular diagnostics as part of routine healthcare.



345

Oral health intervention strategies to improve cognition and microbiome in patients with mild Alzheimer's disease

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Oral microbiomes play an important role in Alzheimer's disease. Specific oral health intervention strategies should be implemented to tackle microbial dysbiosis and cognitive decline.

Objective: To explore the effects of oral health intervention on the oral microbiome and cognitive function of patients with mild Alzheimer's disease and determine the influence on disease progression.

Methods: A total of 66 patients with mild Alzheimer's disease were randomly allocated to either intervention (n=33) or control (n=33) groups. The participants were invited to complete Kayser-Jones Brief Oral Health Status Examination (BOHSE), Mini-Mental State Examination (MMSE), Neuropsychiatric Inventory (NPI), Nursing Home Adjustment Scale (NHAS), and Activities of daily living assessed using the Alzheimer's Disease Cooperative Study-ADL (ADCS-ADL). 16 S rRNA sequencing technology was used to detect patients' subgingival plaque, and the effects of oral health intervention strategies on oral microbiota and cognitive function were analyzed.

Results: After 24 weeks of oral health intervention, the scores of BOHSE, MMSE, NPI, NHAS, and ADCS-ADL were significantly different between groups($P<0.05$). Subgingival plaque in patients with Alzheimer's disease showed significant differences in the diversity and abundance of oral microbiomes. Species analysis showed that the abundance of normal oral flora in the intervention group was higher than that of the control group, while the number of pathogenic bacteria decreased in the intervention group.

Conclusion: Oral health intervention strategies can return oral bacteria to normal levels, reduce the abundance of harmful oral bacteria, and effectively slow down cognitive decline in patients with mild Alzheimer's disease.



347

Co-analyzing the structures and functions involving oral and fecal microbial communities in Chinese patients of Alzheimer's disease

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aims: This study co-analyzed oral and gut microbiota in patients with Alzheimer's disease (AD), and compared their bacterial compositions and functions in patients with mild AD and those with moderate AD.

Methods: A total of 100 subjects were recruited for this study, including 26 patients with mild AD patients and 74 with moderate AD. Subgingival plaque and fecal samples were collected from all subjects. The 16S ribosomal RNA (16S rRNA) sequencing was conducted to analyze both microbiotas.

Results: The results of α-diversity and β-diversity showed that the microbiota in subgingival plaque and feces samples formed clearly separate groups, but the overall structure of the mild AD-associated subgingival and fecal microbiota revealed no significant differences from those in patients with moderate AD. The LEfSe method was applied to identify the key different microbiomes between patients with mild and moderate AD, including Lactobacillus, Alloprevotella, Acidaminococcus, Butyricicoccus, Faecalibacterium, Fusicatenibacter, and Murdochiella. Overlapping network analysis revealed mouth-to-gut microbial transmission in patients with AD, and the results of PICRUSt analysis revealed significant functional changes in the level-2 KEGG pathways of cell growth and death as well as amino acid metabolism in the oral microbiome of the patients. The primary limitation was that COVID-19 prevented the recruitment of patients with severe dementia from the memory clinic.

Conclusions: This study is the first to report a comparative analysis of the oral and fecal microbiota of patients with mild and moderate AD. The composition and functions of the microbiota exhibited varying changes in different stages of AD.



348

Factors associated with dementia attitudes in adolescents

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aim: Negative attitudes towards people living with dementia exist in the general public and appear at a young age. To date, very few studies have focussed on adolescents' attitudes or have attempted to tackle them. The factors that lead to negative attitudes in adolescents need to be addressed initially in order to provide evidence based and effective initiatives to tackle them. However, there is limited literature on what these attitudes are which limit interventions.The aim of this study is to start to understand thefactors associated with dementia attitudes in adolescents.

Methods: A secondary analysis of existing cross-sectional data from 470 British adolescents (12-15 years old) will be conducted. Multiple regression models will be created with adolescents' attitudes towards dementia measures (A-ADS) and theKids insight into dementia survey (KIDS) as dependent variables.Independentvariables will include demographic factors (e.g., age, gender and ethnicity), empathy (Empathy Questionnaire for Children and Adolescents; EmQue-CA) and level of contact with people with dementia (Adolescent Level of Contact of Dementia Questionnaire; A-LoCD).

Results: Descriptive statistics and associations between independent and dependent variables will highlight what factors are associated with dementia attitudes in British adolescents.

Conclusion: Understanding what factors are associated with adolescents' attitudes towards people living with dementia is an important step to understand not only who is most at risk at developing negative attitudes towards dementia, but also factors that need to be accounted for when developing an effective anti-stigma strategy for this age group.

349

An attempt to help people with dementia realize what they want to do

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Ishihara Neurocognitive Clinic, Miyagi, Japan. Steering Committe of DAI (Dementia Alliance International) ED-SiG(Environmental Design Special Interest Group), Ankeny, IA, USA

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Emily, person with dementia from DAI (Dementia Alliance International) said that the greatest fear and concern is feeling 'imprisoned' by the environment other than losing our independence. Unfortunately, many hospitals consider people with dementia as patients only. And doctors have been using medications that restrict behavior until they can't move, or offering advice to move the patient temporarily or permanently to another environment, away from home without little effort.

Aim: We launched a clinic in Japan in April 2021 to provide diagnosis and post-diagnosis support for people with dementia and their family. The aim of the clinic is to help clients and their families continue to live at home as a community member with full of rights.

Method: The clinic director became a steering committee member of the DAI Environmental Design Special Interest Group (ED-SiG) not only to contribute our expertise to the group, but learn from people with dementia, and provide resources to other people with dementia.

Result: The symptoms of people with dementia changed over time. For those who were no longer able to attend outpatient clinics, we provided support through home visits so that they can continue to live at home. Advice from people with dementia in the committee was accepted and practically tried by people immediately after diagnosis.

Conclusion: The results suggest that collaboration with people who have been diagnosed with dementia and those who work with them can contribute to improving the QOL of those who will be diagnosed.

350

Demensia Brunei: raising public awareness towards a dementia friendly community

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

Demensia Brunei was formed in 2018 and a member of ADI since 2020. It strives to achieve a dementia friendly community by raising dementia awareness.

Dementia Care Skills (DCS) Workshops are two-day hands-on interactive workshops to equip caregivers with skills of caring for people with dementia. Public awareness talks were given to different groups, including senior citizens, schools and local companies. Public booths are held in collaboration with the health promotion centre in malls or the city centre on Car Free Sundays. Dementia Friends Brunei helps people learn about living with dementia and encourages action and contributing towards a dementia friendly community. Conventional media such as talk shows on television, radio and newspapers are utilized to deliver information about dementia.

Due to the pandemic, social media was heavily utilized in the last two years, particularly Instagram. The following table summarises the annual number of activities and people reached for 2018 to 2021.

No.		2018	2019	2020	2021
1.	**DCS Workshops:**				
	Number of Activities	4	7	3	2
	People Reached	60	131	70	20
2.	**Public Awareness Talks:**				
	Number of Activities	5	8	6	15
	People Reached	85	350	250	2430
3.	**Public Events / Booths:**				
	Number of Activities	5	11	18	6
	People Reached	550	1750	942	350
4.	Dementia Friends Brunei				
	Number of Activities	5	4	7	2
	People Reached	30	113	175	28
5.	**Media:**				
	Number of Activities	7	13	15	9
6.	**Social Media:**				
	People Reached	-	-	2200	3087
	TOTAL PEOPLE REACHED:	**725**	**2344**	**3367**	**5915**



351

Frontal lobe dysfunction in dementia – case series

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Topic

Dementia research and innovation: Other syndromes and dementia

Abstract

The frontal lobes are involved in sophisticated higher order cerebral function or executive function. They are involved in planning to ensure that the appropriate cognitive tasks are performed at the correct place and time. However, there can be heterogeneity in frontal lobe function, with occasionally contradictory behaviour in different people despite similarly localised frontal lesions. This variability can be starkly contrasting between apathetic indifference to emotional lability and perseveration to impersistence in activities. While there may be minimal deficits on routine cognitive testing, these people are unable to function in the real world. Thus, frontal lobe dysfunction tends to be challenging to diagnose and is easily missed by clinicians.

The features of frontal lobe dysfunction are highlighted in this series of four cases. It is hoped that this will raise awareness regarding frontal lobe dysfunction, a hallmark of the behavioural variant of fronto-temporal dementia. These clinical features should prompt clinicians to specifically evaluate frontal lobe dysfunction using specific tools such as the Frontal Assessment battery (FAB).



352

Mapping stakeholders for the development of the national dementia plan in Vietnam

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Introduction: Development and implementation of a national dementia plan is recommended to be the first public health priority by the World Health Organization. Resulted from population aging, prevalence of people with dementia in Vietnam increases. This study describes stakeholder perceptions and attitudes regarding the development and implementation ofanational dementia plan in Vietnam.

Method: A qualitative study conducted among stakeholders. The mapping tool designed by the World Health Organization was used to interview 16 stakeholders from government office, service providers, civil society, academic institutions, private sector, international organizations and media. We collected information about perceptions of the dementia burden, the level of interest and influence of interviewees and their institution in the development of Vietnam's national dementia plan.

Results: Most stakeholders were aware that dementia is an increasing problem. A national plan and policy dedicated to dementia care and prevention is not available. Although several different stakeholders were interested in developing a national plan and strategy for dementia care, the formal process must officially started from MoH, while other organizations could only contribute to generate evidence, and advocate the issue through a number of agendas and programs. Civil society, other non-governmental organizations, private sector and media were not very influential in policy approval process.

Conclusion: While efforts are needed to convince officers from ministerial office to give higher priority to dementia care in their policy agenda, more active participation of other stakeholders will have a role in other activities of the policy development process.

354

Building moments of connection - A global music therapy program for Persons living with dementia who have resided for several years in a residential care home.

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

In recent years research has highlighted the significant beneficial impact of music on the brain as well as the fact that experiences connected with music offer greater resistance to the progress of Alzheimer type dementia. This conclusion alone positions music as a privileged means of improvement of the lives of Persons living with dementia.

In this area, music therapy appears as an intervention of choice, complementing the continuing care of the Person living with dementia and allowing for the support of the Person during the progression of condition.

Based on the experience of several years working in the Casa do Alecrim Home, founded in 2013 by Alzheimer Portugal and specially devoted to the care of Persons living with dementia, this paper will describe a music therapy program developed with special emphasis on the phases of greatest vulnerability in Persons living with dementia.

Through the use of music and of the presence of the music therapist it becomes possible to create light and delicate moments of communion and connection with the radical humanity of the Person living with dementia. In various situations this accompaniment can take place from an initial stage of the condition all the way to situations of extreme fragility, already in the domain of palliative care.

This paper will describe both individual and group music therapy interventions with visible impact on the wellbeing of the Person living with dementia.



355

Australian behaviour support services: feasible, economical, and delivering meaningful outcomes

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Behaviors and psychological symptoms of dementia (BPSD) are commonly experienced by this population. BPSD are frequently debilitating, can lead to complex care needs including hospitalisation, and impact not only the quality of life of the person living with dementia but also their caregivers.

Despite widespread use, pharmacological treatments (e.g., psychotropics) for BPSD are typically ineffective and are often associated with significant side effects including death. Non-pharmacological interventions, in contrast, are safe and routinely demonstrate meaningful improvements to BPSD.

This session will describe and discuss the model of care, feasibility, and outcomes of the Australian Government funded BPSD support service 'Dementia Support Australia' (DSA). DSA has operated for over 5-years and provides 24/7 support to anyone living with BPSD in Australia. DSA delivers a nationally consistent support including non-pharmacological and person-centered recommendations following a detailed in-person assessment and focus on the de-prescribing of inappropriate medications.

DSA supports over 10,000 people living with dementia every year, most of whom benefit substantially from these services. Specifically, DSA achieves a 61 – 74% reduction in overall BPSD severity, and a 67 – 69% reduction in caregiver distress. These reductions, in turn, are likely to reduce the need for downstream health services, such as hospital admissions due to BPSD. In fact, every dollar spent by the Australian government on DSA is estimated to be repaid by $1.60 in terms of savings associated with reduced health service utilization.

We discuss these findings in the context of emerging BPSD models of care in the United Kingdom and worldwide.



356

Specialist Dementia Care Programs Units (SDCPUs): home-like, person-centred dementia-specific care units in Australia

Dr Mustafa Atee[1], **Prof Stephen Macfarlane**[1,2], Dr Thomas Morris[1], Prof Colm Cunningham[1,3]

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

The vast majorityofpeopleliving with dementia experienceneuropsychiatric symptomswhich frequently have considerable negative social and clinical outcomes, such as inappropriate drug therapy,significantcaregiverburden,frequenthospitalisations and reduced quality of life.As such,dementiarequiresdedicated skills and resourcesandspecialistcare and support, particularly in the advanced stages of the condition.In Australia, this supporthasbeen madepossible through theSpecialist Dementia Care ProgramUnits(SDCPUs). SDCPUsaregovernment-funded,home-likespecialist accommodation units (up to 12 months) that provide a person-centred, multidisciplinary model of care for people with very severeneuropsychiatric symptoms, such as severe aggression,who cannot be cared for by mainstream aged care services in Australia.

Eligibility criteriafor admission to SDCPUsincludereferrals with/who: (1)neuropsychiatric symptomsprimarilylinked todementia; (2)severe or very severeneuropsychiatric symptoms(e.g.,aggression, severe agitation);and(3)demonstratedintractabilityto adequate trials of treatment.Eligibility assessmentsarecompleted bya dedicated team ofconsultants andpsychogeriatricians.

The aim of thissessionistodescribethe features of theSDCPUsand characteristicsof referrals to these units, and discuss outcomes and learningsfrom implementing this model of carein Australia.



358

Evaluating Assistive Spoken-Dialogue Agent System in Daily Living of Elderly People

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Japan is facing a super-aging society and lacks the manpower of nursing care. Our research group has been focusing on the self-care of in-home elderly people (including patients with dementia) through assistive technology. In our previous study, a listening service was developed using a spoken dialogue agent. It is possible to record and analyze the minds of elderly people richer than the conventional sensors. Moreover, a PC Mei-Chan system was also developed. It made elderly people easier to execute a variety of microservices (e.g., web search) just by spoken dialogue with the agent. The purpose of this study is to evaluate the effectiveness of PC Mei-Chan for the elderly self-care at home. The experiments are conducted targeting multiple in-home elderly subjects, evaluating the feelings and frequency of using PC Mei-Chan. Its functions evaluated include a review service, schedule management service, video watching service, and so on. Based on the feedback from the subjects, more effective self-care for elderly people through system improvement is promising.

361

The Care Home Action Researcher-in-residence Model

Mrs Faith Jane Frost, **Dr Isabelle Latham**

Association for Dementia Studies, University of Worcester, Worcester, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

It is known that traditional approaches to engaging care homes in research experience substantial challenges. This project encouraged collaboration between care homes and researchers to explore alternative models of research engagement to improve their care practice and the lives of people with dementia within their care settings.

CHARM used 2 experienced researchers embedded within 4 care homes to build in-house research expertise and support the design and delivery of bespoke research projects of use to the whole care home community. Within the project a series of learning exercises were provided, to enable care home staff to gain knowledge and confidence into the process of conducting research. Action-research was used as the methodology because of its continuous, participatory, flexible, context-specific and improvement-oriented focus.

This introductory presentation will explore how to research collaboratively with care homes by sharing the findings from the CHARM study:

(1) the impact of CHARM on the care homes and staff who took part

(2) the refined CHARM model

(3) facilitators and barriers to successful implementation and

(4) recommendations for future rollout of the model, including a brief overview of the free manual 'The CHARM Framework: A step-by-step guide for care homes to conduct their own research projects'.

This project was given ethical approval by University of Worcester, Health, Life & Environmental Sciences Research Ethics Panel (CHLES REP)



362

Nursing care of people with dementia in an orthopaedic acute care setting

Dr Anders Møller Jensen[1], Prof Rhonda L. Wilson[2], Dr Birthe D. Pedersen[3], Prof Lise Hounsgaard[3], Dr Ellen B. Tingleff[3]

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aims: This integrative literature review is to collect what is known about the care of people with dementia when they require a hospital admission for an orthopaedic surgical procedure, and to contribute to developing an evidence-base to support nursing practice when caring for people with dementia in an orthopaedic setting.

Method: An integrative literature review and qualitative deductive content analysis using McCormack and McCance's theoretical nursing framework (Person-Centred Nursing Framework) of nine studies were undertaken. The process of the review was guided by PRISMA checklist.

Results: The care environment and resistance either in passive form, or through physical intervention, is common in orthopaedic nursing. Planning and delivering care for physical, cognitive and emotional needs is identified as being difficult, resulting in a lack of inclusion for patients, partly due to communication challenges. Finding ways to implement tailored care plans within standard ward routines proves difficult, and the consequence is a less than optimal care experience with adverse effects on patients characterised by an increase in dementia symptoms.

Conclusion: Care for people with dementia in an orthopaedic setting is complex. It needs to be further studied so that more evidence and supporting literature can contribute to improved care for this group of patients.

363

Supporting Timely Diagnosis and Interventions; Ireland's first Dementia Model of Care

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Timely diagnosis and intervention is a priority area within the Irish Dementia Strategy. The Dementia Model of Care (MoC) (forthcoming) was developed to meet this priority; outlining care pathways for all people with suspected dementia or living with dementia, irrespective of age, disability, gender, ethnicity, dementia sub-type or living circumstance.

Evidence, generated through linked diagnostic and post-diagnostic projects (NDO, 2017-2019) led to the model's development by the National Dementia Office, Health Service Executive in conjunction with the Centre for Economic and Social Research on Dementia NUI Galway and the Dementia Services Information and Development Centre. A national multi-stakeholder expert advisory group and a public consultation also informed the approach and content.

The model is underpinned by five core principles – citizenship, person-centred approaches, integration, personal-outcomes and timeliness. These are revisited at each point on the care pathway. Service targets and practice recommendations complement guidance for clinicians and service planners.

There are four key elements to the Model:

- A three-level approach to assessment and diagnosis, within primary, secondary and tertiary care, with a focus on timely, complexity-appropriate and integrated diagnosis.
- Appropriate disclosure, drawing on national and international best practice.
- Care planning, using personalised processes that are inclusive of the person living with dementia and their supporter/carer.

Post-diagnostic treatment and support across five strands:

- Understanding and planning
- Staying connected
- Staying healthy
- Supporting cognition
- Supporting emotional wellbeing



The model is informing resource allocation, service and clinical development in the area of dementia care in Ireland.



364

Single- or multi-occupancy rooms: Patient preferences

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Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

Background: Hygiene procedures are only one factor when it comes to assessing the merits of single versus multi-patient rooms, but little is known about patients room preferences.

Methodological approach and sample description: A total of 313 patients in ten Bavarian hospitals were asked about their room preferences. The study included patients from various departments, accommodated in single, twin and multi-patient rooms.

Results: Disregarding financial considerations, almost half of the patients (48%) were in favour of a double-occupancy room. Around 29% preferred a single room and a further 9% said they would be happy with either a single- or a double-occupancy room. A minority (8%) expressed a preference for a room with three or four beds, and 6% were indifferent.

There were very few differences in room preferences between men and women.

In comparison to patients over the age of 65, a slightly larger proportion of younger patients expressed a preference for a single room, and slightly fewer preferred a double-occupancy room. Shared rooms with three or more beds were more acceptable for the older age group.

Discussion: As the data shows, elderly patients in particular do not like to be alone in the room. They are therefore prepared to accept some disturbances in exchange for company and roommates that can call for help in emergencies.

People with dementia particularly benefit from the company of helpful roommates, though there is also a potential for conflict in this situation and care must be taken not to overload the other patients.



365

MOLECULAR DYNAMICS AND DOCKING STUDIES OF Bacopa. monnieri DERIVED NEUROPROTECTIVE COMPOUNDS AGAINST ALZHEIMER'S DISEASE

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Alzheimer's disease (AD) is the most common form of dementia in which amyloid-beta and tau tangles are significant factors responsible for damaging nerve cells. For the cognitive and functional decline in AD, oxidative stress is considered as one of the significant factors. Till now, only a few FDA-approved drugs are available in the market due to the limitation of adverse effects. For many years, medicinal plants have been used for making drugs. In this paper, 52 novel phytochemicals were extracted from Bacopa monnieri (Brahmi plant), which is a medicinal plant. First, we performed ADMET analysis and toxicity screening and nine primary targets were selected associated based on the association with AD. Then we perform molecular docking followed by molecular dynamics simulation. After screening 52 molecules, we found Bacosine to be more effective against the target molecule 2FLU. The binding Affinity of 2FLU-Bacosine was found -11.22 kcal/mol. The docking study reveals that the significant residues of Ala510, Thr560 were attached to the ligand with hydrogen bonding, the RMSD of the C-α backbone of 2FLU in the complex was demonstrated to be relatively stable with a slight variation of up to 0.2Å. The main aim of the study is to find the most promising compound from *Bacopa monnieri* for the development of the drug and the most promising therapeutic target to treat AD



366

Attuning Mitochondrial Dysfunction in Alzheimer's Disease through Stem Cell Therapy

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

It is widely recognised that Alzheimer's disease is a common type of progressive neurodegenerative disorder that results in cognitive impairment over time. Approximately 152 million cases of AD are predicted to be reported by 2050. The Food and Drug Administration has approved only five medications to treat a small number of AD cases at this time. Stem cell treatment that targets mitochondrial dysfunction was the focus of our research. From the P2X7 receptor to copper homeostasis in AD, this overview covers nearly all of the mechanisms associated with mitochondrial failure. We focused on stem cell therapy, which includes induced pluripotent stem cells, neural stem cells, mesenchymal stem cells, and so on, to resolve mitochondrial dysfunction in AD. We also attempted to cover the current clinical trials of stem cells that are taking place at the time of publication. To tackle this devastating disease, we expect that stem cells will be able to alter therapeutic techniques and be tested in clinical trials within a few years.



367

A Study of blood biomarkers in Preclinical Alzheimer's disease: Comparative Analysis of the Scores of Neuropsychological Test in 110 Subjects

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Introduction: Growing number of Alzheimer's disease (AD) in Recent years, while early detection and diagnosis of AD facing challenges. Compared to neuroimaging and CSF biomarkers, blood biomarkers are less invasive, of lower-cost, and more time-efficient measurements. This research was to seek blood biomarkers with high sensitivity and specificity for the early diagnosis of preclinical AD.

Methods: A total of 110 subjects ≥60 years old diagnosed as Preclinical AD, including as Subjective cognitive decline (SCD) group and mild cognitive impairment (MCI) group from March to August 2021. All subjects were tested by mini-mental state examination (MMSE), Montreal cognitive assessment (MoCA) and blood biomarkers (plasmas BDNF, IL-6, TNF-α, Aβ42, Aβ40, Aβ42/40, p-tau, and t-tau were measured by ELISA) and the correlation of the results was analyzed.

Results: No significant differences were observed between groups in sex, age and education level of the subjects. The average score of MoCA were (25.84±2.10) and (21.89±2.39) in SCD and MCI subjects (P<0.001), respectively. The average score of MMSE were (27.33±1.61) and (26.88±1.61) in SCD and MCI subjects(P=0.158), respectively. No significant differences or correlations were observed between groups in blood biomarkerslevels of the subjects.

Conclusions: MoCA, the most common use to test the general cognitive assessment could effectively distinguish the SCD and MCI subjects. MMSE and blood biomarkers is probably a bit less sensitive tool to diagnosis of preclinical AD. Further research is required to adjust potential confounding factors, improve experiments techniques, and these results are a starting point.



368

The role of microglia in Alzheimer's disease

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Neuroinflammation is a common feature of Alzheimer's disease (AD), implicating the importance of microglia's role in AD progression. Microglia are specialized resident macrophages of the central nervous system that help to clear debris, pathogens, and neuronal synapses. Under physiological conditions, microglia maintain plasticity by providing trophic support to neurons. Under pathological conditions, microglia often prune synapses excessively, increase pro-inflammatory cytokine release, and reduce trophic factor release. **Currently, it is unclear how microglia impact AD.** Although microglia activation is associated with amyloid deposits, a causative relationship to disease progression has not been shown. Using a recently established microglia differentiation protocol, we have converted AD and unaffected control patient derived induced pluripotent stem cells (iPSCs) into human microglia in order to investigate microglia specific changes inherent to AD. The goal of this project is to analyze the transcriptome and functionality of AD microglia cells in comparison to age matched controls. By employing RNA sequencing, we can analyze differences of gene expression between control and AD microglia cells, revealing AD risk factors specific to microglia that may contribute to pathogenesis. Using phagocytosis and activation assays, such as adding synaptosomes or bacteria-like lipopolysaccharides (LPS) with the microglia, respectively, will allow us to assess if microglia functionality is impaired/affected in AD. We hypothesize that AD microglia will exhibit differences in activation potential and duration compared to age matched controls. The findings from this study will elucidate aspects of microglial contribution to AD, potentially offering new therapeutic avenues for treatment.





370

An experience of resilience in a group of formal caregivers of people with dementia in times of Pandemic by COVID.

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Fundación Alzheimer, Cali, Colombia

Topic

Support for dementia carers: Young carers

Abstract

Introduction: The Alzheimer's Foundation has been carrying out training actions to strengthen the team of caregivers. On this occasion, as a result of the pandemic, it identified the need and the challenge of reaching the homes of the affected people and their caregivers, both at the care and psychosocial levels, formally creating the School of Caregivers/Experts with this strategies: 1) Direct care of patients in their homes, 2) Training of nursing assistants, 3) Creation of a space of resignification of the stressful events .

Objective: To know the adaptive responses of a group of formal caregivers (nursing assistants) of person with dementia in time of Pandemic by COVID from the perspective of resilience and emotional containment .

Methodology: During 15 training sessions , in face-to-face and virtual modalities . The main training topics were: Relationship with families, Life and personal grief, Transportation, Communication, Support received from patients and their families, Learning and resilience. Alternative relaxation methodologies were used.

Results: A transformation of the dynamics in the family/caregiver relationship was identified, generating appreciation of their role as caregivers, it was perceived that this served to increase the visibility of this role from the citizenship .The expression of feelings helped the team to have a network of support and emotional containment .

Conclusions: Make visible the value of the nursing assistants' care by the families' manifestations of support. Enriched self-esteem, improve the value of the role in families and society, considering the importance of contribution to the balance, functionality



371

Mapping the diverse pathways to care for persons with dementia in India

Ms Jayeeta Rajagopalan[1], Dr Klara Lorenz-Dant[2], Dr Suvarna Alladi[3], Ms Saadiya Hurzuk[4], Dr Priya Treesa Thomas[5], Ms Meera Pattabiraman[6], Mr Narendhar Ramasamy[7], Ms Adelina Comas-Herrera[2]

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

As per the Alzheimer's and Related Disorders Society of India (ARDSI) Dementia India Report (2010), an estimated 5.29 million people are living with dementia in the country. These numbers are expected to increase considerably over the next few decades. Despite this anticipated rise, currently only a small proportion of persons with dementia receive any diagnosis, treatment or care in India (Dias and Patel, 2009). The care that is sought by families is diverse, influenced by differences in several context specific factors across the country.The Strengthening Responses to Dementia in Developing Countries [STRiDE] project—an international project being conducted in seven low and middle-income countries led by the London School of Economics [LSE] in the UK and carried out by the National Institute of Mental Health and Neurosciences (NIMHANS) and ARDSI in India, used team members insights to map these heterogenous situations that persons with dementia and their families encounter when seeking care. The aim of this exercise was to highlight the challenges associated with existing dementia care services in the country. Low awareness of dementia among health professionals and the general public, poor availability/accessibility to medical services, high out-of-pocket costs associated with seeking care, poor care coordination and limited psychosocial support to unpaid/family carers were major factors identified to influence care seeking experiences. These findings can aid in bringing recognition to gaps in current care services for dementia and facilitate the development of further research into the challenges identified and strategies needed to address them.



372

Facial expression recognition in mild cognitive impairment and dementia: is the preservation of happiness recognition hypothesis true?

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aim: Social cognition encompasses facial expression recognition (FER), theory of mind, and empathy. Although studies examining FER in large numbers of patients with mild cognitive impairment (MCI) or dementia are rare, relative preservation of happiness recognition in dementia was reported in some studies. In this study, we examined performance on FER tests and its relationship to clinical demographics and other cognitive function test scores in patients with cognitive decline.

Methods: The present study administered an FER test and several cognitive tests to outpatients at a memory clinic. The FER test presents four facial expressions (happiness, surprise, anger, and sadness). A total of 187 patients were placed in one of the three groups based on their cognitive status: dementia group (n = 63), MCI group (n = 92), and normal cognition group (n = 32).

Results: The total scores on the FER test significantly differed among the three groups (normal > MCI > dementia). In the recognition of happiness and surprise, the dementia group had significantly lower scores than the normal cognition group. There were no significant differences in the recognition of anger and sadness scores among the three groups. The FER scores for happiness and surprise were primarily related to executive function scores, but the FER scores for anger and sadness were primarily related to age.

Conclusions: We note the difference in recognition of causative factors among the four emotions (happiness, surprise, anger, sadness). Our study raises serious doubts about the preservation of happiness recognition hypothesis in dementia based on FER tests.

373

Knowledge, attitudes and self-confidence on skills of dementia care in physicians at primary health care settings in Vietnam.

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Background: Dementia is a global public health priority.

Aim: This study examined the knowledge, attitudes, and self-confidence on skills on providing dementia care and management among primary health care providers in Vietnam.

Methods: A cross-sectional study was conducted on 405 primary health care providers working at community health stations and district health centers in eight provinces across Vietnam. The questionnaire included 13 knowledge questions (each correct answer was given one score so the maximum score was 13), 16 attitude questions regarding the benefits and risks of early diagnosis, diagnostic procedures, resources, and opinion on treatment options, and 4 questions measuring confidence on skills with a five-point Likert scale (1 = disagree to 5 = agree). Physician practice regarding diagnosis and treatment of dementia was also evaluated.

Results: The results showed that primary health care providers in Vietnam had poor knowledge (the total score of knowledge was (Mean= 6.9; SD=2.1)) and less confidence (less than half of the participants felt confident in diagnosis and treatment for dementia) but the positive attitude toward dementia care and management (majority of respondents agreeing and strongly agreeing with items belong to positive attitude ranged between 52.5% to 70.3% for agreeing; and from 7.0% to 41.4% for strongly agree).

Conclusion: The results suggested that building capacity for primary health care providers is critical to prepare for Vietnam's rapidly aging population and increasing number of people with dementia.



375

Understanding the economics of dementia at the family level in India

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Topic

Dementia as a public health priority: Economics of dementia

Abstract

The dementia care system in India relies on families of people living with advanced dementias (PLWD) to support their care – either providing it themselves, possibly necessitating foregoing opportunities for paid work, or paying for it from the unorganised care labour sector. The sustainability and quality of India's dementia care system therefore depends on the extent to which these economic costs are bearable to families. While there is some evidence about the negative consequences of meeting these costs (Narayan et al. 2015), there has been little engagement with what 'families' means in this context. This paper critically engages with the implied expectation that both wealth and expenditure – that is, dementia care costs and the resources to meet them - are shared among adult members of Indian families to explore:

1. families' decision-making around who can and cannot be appropriately called upon to provide different types of care;
2. the extent to which the families of PLWD experience caregiving as individuals or as family units;
3. the methodological implications of this for understanding the economic impact of providing dementia care and the salience of this for positioning dementia as a public health priority.

The paper is informed by ongoing analysis of a series of in-depth, qualitative interviews (N=55) with 24 *ostensibly* low and middle-income family members of people living with moderate or severe dementias in East and South India, in which reports of income or wealth appear to be contradictory, ambiguous, and associated with family members' understandings of dementia and dementia care.



376

Meeting Centres: regional approaches to community-based support for people affected by dementia

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

A Meeting Centre (MC) is a local resource, operating out of ordinary community buildings, that offers on-going warm and friendly expert support to people and families affected by dementia. The UK Meeting Centre Support Programme was established in 2018 and led by the Association for Dementia Studies (ADS), University of Worcester. The aims of the programme are to help establish new MCs in different parts of the UK; develop a Community of Learning and Practice develop resources and training and support data collection.

During the early stages of the pandemic all MCs in the UK closed their doors and did not start to re-open until August 2020. Some MCs were able to support people affected by dementia remotely (Evans et al, 2021). Despite the pandemic the UK MCSP continued to flourish with the number of MCs funded increasing and a growth in regional initiatives.

Significant regional developments have taken place over the last three years including in Worcestershire, England led by ADS; in Scotland led by Kirrie Connections and Powys in Wales led by Dementia Matters in Powys. This has been driven by different policy decisions and funding opportunities across the three nations.

In the presentation the different contexts and approaches to MCs will be described and compared and contrasted. The audience will gain an understanding of the flexibility of the MC model in meeting the needs of people affected by dementia, different communities, including its relationship with some Dementia Friendly Communities, as well as in different regions and countries.





377

STRiDE PAR: Accessing ongoing dementia care in Brazil: an analysis of case vignettes

Dr Fabiana A F Da Mata[1], Dr Deborah Oliveira[2], Dr Elaine Mateus[3,4], Dr Ana Carolina Franzon[3], Miss Carolina Godoy[1], Dr Adelina Comas-Herrera[5], Dr Cleusa P Ferri[1], Dr Klara Lorenz-Dant[5]

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Background: The number of people living with dementia in low- and middle-income countries is increasing rapidly, and care systems in Brazil are generally not prepared to provide adequate care to this population group.

Aim: Using case vignettes, we explored the likely access to ongoing dementia health and social care by key groups of people living with dementia and their family carers in Brazil.

Methods: We developed ten case vignettes as part of the STRiDE project depicting probable care pathways of people living with dementia in Brazil. The vignettes focused mainly on the likely available support structures and the specific cultural context. We conducted internal and external validation processes, designed a framework to analyze the information contained in each vignette, and explored barriers that may contribute to difficulties in accessing care and support.

Results: Our findings show that people living with dementia may seek help from health care services, community-based services, and residential care. Barriers to access appear to be commonly related to poor awareness of dementia among the general population, poor training in dementia and awareness among healthcare professionals, low educational level and economic status, poor physical infrastructure and public transportation, low service coverage, and stigma.

Conclusion: Public policies need to focus on increasing dementia awareness, reducing inequities among the population, strengthening associations and organisations to improve care and support for people living with dementia and their family carers. Also, establishing dedicated care models for people living with dementia and support to their families.

378

Memory Technology Resource Rooms; Contribution, Value and Role - Findings from an Evaluation of Service

Ms Emma O' Brien[1,2], Mr Kevin Cullen[3], Dr Emer Begley[4,5], Ms Eibhlis Cahalane[6]

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Background: The Memory Technology Resource Rooms (MTRRs) offer a dedicated person-centred post-diagnostic support for people with dementia, families, carers and healthcare professionals. Largely an Occupational Therapy (OT) led service it provides a holistic AT consultation, assessment and demonstration, improving access to AT and enabling the person to continue engaging in meaningful daily activities. Established in 2018 there are now 27 MTRRs throughout Ireland

Evaluation findings

- A 2020 evaluation, focused on the MTRRs contribution, role and value (Cullen, 2020). Key findings show:
- 2,261 people were referred to the service in 2019
- Of these 1,875 people attended
- 36.7% referrals were from community services, 35.3% secondary/acute care and 13.5% self-referrals
- 58.7% of visitors had a diagnosis of dementia, 12.4% had a cognitive impairment; 22.3% undiagnosed
- 89% of visitors were assessed for AT with 34% receiving additional non-AT advice, and 66% were signposted or referred to relevant and community services.
- 90% of visitors rated their visit as very usefuland 98% found potentially useful technology.

Follow-up interviews with 34 visitors show:

- 85.3%found their visit to the MTRR very useful
- 66.7% purchased AT; the majority were orientation products;
- 72% found their AT device very useful and 24% a little useful

Conclusions: The MTRR Network is an important part of the emerging post-diagnostic pathway for people living with dementia in Ireland. It provides continuity of care; offering practical advice and solutions and is a resource for local health care staff. Evaluation recommendations included enhancing the service to deliver post-diagnostic supports such as cognitive therapies and psycho-education.



379

Incidence of mild cognitive impairment in adults aged 60 years or older in Southeast China: a cross-sectional study

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Topic

Dementia risk reduction: Risk factors

Abstract

Background: Mild cognitive impairment (MCI) is an intermediate phase between normal cognitive ageing and overt dementia. Compared with some other areas, there has not yet undertaken a comprehensive study on whether the incidence of MCI in the elderly in Southeast China has its own characteristics. This study aims to explore the incidence of MCI in adults aged 60 years or older in Southeast China.

Methods: A total of 729 elderly people, aged 60 and above and living in Fuzhou, were recruited between January and May, 2018, using a convenience sampling method. All subjects were tested by mini-mental state examination (MMSE) and Montreal cognitive assessment (MoCA). The effects of age, gender, education and recruitment strategy on the incidence of MCI were investigated.

Results: The average score of MoCA and MMSE were (21.26±4.13) and (25.48±2.94) in MCI subjects, and 410 cases of MCI (56.24%) were detected. The chi-square test showed that the incidence of MCI was affected by age, gender and education level ($P<0.05$). No significant differences were observed between groups in recruitment strategies of the subjects.

Conclusions: Higher MCI incidence was identified in Southeast China compared with some other areas, possibly due to more broadened criteria being adopted for confirming the diagnosis. Age, gender and education level were influencing factors for MCI in the elderly. Further research is required to explore the risk factors of cognitive impairment based on the characteristics of the population in different areas. Targeted prevention can be carried out according to the influencing factors.

380

A scoping review of effective strategies for nonverbal communication with people living with dementia.

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aim: People living with dementia (PLWD) experience challenges comprehending language and benefit from nonverbal communication (NVC) supports. Little published empirical evidence exists for care partners regarding effective NVC strategies for PLWD nor those that are person-centred. The current study represents a scoping review of effective NVC strategies used by care partners with PLWD.

Method: CINAHL, PsycInfo, Scopus, and Pubmed databases were searched in December 2020. Eligible publications included empirical studies that examined the effectiveness of NVC strategies used by care partners of PLWD using objective measures, and were published in English in peer-reviewed journals. All publication dates were eligible. Studies were screened by title and abstract, followed by full-text review. An evidence summary table was used.

Results: Sixteen studies were included in the final review. Six categories of effective NVC strategies were identified in the included studies: eye contact, gestures, facial expression, touch, close proximity, and frontal orientation. Studies defined communication as effective based on eight outcomes, with successful task completion and improved responsive behaviour identified most often. There was a lack of person-centered outcomes used to define effective.

Conclusions: Results present a summary of NVC strategies used by care partners with PLWD, considered effective in the current literature. Use of effective strategies can enhance communication between care partners and PLWD and mitigate negative consequences of problematic communication. Disagreement exists in the literature regarding which outcomes define effective NVC with PLWD. Further research should determine the effectiveness of NVC with PLWD and delineate which NVC strategies are person-centered.



381

Quality of life for the elderly is the indispensable gesture of recognition and gratitude of the following generation - with ichó we contribute to fulfill this responsibility.

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Every 3 seconds, one person worldwide develops dementia.

Family members are overwhelmed by the situation and inpatient care facilities are already working at its limit. Humanity often falls by the wayside and the patient's quality of life decreases considerably.

In search of a solution, the founding team, who was personally confronted with the afore described situation, developed the smart therapy system ichó.

Established, analog therapy methods (memory training, basal stimulation, music therapy, relaxation exercises) were transferred into a digital, haptic-responsive and easily accessible spherical device that responds to interaction with light, sound and vibration.

At the 35. Global Conference of Alzheimer's Disease International, we would like to show not only that ichó can significantly improve the quality of life of all involved, but also that the innovative approach can sustainably relieve the burden on the healthcare system, by

- enabling people diagnosed with dementia to take an active part in life and the community (again).
- supporting family members with individual and guided training that can be applied to the current support situation
- equipping professionals with a tool that requires little preparation time and can still be used to address numerous people individually.

We also like to demonstrate the possibilities of authentic data detection, of e.g. reaction times, movement radii and tremor developments, that allow objective insights into therapy and/or disease progression.

Further information:

Website: https://icho-systems.de/

Youtube: https://www.youtube.com/watch?v=Xj0j7J3J3jE

Facebook: https://de-de.facebook.com/ichosystems/

Instagram: https://www.instagram.com/icho.systems/?hl=de

LinkedIn: https://www.linkedin.com/company/ichosystems/

382

100/6000 a dementia conference by people with dementia for people with dementia held on 14th &15th of September 2021 did it work? and where to next?

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Imagine a meeting room with 100 people with dementia what would people see? Workers might see 100 people requiring 100 needs assessments, 100 risk assessments and 100 packages of care. Care home managers might see 100 potential residents. Academics might see 100 research subjects' neurologists may see 100 CT images to be checked. Our view is that there is another way of viewing this group We can look into this room and see none of the above instead we can see at least 6000 years of lived experience, that's 6000 years of wisdom, knowledge and life in one space at one time.

Deepness Ltd a not for profit membership organisation run by and for people with dementia where 10 of the 13 directors have dementia meaning governance is in our own hands. We did imagine a dementia conference where all of the speakers had dementia and others could be present and observe but could not speak The conference ran over two days and covered the following three topics:

1. Human rights for people with dementia in a post pandemic world
2. Peer Support what is it?
3. What should a national care service look like for people with dementia

All discussions were documented and a position paper was written about the three topics but what was the learning from conference? This is the question we will address in this interactive workshop. We will also share music and film that was part of the conference content

Both presenters have dementia



383

Cognitive Training Outcomes in Persons with Mild Cognitive Impairment

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aims: There is growing interest in understanding the benefits of cognitive training in persons with Mild Cognitive Impairment (PwMCI), who are known to be at higher risk of developing dementia. This talk will succinctly summarize the current body of evidence on cognitive training in PwMCI and discuss the findings of a study that examined the benefits of two forms of cognitive training (gist-reasoning training versus new-learning training; random assignment design) on cognitive functions (experimental and standardized measures) and brain mechanics (event-related neural oscillations on Go/NoGo task).

Method: PwMCI in both training groups (n=50) were comparable on mini-mental state examination and logical memory subtest Wechsler Memory Scale-III scores at baseline assessment. They received 8-hours of training over 4 weeks in small groups of 3-5 individuals with two 1-h sessions per week at the end of which they completed post-training assessments.

Results: The gist training group showed significant improvement ($p < .05$) on measures of strategic attention and memory, whereas participants in the new- learning group showed significant improvement in detail memory for text. The gist training group also showed enhanced event-related desynchronization in the alpha frequency band on the Go/NoGo task relative to the new-learning group.

Conclusions: These findings suggest that cognitive training, in general, has a beneficial impact on cognitive abilities in individuals with MCI. More importantly, training that targets higher-order cognitive functions appears to have a broader impact on cognitive and neural functions, providing compelling motivation to further examine the maintenance of benefits.

384

Environmental design values and principles: moving from recommendations to action.

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

In June 2021 Dementia Alliance International (DAI) established a special interest group focusing on the contribution of environmental design to the welfare of people living with dementia, ED-SiG. Founding members came from 4 continents – North America, Europe, Asia and Australia.

In October 2021 ED-SiG agreed on an action plan that has the goal of supporting the implementation of four key recommendations of the ADI World Alzheimer Report 2020. These are: to include designing for people living with dementia in the curricula of schools of architecture and design; to give prominence to the arguments contained in the Convention on the Rights of Persons with Disabilities (CRPD) for the recognition of dementia as a disability and the consequent need to apply design guidelines for people living with dementia in the same way as design guidelines are provided for people living with physical disability; to facilitate the inclusion of environmental design considerations in national dementia plans, and to assist National Dementia Associations to be informed about the available knowledge on designing for people living with dementia and share their information with planners, designers, architects, care operators and developers.

This presentation uses case studies to report on the progress made in each of these areas. It illustrates the value of having an international consensus on the key values and principles underpinning good design for people living with dementia and how this consensus assists in transforming knowledge into action.



385

Empathy mapping: Designing serious games for dementia by students

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Serious games have the potential to keep persons living with dementia (PLWD) active, slow down cognitive decline, and fill in the knowledge gaps of PLWD and their carerson dementia when coping with day-to-day issues. However, ways to discover, discuss and describe associated social and emotional health benefits of PLWD and carers engaged in serious games is currently lacking in dementia research and innovation.

In 2021, forty-five students from an undergraduate technical elective module on serious games for health at a Singapore university were divided into groups of five and given problem statements on dementia to solve. Each group was tasked to design a serious game, simulation or gamified solution for PLWD and/or their carers that can eventually be co-developed with third-party organisations. Storyboarding and user-centered design methodology was adopted to inject the element of play into the students' learning experience. They completed three deliverables, which include designing a care circle diagram, reframing problem statement, and constructing a narrative around the personas and user journeys of PLWD and carers. These instructional methods were designed with empathy, active learning and problem-solving pedagogy to promote groupwork and pique curiosity about the impact of dementia on the lives of PLWD and carers. This endeavour reinforced the need for a learning framework for designing serious games intended for vulnerable groups, which can be used to recommend flow processes and instructional methods to enhance the students' learning experience. Future work includes discussions around the ethics of serious game design and topical consultations with experts.

386

Association between advance care planning and depressive symptoms among people with dementia: an observational cross-sectional study during the COVID-19 pandemic in Japan

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Aims: Dementia diagnosis is associated with an elevated risk of depression. Advance care planning (ACP) could comprise post-diagnostic support for people with dementia. ACP is also an increasing priority for people with dementia during the COVID-19 pandemic.This study evaluated the association between ACP initiation and depressive symptoms among people living with dementia.

Method: We conducted an internet-based questionnaire survey in June 2021. Japanese family caregivers evaluated the level of depressive symptoms in persons with dementia using the Neuropsychiatric Inventory (NPI). Caregivers also rated the quality of life of persons with dementia using the EQ-5D-5L.

Results: A total of 412 family caregivers participated in the survey. Most persons with dementia (89.6%) lived in their own homes with the carers. The mean duration from diagnosis was 67.3 months. Depressive symptoms were reported in 159 patients (38.6%). A total of 175 patients (42.5%) had initiated ACP, of which 99 (56.6%) had care professionals involved in ACP conversation. After adjusting for the characteristics of persons with dementia and caregivers, persons with professional involvement showed significantly more severe depressive symptoms compared to those who did not initiate ACP. There was no significant difference in the quality of life of persons with dementia according to ACP initiation.

Conclusions: Many home-dwelling persons with dementia experienced depressive symptoms during the COVID-19 pandemic, especially in cases where care professionals were involved in ACP conversations. Optimal ACP approaches need to be developed to help people with dementia live with hope in the future.



387

The benefits of post occupancy evaluations on dementia design, the built environment and occupants.

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Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

A Post-occupancy evaluation (POE) is a structured and systematic analysis of the performance of a building measured against specified objectives or standards. By using POE's clients, architects and owners of built environments can gather feedback that will be useful for future projects by informing the brief, design and operating decisions. POE's help clients get the best out of their projects and get to the core of the client and occupants needs to fine tune the way the building delivers these. The more designers, clients and owners learn about how their buildings perform in use, the better their next buildings are likely to meet the complex needs of the clients and occupants – completing a virtuous circle of learning.

This presentation aims to expand the knowledge base and research into enabling dementia design. It will focus on aged care homes in Perth, Western Australia to see how the residents living with dementia use the buildings and if any of the design decisions have improved their quality of life. Whilst the person living with dementia is the centre of the assessment the impact on the staff, carer's and daily operations will be reviewed to see if they have been impacted and how any competing demands can be addressed.

As the brief of each building did not include assessment criteria for a POE the evaluation will be measured against the qualitative goals of the brief, functional performance, technical and environmental performance and anecdotal evidence from residents and staff.

388

A qualitative exploration of the economics costs associated with unpaid care for persons with dementia in India.

Ms Jayeeta Rajagopalan[1], Dr Emily Freeman[2], Ms Saadiya Hurzuk[1], Dr Priya Treesa Thomas[3], Ms Meera Pattabiraman[4], Mr Narendhar Ramasamy[5], Dr Suvarna Alladi[6]

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Topic

Dementia as a public health priority: Economics of dementia

Abstract

Home-based care provided by families is the cornerstone of dementia care in India, as elsewhere. While very few paid-for care (home- and institution-based) services is available to those who can afford it, there is no coordinated formal long-term care provision. However, limited evidence exists on the economic impact of providing such unpaid care to persons with dementia in India. As part of a wider study examining the costs and consequences of unpaid care in dementia under the Strengthening Responses to Dementia and Developing Countries (STRiDE) project, this paper will explore economic costs and resultant consequences associated with providing care for persons with dementia in South India. A series of remote, inductive in-depth interviews (N=55) were conducted between March and September 2021 with 24 family caregivers of persons with dementia who had accessed services provided by the Alzheimer's and Related Disorders Society of India, Hyderabad or the National Institute of Mental Health and Neuroscience, Bangalore. Initial assessment suggested caregivers and their families were of low and middle income. Framework Analysis will be conducted to identify financial costs, both direct (out-of-pocket costs such as expenses associated with consultations, investigations, medications) and indirect (e.g. loss of wage), associated with caregiving for dementia in India. This post-fieldwork analysis will be completed by February 2022. The range as well as the nature of these costs will be summarised in order to aid further research that can offer more large-scale quantifiable information on dementia associated caregiving costs.



389

Health seeking behaviours and dementia care trajectories in India: a qualitative study

Ms Saadiya Hurzuk[1], Dr Emily Freeman[2], Ms Jayeeta Rajagopalan[1], Dr Suvarna Alladi[3], Mrs Meera Pattabiraman[4], Mr Narendhar Ramasamy[5], Dr Priya Treesa Thomas[6]

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

It is estimated that there are 5.29 million people with dementia in India (ARDSI, 2010). Only 10% of persons with dementia ever receive any diagnosis, treatment or care (Martin Prince et al., 2015). A number of factors contribute to this treatment gap, including poor awareness, stigma, and limited availability of services (Alladi and Rajagopalan, 2021). These factors vary significantly across different demographic and geographic regions of the country. As a result, there is a need to understand pathways to dementia care and identify the factors that influence this care-seeking. As part of a wider study examining the costs and consequences of unpaid care in dementia under the Strengthening Responses to Dementia and Developing Countries (STRiDE) project, this paper presents health-seeking behaviours and dementia care trajectories reported by persons with dementia and their families in South and East India. Twenty-four family caregivers of persons with dementia were remotely interviewed in-depth and multiple times via semi-structured interviews (N=55) carried out between March to September 2021. Using Framework Analysis, we explore recognition of initial symptoms, subsequent supports sought and utilization of social care services available. We anticipate post-fieldwork analysis to be completed by February 2022.

390

Including design with people living with dementia in university education: Learning exercises and lessons from a multidisciplinary design team

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Technology is part of the environment, however much mainstream technology leads to exclusion for people living with dementia. To create inclusive technologies, education about design and dementia is required.

Aim: To engage tertiary students in learning exercises about dementia and design.

Methods: A series of student experiences were incorporated within a participatory research and design project co-designing technologies with people living with dementia. The experiences, designs, reflections and feedback from approximately 30 students and team members were described and evaluated, indicating characteristics of meaningful educational exercises.

Results: Learning experiences were conducted with students in technology-related disciplines (research and design projects) and occupational therapy (emerging practice fieldwork). Learning exercises included existing Dementia Friends training, frameworks and guides in design, accessibility, and ethics; collaboration with living experience experts, reflection (group and individual), and multidisciplinary team feedback. Characteristics of learning experiences described as being particularly resonant included: direct interaction and feedback from living experience experts, information centering a person's context and participation needs (not symptoms), and feedback from multidisciplinary teams. Students identified that preconceptions were challenged, the diversity of technology users had been demonstrated, and that the process was rewarding. Living experience experts valued interacting with students. The students' technology designs changed to be more human-centred (and personalisable), usable and related to users' lives and environments rather than symptoms. Designing with people living with dementia helped make designs better for all potential users.

Conclusions: Designing future inclusive technology may be supported by the inclusion of learning experiences relating to dementia and design.



391

STRiDE PAR: Expert perspectives on the policymaking process and scope for dementia-care policy and practice in India: a qualitative study

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Despite the rising numbers of persons with dementia in India, there currently exists no national policy or plan specific to dementia in the country. However, there are programmes/policies for elderly, non-communicable diseases, palliative care etc, which are relevant for persons with dementia. As a part of the Strengthening Responses to Dementia in Developing Countries [STRiDE] project, we aimed to better understand the policymaking process in the Indian context in order to identify factors that influence development of national plans/programmes and to also determine whether/how dementia can fit into existing plans. Twelve semi-structured interviews were conducted with professionals with varied areas of expertise including clinicians, non-governmental organization representatives, current and ex-government officials, and a health economist. Thematic analysis of data was conducted using NVivo. Early insights from interviews have highlighted factors such political will, strong context-related factors, the use of models that have shown regional feasibility and the need for population sensitization as critical in influencing policy development and implementation in India. This can aid in the development of policy recommendations, one of the key objectives of the STRiDE project.

392

Recommendations from the general public, caregivers and health care professionals for improved dementia care in India

Ms Saadiya Hurzuk[1], Mr Narendhar Ramasamy[2], Ms Jayeeta Rajagopalan[3], Mrs Meera Pattabiraman[4], Dr Suvarna Alladi[5], Dr Nicolas Farina[6], Dr Sara Evans-Lacko[7]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

India has approximately 5.29 million people living with dementia (ARDSI 2010 report), but only 1 in 10 persons with dementia receive any diagnosis, care, or treatment (Martin Prince et al., 2015). Lack of awareness among healthcare professionals and the general public is a significant factor influencing the ability to receive diagnosis and care for persons with dementia. As part of the Strengthening Responses to Dementia to Developing Countries (STRiDE) project, we conducted focus group discussions with the general public (n-15), healthcare professionals (n=16), and caregivers of persons with dementia (n=12) in two metropolitan cities in India. This data was analysed thematically using NVivo. We found that participants had difficulties in identifying and articulating the exact initiatives that need to be taken to improve dementia care and support services in the country. However, common recommendations included; 1) enhanced training of medical professionals to recognize dementia and provide treatment services, 2) using media platforms to raise awareness of the condition, and 3) the necessity of government involvement in dementia awareness programmes across the country.



393

Repetition abilities in Greek-speaking individuals with Primary Progressive Aphasia and Alzheimer's Disease

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Speech and language deficits are the prominent features of Primary Progressive Aphasia (PPA) and impaired repetition is a core feature of the logopenic variant of PPA. Alzheimer's Disease (AD) is another degenerative disorder typically presenting with memory problems. Other cognitive domains, including language, may also be affected. PPA diagnosis poses a common and challenging clinical problem and there is no consensus about which tests best capture the linguistic impairment in PPA.

Aims: The aim of the study was to evaluate differences on measures of repetition between Greek-speaking individuals with AD and PPA, as information about typical performance is valuable in documenting repetition deficits.

Method: Ten individuals with PPA, nine cognitively matched individuals with AD and fifteen demographically matched neurotypical adults took part in the study.

Participants were evaluated using a comprehensive battery of neuropsychological tests. Repetition was assessed using 3 different tests: the WAB and BDAE-short form repetition subsets and the Bayles Sentence Repetition test.

Results: The PPA group was impaired on all repetition tasks compared to the control group. Participants with PPA performed worse than participants with AD on two repetition tasks. AD participants could repeat words and most sentences accurately. However, increasing processing difficulty with very long sentences resulted in impaired performance compared to neurotypical adults.

Conclusions: All measures were informative, albeit in a different way. The most informative task for differentiating PPA from AD participants was the repetition of long frequent sentences. Findings should be interpreted with caution considering the small sample size.

394

Registers' Satisfaction Survey on Local dementia Centers (2019~2021)

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Aims: The study applies the Korean Public-service Customer Satisfaction Index to examine the client satisfaction level of Local Dementia Centers. The purpose is to provide evidence needed to improve the quality of services provided at these centers. Since 2019, all local governments across South Korea established LDCs and operated registration management, early screening, case management, and family education.

Methods: The researchers designed the questionnaire of the user satisfaction level as well as that by different services available at LDCs. The PCSI consisted of service quality, social responsibility, service comparison & evaluation, and performance. They surveyed 2,061 people, including patients, their families, non-patients, and cognitive impairment, all of whom used the centers for more than three months in 2021. Those unable to verbally communicate, who passed away, and do not use the service were excluded from the survey.

Results: The overall satisfaction was 89.9 out of 100, and the level in rural areas with relatively sparse dementia-related infrastructure was higher than that in urban. Specifically, the quality-of-delivery, which indicates the attitude of employees, was 95.0, and the satisfaction level in the facilities recorded 93.2. Otherwise, the satisfaction of necessary information was relatively low at 88.3.

Conclusion: The survey on service satisfaction in local communities is a way to determine whether the services are appropriate. The study revealed a relatively high level of satisfaction, but there is a limitation in that data have been collected through phone surveys. In the future, PWD will be interviewed in person to identify their specific needs.



395

A Review of the Korea Dementia Management Act from the Perspectives of the Global Action Plan on the Public Health Response to Dementia

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Before the Global Action Plan on the Public Health Response to Dementia was announced, the Dementia Management Act was enacted for dementia policy in 2012. Korea's efforts for following GAPD are supported by the DMA.

The first action area of GAPD aims to be the establishment of a Dementia Plan in each country. Korea's DMA has been stipulated as a national obligation of the Dementia Plan from the start. The second area aims to implement a nationwide dementia awareness campaign. The DMA also set a national event, the Dementia Awareness Day. Regarding the third area (reducing dementia risk), the DMA has regulations on dementia research. The fourth area's goal is being fulfilled by the early screening test and supporting the expenses of the DMA. The fifth area is to provide programs for caregivers. The DMA has stipulated family counselling and education, recognizing the importance of caregivers. The sixth area has the goal of collecting data through the information system. In the 5th revision of the DMA, the legal basis of the system was derived, and statistics could be monitored up to the local. The seventh area allows the government to work with research institutions. Korea is actively conducting research based on the DMA already.

The DMA has been amended when the government make the new policies. The Korean National Institute of Dementia, which has contributed to the DMA with the government, will continue to revise the DMA based on the understanding of PWD and caregivers.

396

Voice out our opinion for ourselves

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

Since 2018, Taiwan Alzheimer's Disease Association (TADA) has focused on the rights of people with dementia. TADA has added human rights advocacy to the mission of the association and puts more effort into improving this issue. In May 2019, TADA established the first "Dementia Advisory Group" in Taiwan. The members of this group are people with dementia and their care partners. TADA encourages advisers to share their experience to the public to reduce the stigma of "dementia".

Advisers are invited to attend various occasions to share their experiences with the public. Starting in 2020, TADA has organized a series of forums, with advisers and experts. The advisers will share their experiences of living with dementia. At the same time, TADA also hopes to encourage local people with dementia to participate in sharing. So far, TADA has held more than 20 forums across Taiwan, with more than 20 people with dementia and 1,500 participants.

The advisers were also invited to participate in the press conference as the hosts and sharers. In addition, TADA has assisted in arranging interviews for people with dementia in the media and TV programs. We show the public the ability of people with dementia, and let the public understand their feelings and demands.

We hope that through this series of activities, the public could hear and appreciate the voice of people with dementia. Moreover, local advisory groups could be established in various regions to promote the effective implementation of dementia policies in all counties and cities.



397

Training our college students for interactive music-making in dementia care

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Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Community engagement is an increasingly relevant focus of musicians' training, and university music programs are evolving from the traditional models that train performers and teachers towards curricula that include citizen-artist opportunities. At the same time, music as an effective means to engage those who are living with dementia is gaining ever more attention.

Music Between Us now offers resources to train music students for interactive music-making with those living with dementia, whether through in-person, virtual, or hybrid forms of delivery. *Music Between Us*began as a pilot project in 2019, through *ArtistCorps,*the University of North Carolina School of the Arts' community engagement program. It is led by Dr. Allison Gagnon, faculty mentor from the School of Music, and Rebecca Nussbaum, director of *ArtistCorps*.Our current initiative at Williams Adult Day Center in Winston-Salem, North Carolina provides experience from which we have created resources scalable for other college schools of music. Included are the following: guidance for interacting effectively with those living with dementia and their caregivers; information about the power of music to counteract the social isolation that can characterize life with dementia; tips for building sessions and playlists in all modes of delivery; and ideas for connecting with community partners that will welcome music students into care settings.

Engagement is a reciprocal relationship in which both participants and team members give to each other, and everyone is uplifted! Please join us to learn more about *Music Between Us* and our plans to share it with college music programs.

398

How to make dementia more widely known through social media

Mrs Li-Yu Tang[1], Miss Elaine Ee Ning Chan[1], Miss Szu-Man Yang[1], Miss Chien-Hong Hsiao[1], Mrs Huey-Jane Lee[1], Prof Te-Jen Lai[1,2]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Due to the COVID-19 outbreak in Taiwan, Taiwan Alzheimer's Disease Association (TADA) did not hold any dementia exhibition during World Alzheimer's Month this year. Instead, we launched online programs to promote dementia to the public, and the results were unexpectedly fruitful.

Online programs include dance challenges, online experiences, and videos in collaboration with YouTubers. In the dance challenge, we obtained music authorization from Alzheimer's Indonesia and re-written the lyrics and choreography of the song. Then, we chose 30 seconds of music for the dance challenge. This event was promoted on Facebook and Instagram. We hope through such activities, more young people can learn about "dementia." We also work with Internet influencers to promote this event. Finally, 96 manuscripts were received, and a total of 60,000 internet users have viewed the event.

Videos that worked with YouTubers, we invited members of TADA dementia advisory group (advisers) to interact with YouTubers. There are five episodes in total including interactions with advisers, and the experience of interacting with advisers. We hope that through the interaction between people with dementia and Youtuber, the public's stereotypes will be broken, and the public have a new understanding of dementia. These videos not only reached 150,000 people but also received much positive feedback from YouTubers' fans.

It is possible to reach lots of people on social media. This is the first time we have completely transformed physical events into virtual online programs. We will continue to promote dementia awareness through social media to complement physical events.



399

Subjective memory complaints in a representative sample of Brazilians over 50 years: baseline data from the Brazilian Longitudinal Study of Aging (ELSI-Brazil)

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: measure the prevalence of Subjective Memory Complaints (SMCs) in a representative sample of Brazilians over 50 years, and it´s associated factors.

Methods: Secondary analysis of baseline data from the ELSI- Brazil study, sample comprised of 7801 participants with full data, mean age of 62.5 years (sd=9.39) and mean education of 5.64 years (sd=4.37).

Presence of SMC was raised with the question: "Currently, how do you classify your memory", considered without SMCs the answers (Excellent/very good/good) and as with SMC the answers (fair/bad).

A episodic memory test (10-word list) was performed, together with data about sociodemographic factors (sex, age, living alone, education, income), depressive symptoms (CESD-8), subjective health perception, at risk alcohol consumption, smoker status, number of chronic illnesses, and activities of daily living: basic (BADL), instrumental (IADL) and advanced (AADL).

Poisson´s regression was utilized with robust variance to estimate the *prevalence ratio*(PR) and *incidence rate ratio* (IRR) of previous variables with SMCs.

Results: SMCs were present in 41.9% of the sample, prevalence in women was of 42% and in men 36% and raising with older age.

Multivariate analysis demonstrated that women, worst health perception, higher depressive symptoms, multimorbidity, and disability in IADL and AADl were positively associated with SMCs. While smokers, older age, higher education, memory performance, and lower BADL disability were negatively associated with SMCs.

Conclusion: SMCs are common in Brazilian population over 50 years, and are associated with worst memory performance, but also depressive symptoms, health aspects, social factors and disability.



400

EEG-Based Assistive Diagnostic Tools to Deal with Alzheimer's Disease Assessment Circumstances

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Our study addresses some of the main challengesin Alzheimer's disease (AD) diagnosis mentioned in the World Alzheimer Report 2021. We demonstrate how the potentials of EEG biomarkers can overcome some of these challenges.

In EEG signals, power spectral density (PSD) based features (five brain frequency bands of different channels) were investigated in publicly available datasets. Machine learning (ML) algorithms were used for AD detection, consisting of a feature selection procedure (filtering and then embedding methods) and shallow model classifiers (support vector machine, K-nearest neighbors, and Tree classifiers).

Results showed an accuracy of more than 95% for AD detection and higher than 80% for early detection of AD. Higher accuracies were obtained from Delta band in Fz, Cz, and O1 channels, easy to embed in an EEG headset with a few electrodes. Compatibility of our ML algorithm with highly portable and low-cost headsets can lead to easily accessible screening facilities in any small and remote health services, which is even a more serious issue during the COVID-19 pandemic, and in rural areas.EEG-based systems also deal with different diagnostic interpretations due to cultural obstacles and concerns about diagnosing uneducated people using questionnaire-based

Methods: The suggested EEG-based method can distinguish AD, mild cognitive impairment, and healthy control individuals in less than 10 minutes, making it more tolerable for older adults with special needs.

The proposed ML algorithm, with low computational cost, results in an economical systemthat can be used for large populations screening, especially in low- and middle-income countries.



401

Making an impact in the third sector

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

Muistiluotsi centres are provincial expert and support centres run by member associations of the Alzheimer Society of Finland. The centres form a network spanning the whole of Finland. In total, the 18 Muistiluotsi centres employ approximately 85 memory professionals. This national network is coordinated, steered, and monitored by the Alzheimer Society of Finland. The operations are funded by the Funding Centre for Social Welfare and Health Organisations. The network is the result of a long-term development commitment since 2006.

The work of the Muistiluotsi centres is based on their joint aims and quality promise. Centres ensure that people with memory-related disease and their families can access:

- enough information on the various forms of memory-related diseases,
- guidance and counselling on the available services and support,
- and have the opportunity to participate in activities intended to make their everyday life easier (e.g. development of various peer groups and courses).

As sources of expertise and support, the centers play an important role in developing knowledge related tomemory-related diseasesand safeguarding regional expertise.

A joint ERP-system has been developed to support the evaluation and development of the network's activities.The data collected on the organisations' joint activities is transferred to the PowerBi analytics tool, which then makes it easy to monitor and evaluate these activities. The implementation of the network's quality promise is monitored by the quality checklists built-in to the ERP-system, which are used to develop and monitor operations.The ERP-system also makes the work carried out by the entire network visible.

402

CST-International: comparing findings from face-to-face and virtual CST groups in Brazil.

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Overview and Aim: In Brazil, there is a lack of investment in psychosocial treatments for dementia. Cognitive Stimulation Therapy (CST) is a face-to-face intervention that has shown benefits to activities of daily living and mood for people with dementia (PwD) in Brazil. Due to the Covid-19 pandemic, adaptations were made for virtual delivery, and virtual CST (vCST) groups are being conducted. Qualitative analyses allow us to explore the experience of people living with dementia who took part in the therapy groups, and their care partners. This study aims to compare findings from face-to-face CST and vCST groups.

Method: Individual interviews were conducted with the participants of CST groups and their caregivers (n=24). Framework analysis was used to inspect the recorded and transcribed data. The same method will apply to vCST groups (est. n=20).

Results: Two main themes were identified from the analysis of face-to-face CST data: 'Personal benefits of being part of the group' and 'Day-to-day changes'; and seven sub-themes: memory, sociability, language, orientation, mood, behavioural and psychological symptoms, and everyday activities. vCST groups and interviews are ongoing, and data analysis should be completed by June 2022. Initial findings from vCST groups show that it is possible for PwD to engage virtually and vCST is described as a positive experience.

Conclusion: Face-to-face CST groups led to perceived changes for both the carers and PwD. This study will provide information about the acceptability of vCST. Furthermore, it will allow us to compare improvements and experiences from both methods of delivery.



403

Alterations in neuronal metabolic pathways contribute to human cognitive aging and are exacerbated in Alzheimer's disease

Dr Jeffrey R Jones
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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

To find therapies for altering the course of age-related diseases, we first need experimental methods to discriminate between healthy and pathological aging. Nowhere is this need more urgent than in Alzheimer's Disease (AD).AD remains a debilitating, progressive, and ultimately fatal dementia with limited and poor treatment options that currently impacts ~50 million people world-wide.With an increasing aged population, avoiding stark increases in suffering requires rethinking of why existing efforts have been ineffective.

We have developed a system that maintains the transcriptional and metabolic aspects of age and AD *in vitro:*induced neurons (iNs). The iN model allows us to ask; what cellular changes occur in aged neurons to enable AD?

Once matured, neurons never again replicate their genome. As such, neurons downregulate metabolic pathways for the synthesis of DNA building blocks, deoxyribonucleotides (dNTs), and become reliant on the salvage of ribonucleotides (rNTs). We asked if these fundamentally important homeostatic processes are maintained over the human lifespan or in AD. Comparing iNs from over a dozen individuals with AD to those of cognitively normal, age-matched individuals (CN), revealed dramatic differences in NT pools, with a significant increase in rNTs in CN individuals relative to young healthy iNs. This effect was even further exacerbated in AD iNs. The dramatic increases in rNTs results in increased ribo-substitution in nuclear and mitochondrial DNA, promoting increased DNA damage and bioenergetic dysfunction in age and AD. Thus, NT metabolism may underlie cognitive aging and become pathogenic in AD and represents a new therapeutic avenue.



404

Emotional consequences of caregivers providing unpaid care for persons with dementia in India: A qualitative study

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

In Indian society, it is often considered the responsibility of children to provide care for their parents as they age. As a result, care for the vast majority of people living with dementia is provided by families at their own homes (ARDSI, 2010). As in other lower resource settings, the absence of an organized formal long-term care system to support persons with dementia and their families is expected to place significant stress on families to provide the best care possible. Since dementia care can require almost full-time availability at home, this has been reported to affect physical and psychological health of caregivers (Srivastava et al., 2016). An understanding of the different components of stress that could arise from care provision is needed to be able to design appropriate interventions to mitigate the distress. We interviewed twenty-four caregivers using semi-structured interviews (N=55). The interviews were conducted remotely with the aid of a series of inductive and emergent topic guides. This paper will explore the emotional consequences of providing unpaid care experienced by these caregivers. It will consider the changes in career and personal goals that caregivers experienced and the impact of this on their understandings of the care they provide.



405

Family Caregiver Preference for Services Provided Online or In-Person: Lessons Learned from the COVID-19 Experience

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: The NYU Alzheimer's Disease and Related Disorders Family Support Program (FSP) has been providing support for family caregivers and their relatives with dementia since 2016. In March 2020, as a result of the pandemic, the program transitioned from a largely in-person to an entirely virtual format. As of November 2021, FSP activities continue online, providing a serendipitous opportunity to assess caregiver preferences for receiving services.

Methods: A survey was sent via email to FSP caregiver participants in October 2021 to find out whether they benefitted from the services they used, and their preferences for in-person or online delivery. FSP services include individual and family care consultations, support groups, webinars, activities for people with dementia together with their caregivers, including virtual museum visits, art and music making, and arts-based recreation programs for people with dementia.

Results: Among 109 respondents, the majority of caregivers reported that they and the person with dementia benefitted from the online services, especially those conducted in groups. More than half preferred to continue all the caregiver services online. Preferences were evenly split between in-person and online services for their relatives with dementia.

Conclusion. Online services offer a viable and often preferable alternative to in-person services for caregivers who are comfortable with the modality and have the necessary resources to utilize it. While the respondents represent a biased sample, as the survey was conducted online, the results suggest that online services can effectively meet the needs of many caregivers who find in-person services difficult to access.

406

The impacts of home adaptations on health and wellbeing of people with and without cognitive impairment in the English Longitudinal Study of Ageing

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Adapting home environments to improve accessibility for independent living is an effective intervention to promote ageing in place, with positive effects on physical and mental health, wellbeing, fall prevention and individuals' social relationships. Evidence suggests that delays in installing home adaptations can undermine their overall effectiveness and has negative consequences on individuals' performance of daily activities. In England, delays of just one year are estimated to equate to around £4000 increase in homecare costs. Thus home adaptations are an important way to reduce injuries, institutionalisation, and excess healthcare costs as people age.

In spite of this, there is a lack of robust evidence on the effectiveness of major home adaptations, particularly those costing over £1000. To address this research gap, this paper presents the results of secondary data analysis of the English Longitudinal Study of Ageing (ELSA), conducted as part of the Designing Homes for Healthy Cognitive Ageing (DesHCA) project. The analysis aimed to investigate health and wellbeing outcomes before and after adaptations were installed, and to compare the effects of different types of adaptations for individuals with and without cognitive impairment. The examination of health and wellbeing outcomes following the installation of home adaptations has implications for identifying and preventing further health and wellbeing decline which the paper will consider. With this data showing that bathroom adaptations were the most common, linked to wider evidence that bathing disability is a precursor to further functional decline, the paper concludes with recommendations on the need for post-adaptation health and wellbeing evaluations.



407

Lewy Body Ireland (LBI): New support organisation for people living with Lewy bodies and their caregivers

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Trinity College Dublin, Dublin, Ireland

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Background: The Lewy bodies dementias (LBD), second most common form of dementia, often under-recognised and mis-diagnosed in the clinical setting. LBI formed by multiple stakeholders to support people living with LBD and their caregivers.

Objectives: To 1) raise awareness of LBD; 2) build community and support network; 3) disseminate and promote new LBD research; 4) improve clinical services.

Methods: A core steering group meets monthly to develop governance structure, mission, vision and goals. Awareness raising occurs through website and social media. Peer support and community building takes place through 'Teatime with Lewy' online meetings for those with LBD and caregivers. Education for professionals developed through webinars and intensive workshop training. Clinician/research community for LBD in Ireland is linked to website.

Results: After 12 months, *key outputs* include: (1) website and information leaflets relevant to Irish residents with LBD developed; (2) monthly 'Teatime with Lewy' support meetings established, with attendance of >35 participants (300+ dial-ins) to date; (3) first Lewy Body Academy for interactive clinician training in LBD delivered in Belfast, November 2021 (https://bit.ly/3qBCmhj). *Key outcomes*: The support group has international reach (participants from USA and Australia), a growing social media following (197 followers on Eventbrite to date), and positive participant feedback (87% 'very satisfied' or 'extremely satisfied' with platform). The Lewy Body Academy was scored 5/5 for 'Overall relevance to your educational needs' by 90% of clinician delegates.

Conclusion: Civic organisations like LBI can positively impact people with lived experience of LBD and raise knowledge and awareness amongst clinicians.

408

Exploring the role of home adaptations for older people living with cognitive change

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

The way that we think about ageing has changed dramatically over the last two decades as society has shifted away from the institutionalisation of 'the elderly' and towards supporting older people with and without cognitive change to age well and enjoy an active retirement within communities which strive to be ever more dementia friendly. Much of the research that supports these initiatives focuses on shaping the behaviour of either the older person themselves or those living and working within their communities, with additional strands examining the design of shared public spaces, yet the design of the home itself is often overlooked.

This paper presents the results of a systematic literature review conducted as part of the Designing Homes for Healthy Cognitive Ageing (DesHCA) project. This review highlights the importance of proactively engaging with the process of home adaptation throughout the ageing process, with a particular emphasis on the benefits of incorporating home adaptation and supportive design for older adults experiencing cognitive change. Here we observe a tendency for the literature to gravitate towards technological solutions for the problems of ageing, and note the potential issues around the under representation of low-tech and architectural adaptations within the literature.

The review argues that advanced technological solutions must be considered as complementary to analogue approaches, which include both major structural adaptations and an ongoing introduction of minor adaptations and aids that reflect the changing needs of the older person as they age.



409

A PROSPECTIVE COHORT STUDY OF COGNITIVE IMPAIRMENT IN PARKINSON'S DISEASE

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Cognitive impairment is one of the most common non-motor symptoms in Parkinson's disease (PD).Aims:To assess cognitive impairment in PD in a 14-month cohort study and evaluate their relation with clinical and cortisol levels.

Methods: Patients with a diagnosis of PD were evaluated in a prospective cohort of 14-months. They were divided in two groups, with and without cognitive decline in follow-up, according to the presence of impairment in the MoCA test in relation to the baseline. Clinical characteristics and cortisol levels of PD patients were compared between these two groups.

Results: In this cohort study, 65 PD patients, aged 63.44 ± 9.96 years, were recruited and followed for an average of 14 months. There was no significant difference between the MoCA baseline and follow-up scores when all patients were evaluated. In the group of patients that showed cognitive decline the main cognitive impairment was observed in executive functions ($p < 0.001$), delayed recall ($p = 0.004$) and orientation ($p = 0.004$). There was a reduction in serum cortisol levels in PD patients at the follow-up ($p = 0.021$), but that was not related to cognitive decline.

Conclusion: Executive functions, delayed recall, and orientation were the main cognitive domains to decline in one year study.

410

Community dementia alliance: roles and achievements - one year on - a case study.

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

Western Brisbane Dementia Alliance was launched in April this year – in a small window amid the chaos caused by COVID19. In this short time, would the achievements made and roles fulfilled be limited? Our experience is contrary.

In the launch planning I engaged all local medical centres' staff. I increased dementia awareness of my City Councillor, the local news magazine editor and local shopping centre management. They all gave free promotion and/or paid for the launch costs, and the editor printed free an update and gave spontaneous promotions. From this we are able to have engagement with a local church group for our initial aim – an inclusive café.

The café has allowed us to:-

- normalise dementia,
- increase dementia awareness in staff,
- support family care partners and give something to anticipate, and
- educated health professionals.

The local Rotary club has had Dementia Friends training with, the Lions Club soon following, plus the Meals on Wheels, Men's Shed and 50+ Club, to better support people with dementia. The Scouts and Girl Guides will become dementia friends next year, and a local private school, in negotiation – to reduce stigma in the next generation. Future plans are to work with local church leaders – to maintain vital social support networks of parishioners when they or their family are diagnosed.

We also have our State Premier on board – her electoral office will print our advertising material; Federal Representative next. Much more coming, e.g. art and music therapy, so watch this space….



411

Promising individualized dementia cognitive care model

Ms Alison R. Kennedy
Kennedy Cognitive Services, Inc., Winnipeg, Canada

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Purpose: To share insights from pioneering an individualized dementia cognitive stimulation initiative in Winnipeg, Manitoba, Canada (2011-2021).

Project: K. C .S. - E. N. R. I.C. H Program

Kennedy Cognitive Services, Inc. was founded by Alison Kennedy in Winnipeg, Manitoba, Canada in 2011 to address a need for individualized dementia cognitive care. Retired geriatric healthcare professionals have been fully trained and equipped as K.C.S. Cognitive Support Specialists to provide regular hourly, fun, person-centered stimulating sessions to clients with dementia in their place of residence. Families determine the frequency of the sessions. Remote half-hour sessions are available as needed during COVID-19 to capable clients. Families receive feedback immediately following each session via e-mail. The cost of this service is tax deductible with physician support ("tutoring for persons with disabilities").

Outcomes: To date, forty two clients living with dementia have participated; fifty seven percent for over one year, twenty six percent for over three years, one client for a record eight years and ten months. The most common reasons for terminating this program have been death (44%) followed by declining health (14.3%) and COVID-19 (9.5%). Company milestones include international (2014) , regional (2016), and local (2018) recognition, physician endorsement, and warm testimonials from appreciative families.

See: www.kennedycognitive.com .

Insights: This program demonstrates a portable and adaptable method to effectively improve quality of life for individuals with dementia and reduce stress in family caregivers. Significant expansion will require broad professional endorsement and adoption.

Conclusion: This is a promising individualized dementia cognitive care model.

412

Evidence of systemic thiamine deficiency in Alzheimer Disease demands intense research focus

Ms Alison R. Kennedy
Kennedy Cognitive Services, Inc., Winnipeg, Canada

Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aim: To stimulate essential new research focused on the cause and treatment of thiamine deficiency in Alzheimer's Disease (AD)

Methods: Scientific literature review on topic of thiamine and/or AD

- PUBMED scientific papers
- elibrary.wiley.com
- mspace.lib.umanitoba.ca

Results:

1. Scientific evidence supports a unified theory that AD is a thiamine deficient state of unknown cause.
2. Thiamine supplementation can potentially correct the AD cholinergic deficit and abnormalities in B-amyloid, tau, neuroinflammation and memory (key target of AD research) .
3. To date, limited oral thiamine supplementation trials in AD have had mixed results.

Conclusions:

There is an urgent need for new studies into the cause and treatment of thiamine deficiency in AD. Collaboration of scientists from multiple disciplines is required in the hope that AD can be prevented, slowed or cured.

Research priorities:

- Phase One: What causes thiamine deficiency in AD?
- Increased thiamine requirement?
- Impaired thiamine absorption?
- Impaired thiamine transport?
- Increased thiamine excretion?
- Problems with thiamine metabolism?
- Other?

Phase Two: What is the potential of thiamine supplementation?



Form (oral, intramuscular injections, IV, combination treatments), formulation, dosage, timing, duration, safety, bioavailability (in GIT and brain) and disease stage of thiamine treatment?

Control for medications, medical conditions and dietary components affecting thiamine utilization

Primary endpoints?

413

Identifying hearing and vision loss in long-term care residents experiencing dementia

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aims: Vision and hearing loss are highly prevalent among older adults experiencing dementia, including those living in long-term care (LTC). Sensory loss can contribute to a risk of falls, social isolation, cognitive communication difficulties, and more rapid cognitive decline. In LTC settings, sensory loss can go underreported and untreated. This multidisciplinary research aimed to find the most suitable measures for nursing staff to screen for hearing and vision loss in LTC residents experiencing dementia.

Method: A feasibility study of sensory screening tools in LTC was informed by scoping reviews of the literature, environmental scans of nursing and sensory professionals, and through consultation with sensory and neurocognitive experts. Selected hearing and vision tools were used by nursing professionals, as well as by hearing and vision health professionals,to screen for sensory loss in 17 LTC residents experiencing varying degrees of cognitive impairment.

Results: The feasibility and reliability of six hearing and seven vision measures are reported. Recommendations for the effective screening for vision and hearing loss in older adults with dementia are discussed.

Conclusions: Objective measures of hearing and vision can be used to identify sensory loss in older adults with dementia, once requisite training in their use, adaptation and interpretation is provided to healthcare professionals. Nursing curricula do not provide sufficient education on the implications of hearing and vision in loss in older adults who are also experiencing cognitive decline. Further professional training and cross-disciplinary collaboration are urgently required to address the care needs of LTC residents living with dementia.



414

The application of Mobile learning in the field of supporting dementia caregivers

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: Dementia is a progressive and persistent cognitive degeneration disease that is relatively gradually increasing the burden on caregivers; the old-style access to relevant care knowledge can no longer meet the needs of caregivers; With the popularization of the Internet and mobile devices, the trend of zero contact in the epidemic era , The development of dementia care learning application is an important strategy for the future ; However, research has found that there are few related applications and the developed programs cannot meet the needs of users. Therefore, the purpose of this research is to explore the user requirements and the program development design framework for the development of dementia care mobile learning applications.

Method: The study use a Qualitative research design. The research participants were collected from a hospital in Taichung City, Taiwan through purposive sampling. The first stage is to design the interview guidelines based on the theoretical framework of the technology acceptance model, we will discuss how to effectively use, easy to use, user attitudes, behavioral intentions, and external variables. In the second stage, interviews were conducted with focus groups to confirm the application architecture.

Analysis: Use the content analysis method to collate the data obtained from the group and in-depth interviews to confirm the caregiver's development needs and program structure for the dementia care mobile learning application program.

Expected benefits: Establish the design framework of the dementia care Mobile learning application program to provide reference for future planning of dementia care service design and policy planning recommendations.

416

Practice of peer support by people with dementia

Mr Hironori Usuki
Nishikagaw Hospital, Mitoyo city, Japan

Topic

Dementia diagnosis, treatment, care and support: Importance of peer supporting and living well with dementia

Abstract

We have been running our own Dementia Café since 2014, which is attended by people with dementia and their families who attend the Outpatient Memory Loss Clinic.

In June 2017, the hospital hired Yasuhira Watanabe, a dementia patient, as a part-time consultant to develop peer support for dementia.

At the café, Mr. Watanabe shares his own experiences and listens to the stories of people with dementia. Since Mr. Watanabe started working as a consultant there, he has been involving with many people with dementia and has found that there are things that he can understand and share with them because he himself a person with dementia.

Mr. Watanabe said, "People who were depressed and looked down when I first met, as I talking and listening, they became to look up, smile, talk, and expand their range of activities. That is the greatest joy for me when their eyes light up and they feel they have regained their identity".

Mr. Watanabe, who has dementia, will report on the rewards of his peer support activities, his sense of contribution and the potential of peer support for dementia.



417

Peer Support for a Positive Life

Mr Yoichi Ino
Nishikagawa Hospital, Mitoyo city, Japan

Topic

Dementia diagnosis, treatment, care and support: Importance of peer supporting and living well with dementia

Abstract

We have been running our own Dementia Café since 2014, which is open to people with dementia and their families who are visiting the Outpatient Memory Loss Clinic. The people with dementia and their families who visit the hospital are introduced to the café after their doctor has explained to them the negative image of dementia and the prejudices that exist, and has tried to improve their view of the disease as much as possible.

The people with dementia who attend our café listen to the experiences and thoughts of the consultant, who is a person with dementia and employed by the hospital, and also speak out themselves, encouraging each other and coming to terms with their situation.

The peer support provided at the hospital is expected to reduce their feelings of loneliness and anxiety. It is considered to give them a sense of solidarity and stability, and to let them have hopes and a positive change in life through the cheerfulness of the consultants.

Here, the people with dementia and their families can think and learn from each other about how to spend their time and how to think and perceive in the future through consultation and discussion.

Peer support also provides a valuable opportunity to learn how to live better with dementia. The following is a report on a case where peer support at our hospital was effective.

418

Art With You (AWY): An exploratory impact study on art museum-based programme for families living with dementia in Singapore.

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Global research has demonstrated the multifaceted benefits of art engagement programmes on persons living with dementia (PLWDs) and their family care partners. "Art With You" (AWY) is a dementia-specific art museum-based engagement project co-created by National Gallery Singapore and Dementia Singapore. This study evaluates the impact of the programme on the well-being of PLWDs and their care partners' experience.

Two pilot runs were completed with 18 persons living with mild to moderately severe dementia and their family care partners. Dementia Care Mapping™ (DCM™) and focus group discussions (FGDs) were analysed to explore the lived experiences of PLWDs and their care partners.

Results from DCM™ showed that all participants living with dementia achieved positive well-being scores. High potential behaviours commonly observed included leisure, reminiscence, and creative expression. FGDs findings revealed that the session themes, artworks and art-making workshops were well-selected and enabled new insights in art appreciation for participants. This programme created personalized opportunities for meaningful interactions between different family groups.

The positive experiences observed in the participants reflect the potential of AWY programme as a promising art museum-based social prescription for the overall health and well-being of PLWDs and their families. There is ongoing effort to extend this programme to include more diverse demographics and levels of disease severity of dementia groups.



419

Support Of, By, and For People Living With Dementia

Ms Noriyo Washizu
Alzheimer's Association Japan, Kyoto, Japan

Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Along with the improvement of diagnostic measures and social awareness of dementia, many people have become diagnosable at an early stage. Dementia is a progressive disease, and in many cases, there is no definitive treatment yet. In addition, there is still stigma caused by misunderstanding of dementia.

Therefore, a person and their family face fears and despair immediately after diagnosis, and they are more likely to be detached from the community. This situation causes physical and mental degeneration, and their quality of life is getting worse.It is the start of a vicious cycle. Early diagnosis should be the starting point of living well with dementia. However, early diagnosis without timely and appropriate support turns out to be the beginning of the vicious circle.

To prevent and stop the negative circle, people living with dementia have started to provide peer counseling sessions, collaborating with medical/social professionals in some places in Japan.

Those approaches have brought about great success not only for receivers but providers and society as well.

This presentation introduces an overview of the practices of (dementia) peer counseling in Japan and describes an example of a successful approach at one hospital with collaboration by professionals. In the conclusion, an argument is made for the adoption of this system at hospitals and clinics administering dementia diagnoses.

420

Dementia situation in Vietnam and among the Vietnamese diaspora: A systematic review of quantitative studies

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Topic

Dementia as a public health priority: Healthcare system readiness

Abstract

Background: As part of the effort to gather research evidence for the development of Vietnam's National Dementia Plan, a systematic review was conducted to map dementia research in Vietnam or among the Vietnamese diaspora. This paper aimed to report the quantitative research evidence on dementia situation in Vietnam.

Method: Systematic searches were conducted in June 2021 using Medline, Embase, PsychInfo, CINAHL, and Cochrane Library, as well as grey literature. Keywords and Medical Subject Headings [MeSH terms] for dementia and associated terms were combined with keywords for Vietnam and its provinces. Quantitative research articles published in English or Vietnamese were included to examine evidence on dementia situation in Vietnam and among the Vietnamese diaspora using a narrative approach.

Result: Our searches resulted in 3,940 papers, from which 48 quantitative research studies were included for final analysis. The majority of research was conducted in Vietnam (n=42) and in the hospital setting (n=31), with fair quality. The dementia prevalence in older Vietnamese adults (≥ 60 years) ranged from 1.4% to 9.9%, with a pool estimate being 4.1%. Potentially inappropriate use of medications occurred in 41% of people with dementia and family carer interventions reduced carer burden (ZBI score 1.2 SD lower – p=0.02).

Conclusion: The existing dementia research in Vietnam and among the Vietnamese diaspora has mainly focused on dementia prevalence, usually in small samples at a provincial level. Future research is needed on dementia risk factors and prevention, diagnosis, pharmacological and non-pharmacological treatments, care and support for people with dementia and their carers.



421

The Dementia Enabling Environments website - Alzheimer's WA (Western Australia) launched the DEEP virtual information centre almost 10 years ago. This innovative resource continues to help translate enabling environments research into practice. Learn about the website's history and plans for the future.

Ms Ash Osborne
Alzheimer's WA, Perth, Australia

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Alzheimer's WA's Dementia Enabling Environments website (enablingenvironments.com.au) provides practical tips, guides and resources to help make the places where we live more dementia enabling. Since it was launched almost 10 years ago, the website has evolved and continues to provide evidence based information for the home, residential aged care, public buildings, gardens and hospital settings.

An enabling environment will encourage a person with dementia to lead as full and independent a life as possible. This site allows users to explore different settings and learn more about key design principles in each area of the environment types and to download useful information and resources.

The Dementia Enabling Environments website can help anybody develop an enabling environment for a person living with dementia, making a significant difference to their independence, quality of life and wellbeing.

A well designed environment, planned with cognitive impairment in mind, can help to maintain abilities and enhance meaningful engagement through the inclusion of essential prompts, accessibility and reducing risks to support a person with dementia. A poorly designed environment can be confusing, disorienting and at worst, disabling and even dangerous for people living with dementia.

This Virtual Information Centre responds to the increased demand for enabling environments for people living with dementia. It helps translate enabling environments research into practice with its focus on not only the physical environment, but also how it is used. This presentation will chart the website's history and the next phase in its development.

422

Common patterns of multiple long-term conditions in people living with dementia and their associated risk of mortality: A population-based cohort study

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aims: People living with dementia often have multiple long-term conditions (MLTC) (multimorbidity) with potentially heterogeneous patterns. This study aimed to identify common patterns of MLTC in people with dementia and their associated risk of mortality.

Method: Older persons aged 65 years or above that were newly diagnosed with dementia between 2007 and 2016 were identified from the Hong Kong Clinical Data Analysis and Reporting System (CDARS) and followed until December 31, 2019. We applied latent class analysis to a set of 59 long-term conditions to identify common patterns of MLTC in people with two or more conditions in addition to dementia. Cox proportional hazard models were used to examine the risk of mortality associated with specific MLTM patterns.

Results: A total of 86,931 individuals were identified. MLTC were highly prevalent. Individuals with≥2 and≥8 conditions accounted for 77.8% and 14.2% of the total sample, respectively. Individuals with dementia were classified into nine groups, including an unspecific group (no condition that uniquely characterized the pattern, 23.2%), diabetes (17.0%), heart failure and atrial fibrillation (11.3%), cerebrovascular and other neurological diseases (10.7%), eye diseases (8.8%), heart failure and chronic kidney disease (8.5%), other neurological diseases (7.9%), musculoskeletal diseases (6.6%), and respiratory diseases (5.9%). Mortality risks associated with different patterns remained statistically and considerably different even after adjusting for the number of conditions.

Conclusions: These findings may be used to identify homogeneous groups of persons with dementia who have similar prognoses and can benefit from similar interventions that are tailored to this group.



423

Protective effect of sorghum polyphenolic extract on Amyloid-β-induced neurotoxicity invitro

Ms Nasim Rezaee[1], Dr W.M.A.D Binosha Fernando[1], Dr Eugene Hone[1], Prof Hamid R Sohrabi[1,2,3], Prof Stuart K Johnson[4,5], Dr Stuart Gunzburg[6], Prof Ralph N Martins[1,3]

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Aims: Alzheimer's disease (AD) is a rising health concern and without any effective prevention and treatment method. Epidemiological evidence suggested food rich in polyphenols as potential natural therapeutics for AD due to their neuroprotective actions including their anti-inflammatory, antioxidant and anti-Amyloid β (Aβ) aggregation activities. The main objective of this study was to evaluate the protective effects of polyphenolic extracts from six different genotypes of sorghum plant on attenuation of Aβ42-induced neurotoxicity.

Method: To determine the phenolic and flavonoid content, total phenolic content (TPC) and total flavonoid content (TFC) assays with HPLC-DAD analysis were used. A cell viability assay 3-(4,5-dimethylthiazol-2-yl)-5-(3-carboxymethoxyphenyl)-2-(4-sulfophenyl)-2H-tetrazolium) (MTS) was utilized to verify the protective effect of extracts in different solvents and dosages.

Result: Of the six tested genotypes of sorghum, Shawayashort black-1and IS1311C had the highest phenolics and flavonoids levels. In the M17 neuroblastoma cell model, all the extracts screened through MTS assay (dissolved in DMSO), significantly increased the cell viability. Of the six extracts, the QL33(2000 ɱg/ml) demonstrated the greatest protective effects in decreasing cell death (28%) induced by Aβ neurotoxicity ($p < 0.01$) and B923296 showed the lowest protective effect of 11% ($p < 0.01$) compare to Aβ group. For the extracts dissolved in treatment media, QL33 (2000 ɱg/ml) demonstrated a greatest protective effect of (15%).

Conclusion: Sorghum polyphenolic extracts demonstrated promising neuroprotective effects against Aβ-induced neurotoxicity. However, further analysis in other cellular model, animal studies and clinical trials are needed to confirm their anti-AD effects.

424

START (STrAtegies for RelaTives) for family carers of people with dementia: Cultural adaptation and feasibility in India (START-India)

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aim: START (STrAtegies for RelaTives) is an evidence-based manualized intervention for family caregivers of Persons with Dementia (PwD). START consists of eight weekly sessions delivered individually to the caregiver by a trained facilitator. It emphasizes on psychoeducation, behavioral management, thought analysis, communication, planning for future and behavioral activation.The study aimed to culturally adapt START and test its feasibility in a Low- and Middle-Income Country (LMIC) like India.

Methods: The adaptation process followed the Medical Research Council guidelines for adaptation of complex interventions with five phases of formative method for adapting psychotherapy (FMAP). Professional and caregiver stakeholders were qualitatively interviewed (N=21) and the data was analyzed using the Cultural Treatment Adaptation Framework (CTAF). The intervention was also adapted for virtual delivery using zoom due to the COVID-19 pandemic. Recruitment, retention, attendance, adverse effects, and fidelity were recorded while testing feasibility.

Results: Main themes identified that the manual did not require any core modifications. Subsequent themes suggested developing a good rapport with caregivers before beginning sessions and using flexible modes of delivery. Sixty-seven caregivers were contacted out of which forty agreed and started the intervention. Thirty-two completed the sessions with full attendance and there were eight dropouts. There were no adverse effects identified. START received positive feedbackand participants expressed that the intervention provided them a safe platform to express their emotions and increased their knowledge and skills about taking care of PwD.

Conclusions: Overall, START was feasible for delivery in India with potential to improve well-being of caregivers of PwD.



425

Inverse release of drugs to the cerebrospinal fluid:a new route of delivery for neurodegenerative dementias

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Drug delivery to the central nervous system (CNS) is hampered by blood–brain barriers (BBB). Many drug delivery techniques are under development with the aim of facilitating BBB crossing, apart from the classic injection of therapeutics directly into the cerebrospinal fluid (CSF), i.e., intrathecal delivery. We have developed the concept of intrathecal inverse release of drugs, a radically new way of administering drugs that may be useful for neurodegenerative dementias where clearing molecules from the CNS may be beneficial. With this novel approach, drugs are not directly delivered into the organism but remain confined into a subcutaneous reservoir. The main advantages of this new strategy are that acting on the CSF directly is expected to be much more effective than delivering the drug peripherally while no side effects or immune responses are expected from drugs, as they do not enter in contact with cells (immunoisolation).

Here we provide proof of concept of the feasibility of using this device as an alternative route to deliver anti-amyloid compounds such as monoclonal antibodies (mAbs). A fully implantable device has been designed and prototyped to be used in rodents. Mice were implanted with the device and mAbs infused into it for different periods of time. Animals experienced no serious side effects.

This new route offer a new way of delivering drugs for neurodegenerative dementias . More studies and collaboration with industry are needed to further explore the feasibility, safety, and efficacy of this new therapeutic strategy.

426

Changes in attitude toward dementia before and after completion of "Dementia partner education", an online education program to improve dementia awareness

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: This survey aims to determine whether "Dementia partner education", an online education program to improve dementia awareness, effectively improves attitudes toward dementia by identifying differences between the attitudes of subjects before and after completing the program. The program consists of five videos to educate the general public on how to live with a person living with dementia based on their knowledge and understanding of dementia.

Method: Online surveys were conducted with 908 subjects to assess their attitudes toward dementia before and after completing dementia partner education. The Dementia Attitudes Scale(DAS) was employed, which consists of a dementia-attitude-knowledge scale to evaluate cognitive aspects and a dementia-attitude-comfort scale to evaluate emotions and behaviors. The higher the score on this scale, the more positive the attitude toward dementia.

Results: The dementia attitude score of the subjects increased from 94.75 points before dementia partner education to 105.45 points after completing it ($t=-26.90$, $p<0.001$). Similarly, the knowledge scale score increased from 50.86 points to 54.67 points ($t=-17.93$, $p<0.001$), and the comfort scale score increased from 43.89 points to 50.78 points ($t=-25.47$, $p<0.001$).

Conclusion: The results indicated that dementia partner education is effective in improving attitudes toward dementia. In addition, since the comfort scale score increased more than the knowledge scale score, dementia partner education is more effective in improving emotional and behavioral aspects compared to cognitive aspects of the public perception of dementia. Thus, dementia partner education positively changes the general public's attitude toward dementia and effectively contributes to establishing a dementia-friendly society.



427

A new rehabilitation paradigm for people with Major Neurocognitive Disorder (dementia): "StArt" project. The role of visual arts in Cognitive Activation Therapy in supporting and maintaining cognitive and functional abilities, and empowering the person while decreasing social stigma.

Dr Donata Gollin[1], Dr Marco Simoni[1], Dr Cristina Ruaro[1], Dr Barbara Luciana Cenere[2], Dr Alessia Gallo[2], Dr Alessandra Codemo[1], Dr Elisabetta Gasparoli[1], Dr Mariella Casa[1], Prof Sofia Pavanello[2], Dr Carlo Gabelli[1]

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Background: Major Neurocognitive Disorder (M-NCD) compromises cognitive-functional abilities, representing one of the principal causes of disability, demanding a significant amount of resources. People with M-NCD and their care partners experience significant stigma. Cognitive stimulation showed efficacy on people with M-NCD. Recent studies report museums and figurative arts as a source for new cognitive stimulation paradigms.

Aims: Clinical Center for the Aging Brain (CRIC), with the University and the Municipality of Padua, developed the "StArt project", a new rehabilitation paradigm combining visual arts and a standard rehabilitation protocol (Cognitive Activation Therapy-CAT).

"StArt" project has been conceptualized to be effective on

- supporting and maintaining cognitive-functional abilities;
- supporting social inclusion;
- decreasing social stigma;
- improving well-being;
- creating economically sustainable interprofessional collaborations;
- providing non-health workers specific professional skills to work with people with M-NCD.

Material-Methods: 27 people with M-NCD were included in the study; 7 of those had a diagnosis of Younger-Onset Dementia. Before and after the treatment participants underwent a cognitive-functional evaluation. Patients and caregivers completed a questionnaire on the therapeutic experience and perceived QoL.The treatment consisted of 14 group sessions of physical and cognitive-communicative therapy (CAT) and 3 visits to the museum.

Results: Preliminary results showed that the "StArt" project plays a significant role in supporting and maintaining cognitive-functional abilities of people with M-NCD. Participants reported positive mood

modification, renewed interest in culture, and greater communicative engagement. Since the "StArt" project showed possible application in other museums, a book describing the rehabilitation protocol it's in press. Data collection is still ongoing.



429

The feasibility of involving community health workers in identifying and referring older persons with cognitive impairment in Wakiso district, Uganda

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: 1. To assess the feasibility of involving Community Health Workers (CHWs) in identifying older persons with cognitive impairment in Wakiso district, Uganda. 2. To assess the feasibility of involving CHWs in referring older persons with cognitive impairment for care in Wakiso district, Uganda.

Methods: This was a cross sectional study carried out on 385 older persons and their caregivers in Wakiso district- Uganda. We included older person 60 years and above with their caregivers aged 18 years and above. Socio-demographic data was collected from the CHWs, older persons and their caregivers.

We conducted a 2-day training for the CHWs on cognitive impairment. The CHWs assessed the older persons for cognitive impairment using the AD8. The researchers then administered the AD8 followed by the Mini Mental State Examination to older persons assessed by the CHWs. We also conducted Focus Group Discussion for the older persons, the caregivers and CHWs. We compared numbers screened positive by the CHWs with those of the researchers.

Results: Out of the 57 older persons identified by the CHWs to have cognitive impairment, 49 were identified by the researchers giving an almost perfectagreement between researchers and CHWs in identifying cognitive impairment. Of the 57 identified to be impaired by the CHWs, 94.7% (54/57) were referred for further management.

Conclusion: CHWs are a readily available resource that can be trained to identify and refer older persons with cognitive impairment within the communities they live.

430

A new rehabilitation software for people with Major Neurocognitive Disorder (dementia): "INFORMA" project. The role of adaptive and user-centered technology on Cognitive Activation Therapy to support and maintain cognitive and functional abilities, and provide long-distance assistance, increasing engagement.

Dr Marco Simoni[1], Dr Donata Gollin[1], Dr Cristina Ruaro[1], Dr Mariella Casa[1], Dr Alessandra Codemo[1], Dr Elisabetta Gasparoli[1], Prof Andrea Zanella[2], Dr Carlo Fantozzi[2], Dr Carlo Gabelli[1]

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Background: Digital technologies have shown potential applications to people with Major Neurocognitive Disorder (M-NCD). The pandemic has increased the need for innovative technological tools able to guarantee continuous long-distance assistance.

Aims: Clinical Center for the Aging Brain -collaborating with the Department of Information Engineering (University of Padua)- developed the "INFORMA" project, an innovative user-centered App for tablets, based on standard rehabilitation protocol (Cognitive Activation Therapy-CAT).

"INFORMA" software has been conceptualized for:

- offering novel errorless cognitive stimulations exploiting the features of modern digital devices;
- providing users with a tailored, engaging APP;
- providing clinicians with adaptive activities, organized in themes based on the person's interests and adigital dashboard to plan, monitor, and follow-up;
- collecting quantitative data on user's performances;
- assisting people unable to reach the clinic.

Material-Methods: A multidisciplinary team composed of people living with M-DNC, doctors, speech therapists, psychologists, engineers, and designers developed the "INFORMA" App. Maintaining a constructive dialog, the team encountered different phases:

- conceptualization of software's purposes;
- study-design of software's architecture;
- selection of the hardware;
- study-design of rehabilitative contents;
- study-design of User-Interface and User-eXperience;
- user testing involving people living with M-DNC;



Results-conclusions: The collaboration between different professionals has led to an innovative digital tool for cognitive stimulation, providing flexible type, difficulty, timings, and subjects of intervention to match users' abilities and preferences. The software is an alternative/integration to the in-presence rehabilitation, reaching people at their homes, monitoring performances, and interacting remotely via-chat. A clinical trial is currently underway; data collection is still ongoing.

431

The NewDirection Way - Normalising Ageing and Dementia

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

NewDirection Care (NDC) Bellmere is an Australian and world first, an inclusive MICRO TOWN® community for the elderly and those living with younger onset dementia and complex care needs.

With 17 houses, each supporting 7 residents, 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. This community recreates life in the real-world, allowing residents to live as independent a life that their condition allows in a familiar home-like environment.

There are no restrictive practices employed at NDC Bellmere; chemical, physical, environmental, or otherwise.

The model of care at NDC is best highlighted in the lived experience of its residents. NDC Bellmere provides residents with agency over their lives and our non-tasked based approach means residents are actively encouraged to participate and retain independence, For instance, residents:

- choose what, when and where they want to eat, just like any normal home.
- choose when they go to bed, wake up, if they want to see a visitor or for them to stay overnight.
- choose what and when personal care is provided and who provides this care.
- are enabled to cook, clean, launder, garden, and more
- have diverse and personal opportunities to engage in and with their community.

The NewDirection Way® is proving that by normalising ageing and dementia care it is possible to continue to live a life filled with joy and purpose supported by clinical care that ensures quality of life and a "good death".



432

Support Needs of Family carer for people with dementia in Japan

Miss NAOKO HARA[1,2], Dr Hajime Takechi[1,3], Miss Kyoko Eguchi[1,4], Miss Shoko Inomata[1,5], Miss Miwa Shibuya[1], Miss Naomi Onouchi[1,6], Dr Noriyuki Ogawa[1,7]

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: To identify the support needs of families of people with dementia.

Methods: A questionnaire survey of family carer was conducted (October to November 2021). We printed 30,000 copies of the questionnaire and distributed them to medical centers for dementia diseases and regional comprehensive support centers in Japan, as well as to about 10,000 members of the Alzheimer's Association Japan.

Survey contents: The questionnaire included basic attributes of the respondents and people with dementia, contents and satisfaction level of explanations received before and after the diagnosis of dementia, consultation partners, problems encountered due to lack of consultation, impact on the lives of caregiving family members, and necessary support.

Ethical considerations: The study was conducted after review by the Ethics Committee of the association. The survey was funded by a grant from the Ministry of Health, Labour and Welfare in Japan.

Results: Responses to the questionnaire are being accepted until the end of November, and as of November 18, 1400 responses have been received. A detailed analysis of the results will be reported. The main needs of the respondents were to promote the understanding of dementia in the society, to listen to their family members, to get in touch with peer support for people with dementia and their family members as soon as possible, and to have a break from caregiving.

Conclusion: We know that there is insufficient support before and after the diagnosis. Based on these results, we have created a guide for supporters.

433

Early and accurate diagnosis of dementia: priorities for health system preparedness in the UK.

Dr Susan Mitchell, Dr Madeleine Walpert, Mr Farhan Khan

Alzheimer's Research UK, Cambridge, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims Alzheimer's Research UK (ARUK) aims to set out a roadmap to develop a health system in the UK that enables accurate dementia diagnoses earlier in the disease course, when interventions could have the greatest impact.

Method Multi-year UK focused initiative investigating:

(1) dementia diagnosis backlog in England caused by COVID-19: quantitative assessment of the backlog and drop below the two thirds national diagnosis rate ambition.

(2) Old-Age-Psychiatrists' views on the preparedness of services to deliver future disease modifying treatments: quantitative and qualitative study with the Royal College of Psychiatrists, consisting of an online survey (n=493) and focus groups (n=42).

(3) the role of existing and future diagnostics for dementia: thought leadership report to outline ARUK's position and a stepwise approach for improving system readiness.

Results: (1) 31,480 people estimated to be waiting for a dementia diagnosis, requiring approximately £292 million. (2) Psychiatrists outlined areas for attention to ensure that their services are core to the delivery of future treatments: improving access to biomarkers, up-skilling staff and changes to care pathways. (3) ARUK further recommends the development of NICE guidelines for Mild Cognitive Impairment, better national data on diagnostic services and for NHS England to invest in diagnostic infrastructure, resources and clinical workforce.

Conclusion: There is a clear case for investment and action to now improve diagnostic accuracy and to next prepare for earlier diagnosis and the arrival of future treatments. Post-pandemic recovery plans should incorporate and build towards these long-term needs.

434

The Dementia Carers Campaign Network journey; sharing our learning experiences good and bad, warts and all!

Ms Judy Williams, Ms Judy Williams

The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia as a public health priority: Engaging people with dementia and carers in policy

Abstract

Background: The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of **Ireland**, is an advocacy group of carers who support loved ones with dementia. The group aims to be avoice of and for dementia carers in Ireland, and to raiseawareness of issues affecting families living with dementia.Since its establishmentin 2013, members participate in research, speak at conferences and events, and have been involved in monitoring the implementation of Ireland's first National Dementia Strategy. They provide feedback on national dementia policy and campaigns, meet with political representatives, and take part in awareness raising activities. The group also influences the work of The Alzheimer Society of Ireland.

Content: The DCCN formed to facilitate the inclusion of thedementia carers' voice in policy affecting them and the people they care for. The group passionately believe that their voice is important and must be included in public policy.The group will offer insights into:

Successes:

- being included in critical policy consultations
- raising awareness of issues affecting families living with dementia and the needs of carers and supporters
- the innovative use of art as a communication tool to connect with a wider audience outside the dementia community

Mistakes and pitfalls

- initial lack of structure
- collecting insufficient information for advocate participation
- failing tosay 'no' when appropriate.

DCCN members will share their lessons learned and hope to inspire and help other carer advocacy groups.

435

Caring as a continuum. Exploring a lived experience concept of care.

Dr Ruth Bohill
Dementia Australia, Adelaide, Australia

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Recently I was referred to as a 'former carer' by a researcher engaged in research about people living with dementia. As an informal familial carer of a person living with dementia, I was for a moment entirely speechless. Though I had recently placed a relative in care, I still managed a broad range of her care needs. These included activities focused on advocacy, health care, social wellbeing, family connectedness and the administration of all her financial and administrative affairs - activities that many informal carers find themselves undertaking after placing a loved one in care.

In exploring my irritation at the use of the term 'former carer' that discounted my lived experience, I wondered why care was often associated with primary care or activities of daily living rather than broader notions of care that may better reflect the lived experience of informal carers.

This presentation explores a lived experience of care as a continuum. It outlines several stages of care that an informal carer may experience, including primary care as one potential element of care in a caring continuum. Other elements of care may include non-physical and intangible aspects of care that enable a person living with dementia to be supported in all aspects of their life by an informal carer. A lived experience concept of care may contest formal notions of care and have implications for carer rights, the visibility of informal carers and care work and an increased awareness of informal care work in dementia, labour and healthcare policy.



436

'There to Care' .....Preserving your own identity while caring

Mrs Helena Quaid
The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: Helena is a wife, a mother, a stepmother, a grandmother, a complementary therapist, a friend, and a family carer. Her husband Kevin was diagnosed with Young Onset Lewy Body Dementia at the age of 53, following a diagnosis of Parkinson's Disease two years previously.

It is very important to Helena and Kevin not to allow Kevin's condition to define them and to retain their own identities. They are both passionate advocates for those living with dementia, and their families, carers, and supporters.

Helena is Chair of the Dementia Carers Campaign Network (DCCN), a voluntary advocacy group supported by The Alzheimer Society of Ireland, and in this role, she takes part in many engagements including policy consultations, media, research, and speaking at events and conferences.

Content: Helena is constantly navigating being a family carer while still being a wife and all her other roles.

This brings many personal challenges and at the conference, Helena wishes to:

- discuss these challenges and share her insights
- offer advice to other carers who might be navigating similar situations
- improve the understanding of the professionals present about the caring role

'There are many terms that describe what I do for Kevin – carer, caregiver, care partner, supporter, but first and foremost I am his wife, and I always have Kevin's best interests at heart', Helena Quaid

437

Our Advocacy Survival Kit (advice from the Irish Dementia Working Group)

Ms Marguerite Keating[1], Dr Helen Rochford Brennan[1], Mr Kevin Quaid[2], Ms Saoirse Kelly[1]

[1]The Alzheimer Society of Ireland, Dublin, Ireland. [2]The Alzheimer Socirty of Ireland, Dublin, Ireland

Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Background: Marguerite, Helen and Kevin are all members of the Irish Dementia Working Group. The Irish Dementia Working Group is an advocacy group of people living with dementia. The group is an independent campaigning voice for the lived experience of dementia with members throughout Ireland.

Marguerite and Helen both received a diagnosis of young onset Alzheimer's disease and Kevin received a diagnosis of Lewy body dementia. All three members are on the steering group committee and advocate tirelessly for the rights of people living with dementia.

Content: Marguerite, Helen and Kevin believe advocacy work has kept them well and they want to share their top tips for advocate survival:

- Be sure the people you are working with give you all the information you need
- Work in an environment where everyone is equal. Ensure there is shared power and shared decision making
- Be sure to have fun and enjoy your advocacy work

Members hope that by sharing their knowledge and expertise it will encourage other people to become advocates.

Members will also encourage the professionals present to use the Hear*Our Voice! Guidelines for Involving People with Dementia in policy, advisory, consultation and conference activities*. The group developed this guide in collaboration with Dr Fiona Keogh, The Centre for Economic and Social Research on Dementia and The Alzheimer Society of Ireland.



438

Dementia Enquirers: people with dementia in the driving seat of research

Ms Rachael Litherland[1], Ms Philly Hare[2]

[1]Innovations in Dementia, Exeter, United Kingdom. [2]Innovations in Dementia, Outer Hebrides, United Kingdom

Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Dementia Enquirers is a new approach to research – led and controlled by people with dementia. It has been supporting 20 groups of people with dementia (from the UK DEEP network) to carry out their own research projects on issues that they find important. The programme is shaped by an advisory group of 9 people with dementia called the Pioneers. As well as people with dementia gaining skills, knowledge and confidence by leading their own research enquiries they are influencing discussions about user led research in dementia.

Our presentation will describe the set up of the Dementia Enquirers programme, the range of research that has been carried out by people with dementia and the learning and impact that has come from this work so far. We will describe some of our broader work including a co-produced accessible research pack. We will also discus some of the barriers to user led research including existing research systems. To support this we will highlight our work around the DEEP-Ethics Gold Standards for Dementia Research. We will also reflect on what could happen if people with dementia were empowered to be more in the driving seat of research.

439

Older adults' experience of neuropsychological assessments for dementia screening in South India: a qualitative study

Dr Bharath Dabbadi Umpathy[1], Dr Steven Jones[2], Dr Jan Bailey[2], Dr Poornima Rao S[3], Dr Mina Chandra[4], Dr Sridhar Vaitheswaran[5], Dr Shaji K S[6], Dr Satyapaul Puri Goswami[7], Dr Aimee Spector[8], Dr Emily Fisher[8], Mr Satish G[1], Dr Murali Krishna[1]

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: In community settings, neuropsychological assessment is the most commonly employed method for early recognition of dementia. However, little is known about the experience and perspectives of older adults when they undertake neuropsychological assessments in low-and middle-income countries (LMICs), including India.

Methods: We conducted semi-structured interviews for 11 individuals (aged between 64 and 88 years) whohad undergone cognitive assessment in the CST International (Cognitive Stimulation Therapy- International) study and were free from dementia.The transcripts were analysed manually utilizingInterpretative Phenomenological Analysis to develop key themes.

Results: When data wereanalysed three superordinate themes (experiences related to the process, content and outcomes) each with a set of subordinate themes emerged.

Conclusions: This study highlights the need for a thorough planning of pre-assessment briefing for equipping participants with adequate information related to the neuropsychological assessment: its indication, length of procedure, contents of the test, possible outcomes, medical implications of those outcomes, possible therapeutic options if diagnosed with lower cognitive function.We discuss our findings in relation to extant knowledge and explore issues clinicians should consider when conducting neuropsychological assessmentsin LMIC settings.



440

The Research on the Application of Aging in Place for Dementia People and the Elderly in Congregate Housing

Miss Chi-Chieh Huang, Prof Po-Tsung Chen, Prof George Yao

National Cheng kung University, Tainan, Taiwan

Topic

Dementia awareness and friendliness: Dementia and design

Abstract

The purpose of this study was to investigate how to provide more spaces and support for elderly dementia residentsin public facilities of existing congregate housing, so that they can receive assistance and welfare from their overall life in the more friendly living spaces.

This study examined the literature review by exploring the concept of assisting the infirm in achieving successful aging and local aging in recent years, and concluded three basic aspects that must be considered when managing self-life and receiving care services for people with dementia: Life Supportiveness, Continuity of Care, and Social Interaction. Moreover, the Analytic Hierarchy Process (AHP) was conducted to discuss the considerations of the planning and designing of residential buildings.

The results of the study discovered that it is important to support dementia residents to manage their own lives and receive care in existing congregate housing. Except for the first three basic principles, it must also conform to the following five design considerations: (1) Ensure the safety of activities. (2) Continue the local lifestyle. (3) Promote the healthy life. (4) Support daily life and long-term care. (5) Connect to the community. All of these are the design criterion for the establishment of public facilities incongregate housing.

The principal conclusion was that the concept of “successful aging” and “aging in place” is to explore the setting of public facilities in a friendly residential environment for the senior and dementia residents so that they can live in a more comfortable, stable and supportive local lifestyle.

441

Adaptation and Validation of the Person-Centred Assessment Tool for the Acute Care Setting

Dr CHONG JIN NG[1], Dr CHIN YEE CHEONG[1], Ms HUI EN FELICIA TAY[2], Dr LIN KIAT PHILIP YAP[1]

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Introduction: Person-centred care (PCC) is synonymous with best practice in the care of persons with dementia. However, person-centredness is not routinely assessed and there is no assessment tool available in the acute setting.

Aim: We aimed to validate the Person-Centred Assessment Tool (P-CAT), a commonly used assessment tool in the long-term residential care, in an acute tertiary hospital.

Methods: P-CAT was administered independently to 162 nurses (n=16, from a specialised dementia unit with PCC training; n=116, geriatric wards; n=30, medical/surgical wards). We employed confirmatory factor analysis (CFA) with principal component extraction to explore the three- and two-factor solutions. A one-way between groups ANOVA was then used to investigate group differences in the P-CAT score.

Results: Factor analysis revealed the two-factor solution (explained variance 42.28%); (i) extent of personalising care, and (ii) amount of organisational and environmental support. Out of the 13 items, only two items did not load as expected. The internal consistency reliability of the scale was satisfactory (Cronbach's α = .77). Nurses' P-CAT scores were significantly different across ward settings [Welch's $F(2,37.20) = 13.01$, $p<0.001$, $\omega 2=0.09$], with the highest among those PCC trained. Post hoc analyses revealed a significant difference in mean subscale scores between PCC-trained nurses and nurses from the other two ward settings. P-CAT scores were not significantly correlated with age, $r(159 = 0.01, p=0.861$, or with nursing experience, $r(159)=0.04$, $p=0.615$.

Conclusion: P-CAT provided validity and reliability as a quantitative assessment tool of person-centred care in the acute hospital.



442

Therapeutic effects and proteomic alterations following mitochondrial transfer therapy in 5XFAD transgenic Alzheimer's disease mice

Mr Nir Suissa[1,2], Dr Keren Nitzan[2], Dr Sahar Sweetat[2], Dr Michal Lichtenstein[3], Dr Sandrine Benhamron[2], Prof Ann Saada[2], Prof Haya Lorberboum - Galski[3], Prof Hanna Rosenmann[2]

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Background: The pathogenesis of neurodegeneration involves dysfunction of the mitochondria, one of the most important cell organelles in the brain. Aiming to affect as many of the mitochondrial complex functions, rather than a mono-drug related therapy, we investigate the effect of transferring normal intact mitochondria organelles in Alzheimer's-disease (AD) mice. We have previously shown the beneficial effect of mitochondrial therapy in the short-term AD-mouse model (ICV-injected amyloid-beta), an effect that is mediated via the liver rather than by mitochondria crossing directly the BBB. We here investigated the mitochondrial transfer therapy in the chronic transgenic model of AD, for exploring the multiple effects of this therapy, including the involvement of the liver and responsiveness of the brain.

Methods: Familial-AD-mice (5XFAD) were IV-treated with fresh mitochondria isolated from HeLa-cells. Cognitive, histological, biochemical and proteomic analysis were performed.

Results: Amelioration of cognitive deficits, neuronal loss, amyloid-burden and increased brain/liver mitochondrial enzymatic activities was noticed in the mitochondria treated AD-mice. Brain proteomic analysis revealed alterations in various proteins, including phagocytosis-associated, proteasome mediated protein ubiquitination, and synaptic related proteins - alterations that may be associated with the reduced amyloid plaque burden, with improved cognition, and others. Liver proteomics suggested various metabolic responses, including alterations in the level of Insulin Growth Factor binding protein (IGFbp2), which may affect the availability of the neuroprotective IGF.

Conclusions: Mitochondrial transfer in AD-mice has multiple beneficial effects, involving the responsiveness of various cellular pathways and components in liver and brain. Mitochondrial transfer may offer a novel therapeutic approach for AD.

443

e-DIVA: Developing a culturally-relevant digital intervention for informal carers of people living with dementia in Aotearoa New Zealand

Dr Tara Puspitarini Sani[1], Dr Gary Cheung[1], Dr Susan Yates[1], Dr Kathy Peri[1], Ms Beryl Kaa[2], Ms Bobby Nepia[2], Prof Sarah Cullum[1]

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: Caring for a person with dementia is often demanding and can significantly influence carers' health and wellbeing. The World Health Organisation has developed iSupport for Dementia, a self-administered training manual for dementia carers. The aim of this study is to adapt the iSupport manual to be more relevant for use in Aotearoa New Zealand (NZ) and develop a digital application based on it, named the iSupport Virtual Assistant (VA). This study is part of a partnership between researchers in Australia, Indonesia, Vietnam, and NZ called 'empowering Dementia Carers with iSupport Virtual Assistant (e-DiVA)'.

Methods: We will recruit 4-6 health or social care practitioners and 6-8 informal (unpaid) carers to join separate group discussions on necessary changes on iSupport. Based on the discussions, we will develop materials for the iSupportVA including videos and animations using a co-design approach. We will invite the same participants to a series of meetings to develop digital application materials together with the research team. Participants will then be invited to give feedback on the final version of the application. These procedures will be conducted in parallel Māori and non-Māori streams of the project.

Results: Through this co-design process, we will produce two versions of iSupportVA, for Māori and non-Māori informal carers. In the next phase, we will conduct a pilot RCT to test its feasibility, acceptability and potential effectiveness on wellbeing and quality of life of dementia carers.

Conclusion: We will present findings from the initial co-design discussions and preliminary application materials in this conference.



444

STRiDE PAR: Developing The STRiDE Kenya Dementia Anti-Stigma Intervention

Dr Christine W Musyimi[1], Dr Sara Evans-Lacko[2], Dr Nicolas Farina[3], Mrs Elizabeth Mutunga[4], Prof David Ndetei[1,5]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: Addressing dementia-related stigma contributes to improved diagnosis.Within STRiDE, one of our primary goals is to develop a culturally-sensitive intervention to reduce stigma in rural Kenya.

Method: We reviewed existing literature and interviewed carers of people living with dementia, members of the general public and health care workers to understand the nature and extent of stigma in relation to people living with dementia (step(S) 1), and contributing factors that significantly increase access to care and support (S2). In S3, we identified potential change mechanisms, and clarified how these could be addressed through public engagement workshops (S4). Feasibility testing (S5) will be conducted among 50 community members, before testing for effectiveness (S6). This procedure alignswith the sixsteps in quality intervention development (6SQuID) model.

Results: We developeda train-the-trainer program aimed at community health workers. The program involves four psycho-educational group sessions with a video-based social contact element to allow individual experiences of regaining a fulfilling life. Sessions include: i) Understanding dementia; ii) Addressing common myths and misconceptions; iii) Indirect contact (video-based) to amplify voices of people living with dementia and their carers; and iv) social inclusion for people living with dementia and their carers.

Conclusion: Involving people living with dementia, their carers and key stakeholders in developing and implementing anti-stigma interventions by allowing them to express their views is crucial to ensure that the interventions are specific to its target users. This also encourages individuals to make decisions about their health and promote early uptake of services.

LINKED IMAGES MISSING

445

Can equine-assisted activities benefit people living with dementia: Two case study examples.

Ms Alison Rood, Ms Sienna Taylor, Dr Jane Williams

Hartpury University, Gloucester, United Kingdom

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aim: As cases of dementia continue to rise so does the emphasis on using non-pharmacological approaches to improve quality of life (QoL). This research aimed to investigate what benefits equine-assisted activities (EAA) have on QoL of people with dementia.

Method: Case studies of two participants with dementia were undertaken. The QoL-Alzheimer's Disease (QoL-AD) measure was used to assess impact on QoL pre/post completion of four interventions: walking (greenspace), stroking, grooming and leading (horse). Interventions undertaken over a five-week period. Participants accompanied by their carers. Mood was self-rated by the participant and assessed by their carer immediately pre/post each intervention. Interventions were filmed and analysed using an ethogram. Frequency and duration of 12 behaviours were recorded. A dementia care professional provided independent analysis using filmed footage.

Results: QoL-AD found no overall improvement in QoL. Participant mood consistently improved after EAA, unlike the greenspace intervention. Grooming was undertaken for the longest duration whilst conversation was the most frequent behaviour. Leading the horse produced the most laughing and smiling behaviours. Excitement, enjoyment of the stable environment and horses, and increased confidence were reported by participants and carers. Findings were confirmed by the dementia care professional.

Conclusions: This preliminary study found EAA, when compared to the greenspace intervention, appeared to have a more positive short-term impact on QoL, however the duration of this influence is unknown. Longitudinal research with larger participant numbers is required to enable development of suitable EAA activities and explore the benefits of EAA for people with dementia.



446

Growing a dementia friendly online chat forum for positive dementia care

Ms Karrie Marshall[1], Ms Mary L Stott[2], Ms Berna Huebner[3]

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

In 2011, when there was not much positive news about dementia, someone took to Twitter with an important question. They wanted to know how to communicate with a relative living with dementia, when the rest of their family and friends did not believe it was possible. A volunteer from the Hilgos Foundation responded. This led to setting up an online chat forum called #AlzChat. The Twitter sessions were soon joined and co-facilitated by a volunteer from Creativity In Care, another not for profit organisation working with people living with dementia.

#AlzChat has grown into a global grass-roots Twitter forum full of tips for positive dementia care. It attracts individuals sharing their experiences of living with dementia, families sharing ideas about what they have found helpful, health and social care staff, former carers, students, researchers, doctors, and designers all listening or contributing to the rich conversations. These shared dialogues have continued every Monday 3pmEST/8pmUK for over 10 years with the same two volunteers.

Social media forums create a space to share ideas about ways to reduce stigma, manage change, increase self-esteem, communicate more effectively, ask for help, or plan for living and dying well. People suggest topics, some of which are repeated, but with a deeper level of insight and understanding. People say what matters and we learn from one another.

The presentation shares aspects of people's favourite topics from well over 500 Mondays, and a wealth of recommendations for facilitating an equalities-based, online dementia chat forum.

447

Creating a New Performance of Dementia

Ms Mary Fridley
East Side Institute, New York, NY, USA

Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

As viewed through a biomedical lens – which remains the dominant way in which dementia is seen – Alzheimer's and related dementias (ADRD) is seen primarily as a condition of loss of capabilities within an individual: of speech, of cognitive abilities, of physical capacities and, eventually, of life while research and treatment is largely directed toward the individual. Dementia activists across the globe are now raising the question: Is the "tragedy narrative" and the shame, stigma, and isolation in produced a result of this very narrow lens through which dementia is understood?

People living with dementia, care partners, activists, academics and artists are developing and advocating for approaches to practice and policy that support *everyone* in the "dementia ensemble" to be intimate and to creatively express their humanity. We will present on of the approaches and a project it has helped inform: The Joy of Dementia (You Gotta Be Kidding!), a workshop/conversation series that offers a playful, philosophical, and conversational collective exploration of the dementia experience through the lens of community-building and development. Through this lens, humans are viewed, not as discrete and isolated individuals whose condition is "inside them," but as relational beings, connected to one another in ways that allows us to build and grow with, rather than fear, uncertainty. Participants are supported to challenge deeply held assumptions about what we "know" about the dementia experience, and it is within this collaborative ensemble building activity that the joy ofcreating a new performances of dementia is discovered.



448

The impact of Be EPIC: A dementia-specific person-centered communication for formal carers

Dr Marie Y Savundranayagam, Ms Shalane Basque, Ms Reanne Mundadan, Dr Joseph B Orange

Western University, London, Canada

Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aims: This study assessed the impact of *Be EPIC*, a person-centered communication intervention for personal support workers (PSW) caring for persons living with dementia (PLWD). *Be EPIC* focuses on the [E]nvironment, using [P]erson-centered communication, client relationships ([I] matter too), and incorporating the [C]lient's abilities, life history and preferences during routine care.

Method: Video-recorded conversations between PSW and simulated PLWD assessed *Be EPIC's* impact on an intervention group (n=16) versus a wait-list control group (n=23). Outcome measures included the proportions of person-centered communication utterances (recognition, negotiation, facilitation, validation) and the proportions of missed opportunities for person-centered communication.

Results: A Two-Way Mixed ANOVA showed a significant group by time interaction for person-centered communication. Simple main effects analysis showed a significant increase in the proportion of person-centered communication utterances among *Be EPIC* participants compared to the control group. Similarly, there was a significant group by time interaction for missed opportunities for person-centered communication. Simple main effects analysis showed a significant decrease in the proportion of missed opportunities for person-centered communication among Be EPIC participants compared to the control group.

Conclusion: Findings show that Be EPIC enhanced person-centered communication, which is essential for optimizing quality of care.

449

Making Wembley Stadium dementia friendly - a collaboration between Alzheimer's Society's Sport United Against Dementia (SUAD) campaign and the Football Association (the FA)

Mr Matt Hughes-Short
Alzheimer's Society, Hitchin, United Kingdom

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

More than 850,000 people in the UK are living with dementia – enough to fill Wembley Stadium ten times over. COVID-19 has exacerbated health inequalities leaving people affected by dementia with reduced confidence and increased loneliness. Reconnecting people affected by dementia to the activities they love has never been more important.

As part of Alzheimer's Society's Sport United Against Dementia campaign and a two-year partnership with The FA, both organisations wanted to see how they could make Wembley Stadium dementia friendly by improving accessibility and inclusivity.

The FA invited 24 people affected by dementia to attend two England matches at Wembley Stadium to provide feedback on their experience. Participants were asked to consider challenges they encounter from the physical environment, staff at the Stadium, and the processes required to get from "sofa-to-seat". Data was collected through feedback sheets and follow up interviews. It was then themed to identify key recommendations.

Challenges identified included entering and exiting the stadium, navigation, and clarity of accessibility information on the website. Several recommendations were presented, including website changes, seating areas for people with cognitive conditions, training for staff, and increased visibility of meet-and-greet services. The Stadium is now working with Alzheimer's Society to pilot a dementia friendly initiative.

This work has demonstrated the scope for stadiums and matchdays to be made dementia friendly across the sector. It demonstrates the importance of engaging people affected by dementia directly, with their participation a continued focus for Sport United Against Dementia and The FA moving forward.



450

Childhood perspectives of parental young onset dementia: A qualitative data synthesis.

Mr Cathal Blake, Dr Louise Hopper

School of Psychology, Dublin City University, Dublin, Ireland

Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

*Background:*While it is less common, young onset dementia manifests at a significantly younger age (< 65). Many people with young onset dementia are parents, however, little is known about impact of the condition on children and young adults. A qualitative thematic analysis was conducted to synthesise the literature on the perspectives of children and young adults with a parent living with young onset dementia.

Methods: Electronic databases were searched in order to identify all peer reviewed literature in relation to the perspectives of children and young adults with a parent living with young onset dementia. A thematic analysis was conducted on the relevant literature.

Results: The electronic database search resulted in 15 full texts articles.Four main themes with related sub-themes emerged from the thematic analysis. The four main themes were:changing family dynamics; psychological & physical strain; stigma and coping strategies.

Conclusion: The current synthesis outlines the perspectives of children and young adults with a parent living with young onset dementia. There is a significant lack of research in this area which adds to the stereotypical view of dementia as an older persons disease. This can lead to children and young adults being impacted by lack of awareness and stigma resulting in significant psychosocial problems. As the number of people living with dementia (including young onset) is set to increase, future research with children and young adults with a parent with young onset dementia is important in order to better support this cohort.

451

Predictors of good quality of life in people with dementia in South Africa and Indonesia: Data from the STRiDE programme

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Poor quality of life is not an inevitable part of dementia. However, there are a number of factors that increase the risk of poor quality of life of people with dementia. There are relatively few data on quality of life in dementia in low- and middle-income countries and two which lack that data are Indonesia and South Africa. As part of the Strengthening responses to dementia in developing countries (STRiDE) programme, we are conducting a household survey of older adults (aged 65+) residing in four locations in Indonesia (Jakarta and North Sumatra; n≈2,200) and South Africa (Limpopo and Cape Town; n≈ 800). All participants are asked to complete a comprehensive set of questionnaires spanning cognition, functional status, caring context, lifestyle habits, neuropsychiatric symptoms, and stigma. Using the 10/66 short schedule for diagnosis, older adults with probable dementia will be identified. The analysis will explore the factors associated with quality of life (e.g., DEMQOL, EQ-5D) in people with probable dementia and how it differs between settings. In understanding what factors are associated with good quality of life in these countries we can develop better strategies to maintain and improve the lives of people living with dementia.



452

Using Activity Based Workshops as part of Patient and Public Involvement

Dr Kyle Harrington, Dr Michael Craven, Dr Max Wilson, Dr Aleksandra Landowska

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

We report on a series of activities conducted with Public and Patient Involvement volunteers to elicit perceptions and attitudes towards cognitive training and cognitive screening technologies for people living with, and at risk of dementia. In total, four workshops were conducted with six participants, each split in to two sessions. We will discuss how activity-based sessions for people living with dementia and their carers contributed to the success of the involvement activities, helped to foster a sense of group cohesion and led to interesting insights in our research. For instance, we introduced the topic ofMotivation and Learningby asking involvement volunteers to bring an item which represented their hobbies and interests. Using this physical prop, volunteers discussedmotivation,which led to a broader discussion about how the developers of cognitive screening and training technologies may wish to embed some of thesefactors into their own applications. In another workshop wewanted to gauge the extent to which people consideredintelligenceto be eitherfixed or static,and rather than simply asking questions verbally; we asked participants to physically move between a series of dichotomous statements. Oneworkshop included ideation cards to facilitate discussion of digital rights, and another included a demonstration of Virtual and Augmented Reality systems. These activities kept volunteers engaged during lengthy workshop sessions and facilitated a broad depth of talking points. We will propose how activity-based workshops can be used in Public and Patient Involvement and other qualitative research for people living with dementia.



453

Customisable Memory Karaoke enables you to sing your way into the Universe of Memory to reminisce, retain and recall.

Ms Vidya Shenoy
Alzheimer's & Related Disorders Society of India (ARDSI), Mumbai, India. Indian Federation of Neurorehabilitation, Mumbai, India

Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Memory Karaoke, the latest innovative,customisable tool, is a successful marriage of music and technology for supporting ageing population with MCI or those living with early Alzheimer's. It is designed keeping in mind memory loss, authentic situations in daily life and challenges of carers. This sing-along tool with blanks for inserting personal information, catchy tunes and rhythm, familiar-sounding music reinforces their ability to respond, reminisce and retain for future recall. Music is an impactful, therapeutic intervention on psycho-social, emotional, physical health and well-being as also shown to improve memory.

This customisable tool is user-driven and easy to use. If used daily with supervision or assistance of family members or their caregivers, this fun tool becomes a method of engagement offering an emotional bonding time for both. Further, a boon that catalyses sensory stimulation and a great platform to improve communication between them. Memory Karaoke songs have helped to perform and handle ADLs better that might have otherwise been difficult, given opportunities to families and caregivers, supported and assisted those with dementia by enabling them to recall old memories otherwise forgotten or daily activities that have just been performed. It has been observed to improve focus and provide support to overcoming memory lapses to a certain extent.

Singing sweetly and to be able to glide into the 'Universe of Memory', this non pharmacological, therapeutic intervention of Memory Karaoke requires much love, empathy, patience and perseverance to practice!



454

Stop Wasting Precious Time

Mr Kevin Quaid
The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Kevin Quaid is 57 years of age and lives in County Cork. Kevin was diagnosed with Lewy Body Dementia in 2017. Kevin is a loving husband, father and grandfather. He is a member of the Irish Dementia Working Group and vice chair of European working group of people with dementia.

Throughout his dementia journey Kevin has continuously met people living with dementia who have not received a proper diagnosis. Kevin believes once people receive a correct and timely diagnoses, they too can live a meaningful life.

Content:

Kevin will speak from his own lived experience about

- The importance of a proper and timely diagnosis
- How critical it is the correct type of dementia is diagnosed
- How receiving a diagnosis of Lewy Body Dementia has shaped his dementia journey
- What he would like clinicians to know when giving a diagnoses of dementia

Kevin believes the fear of the unknown for people and the uncertainty of their future can be more debilitating than the diagnoses itself. The correct diagnoses can be the start of a new and powerful journey.

Kevin is looking forward to representing and amplifying the voice of the person living with Lewy body dementia at the Alzheimer's Disease International Conference.

455

Study of serum Neurofilament light protein as a biomarker in subjects with Subjective Cognitive Decline

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Neurofilament light protein (NfL) is a neuronal cytoskeleton protein, which has been studied as a blood-based neuro-axonal damage marker in Alzheimer's disease. Subjective Cognitive Decline (SCD) is a prodromal stage of dementia where there is self-reported decline in cognitive function, not evidenced by objective neuropsychiatric tests. However, the relationship between serum NfL and SCD remains to be elucidated. Self-reported cognitive complaints may represent an early metacognitive recognition of impairment and studying simple blood-biomarkers in this early stage could facilitate identifying and planning interventions and delaying the progression of the disease. We aimed to investigate NfL in blood as a marker for SCD.

Method: This was a case-control study, 40 SCD individuals, 40 cognitively normal older adults(≥60years), 20 young controls (40-60years) were included. Each participant underwent neuropsychological testing various domains of cognition. Serum NfL was measured using ELISA kit. The association between NfL and three groups was measured using Kruskal Wallis test.

Results: Mean age of SCD, old and young control was 68, 67.5 and 47.5 years respectively. The median of serum NfL was 2.78 ng/ml (1.01-17.01), 2.81 ng/ml(0-18.75) , 3.50 ng/ml (0.31-18.75) in SCD, old and young controls respectively and no statistically significant difference was found between the three groups.

Conclusion: These findings imply that serum NfL could not differentiate individuals with normal cognition and SCD. Further longitudinal studies are needed with a larger study population, evaluating the trend of NfL in the disease course which might help in monitoring the progression of disease.



456

STRiDE PAR-Pathways of care: The experience and costs of caring for family members living with dementia in Mexico

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Topic

Dementia as a public health priority: Economics of dementia

Abstract

Background: Mexico's formal health and social security systems are unequipped to respond to increasing dementia prevalence, estimated between 5.2% - 7.9% (Mejía- Arango etal., 2011; Llibre et al., 2008). Care for people living with dementia is primarily, if not exclusively, provided by family members (López-Ortega, Aranco, 2019; Gutiérrez-Robledo & Arrieta-Cruz, 2014). While the economic, social and health consequences of providing this care underpin the sustainability and equity of Mexico's dementia care reality, very little is known about the experiences of those called upon to provide it.

Aim: this paper presents families' health and social dementia care seeking trajectories and the structural factors that shape them.

Methods: Based on highly inductive fieldwork carried out before and during COVID-19 pandemic, including 52 in-depth interviews with 23 unpaid family carers. Results show the impact that timely access to comprehensive care facilities and home-based services, information about dementia, and healthcare practitioners' communication around diagnosis and symptoms, have on when, where and if families obtain appropriate health and/or social care, and the consequences of this for them. We found high opportunity costs borne by family members who change, reduce or stop paid work, the impact on their social life, health and mental well-being, and strategies that are (or not), employed by family members to alleviate the negative consequences of caring.

Conclusion: Increasing awareness and support strategies for unpaid family carers are urgently needed in order to stop or decrease current the social and economic impact of dementia care on families and society overall.

457

Alzheimer's, related disorders and language: How we talk about ''dementia'' is key to building community bridges.

Mr Arnaud Francioni[1,2], Prof Melissa Park[2,1,3], Ms Seiyan Yang[2], Ms Chesley Walsh[4], Prof Thomas Valente[5], Prof Patricia Belchior[1,6]

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Topic

Dementia awareness and friendliness: Language challenges and how to overcome them

Abstract

The*What connects us~Ce qui nous lie* is a Community Investment project funded by the Public Health Agency of Canada. The aim of our project was to bring together arts/cultural, mental health, academic, and community-based partners with the vision of creating an inter-connected community for all.Working with our community-based partners to support people living with Alzheimer's and other related disorders and their carers raised numerous challenges. One often overlooked challenge was language.In Canada, we have two official languages. This heightened our attention to the tensions related to terminology used by our community-based partners.

Method: We will present the everyday experiences of our project team and the challenges that Alzheimer's terminology played in creating challenges to a cohesive intersectoral network. Using an audit trail, we will describe how we continually adjusted to the vocabulary chosen between our partners, the reasons why, and the sensitivity required to the implications of different terms depending on the primary language of choice (French or English) or the sector (health or community-based).

Conclusion: Our experience points to a call for greater discussion about the words we choose and what they mean as well as the sensitivity of each sector about language surrounding ''dementia''. This discussion matters as it can create some common ground to build long-term and more efficient relationships between all organizations.



458

ALPS:Assisted Living by Personalized Speakers for People with Dementia

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

In Japan, we have become a super-aged society, and the number of elderly people is increasing year by year not only in Japan but also in the world. As a result, the number of elderly people with cognitive problems is increasing, and support for these people in their home life is necessary. In this study, we aim to realize an assistive technology that presents necessary information to elderly people with cognitive concerns or dementia in a way that is adaptable to their home life. We proposed and developed ALPS, a system to present audio information at an appropriate place and time by deploying simple IoT speakers in the home. ALPS is an acronym for Assisted Living by Personalized Speaker. The IoT speaker was created using a Raspberry Pi, motion sensor, and speaker, and ALPS was implemented. In our laboratory, we conducted an experiment to see if we could receive support information. As a result, it was confirmed that ALPS was able to present information registered in advance on a rule-by-rule basis by voice in cooperation with ECA (Event-Condition-Action) rules in the cloud.

459

Equity and balance in clinical dementia research: A Charter of Conduct for global collaborations

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Aims: Dementia research capacity in many low- and middle-income countries (LMIC) is still developing and often depends on international collaborations with high-income country (HIC) partners. Such collaborations present important equity risks and partnership imbalances. Our objective was to develop a Charter of Conduct to guide future international collaborations for dementia research.

Methods: Using modified consensus methods and interactive, facilitated discussions, we developed a Charter of Conduct through workshops with 63 dementia experts from across the global South and North.

Results: Key recommendations to guide current and future collaborations between researchers from LMIC and high-income countries include strategies to: (1) ensure transparency; (2) maximize power sharing; (3) consider equity and inclusion; (4) learn bidirectionally; (5) build interdisciplinary dementia research capacity and capability; (6) develop long-term, sustainable collaborations that include members of civil society; and (7) align the work with local, national and global goals.

Conclusion: International partnerships in dementia research, if genuinely equitable, can engender progressive exchange and bidirectional innovation and learning among partners, leading to important scientific advances, including a reduction of the global burden of dementia. However, navigating these relationships can be challenging, and without careful consideration and true collaboration, partnerships will fail to optimise these important opportunities, which may be hampered by existing complexities such as coloniality and deep-rooted power structures. Our Charter of Conduct, operationalised as a researcher checklist, will support international collaborators and represents an important step in supporting more equitable, ethical and balanced dementia clinical research globally.



460

The Development of a National Evaluation Framework for the First Link® Program Across Canada

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Aims: In Canada, the Alzheimer Society's First Link® program connects people living with dementia and their caregivers to the information, supports, and services they need as early as possible and throughout the progression of their condition. Since its launch in 2002, First Link® has been implemented in all provincial societies across Canada. We aimed to develop a national evaluation framework to assess the impact of First Link®.

Methods: This work was conducted with active engagement and consultation with provincial Societies, persons living with dementia and their care partners, and other stakeholders. A contribution analysis lens was used to understand how the First Link® program may contribute to health system outcomes. We first assessed the state of the First Link® program across Canada and developed a theory of change. Key informant interviews with First Link® staff, clients, and community partners were used to gather evidence to build upon and test the theory of change.

Results: We mapped all available and potential data sources to the theory of change to develop an evaluation framework with indicators that demonstrate program impact. Collaborative co-design methods were used to develop scripting and protocols for data collection.

Conclusions: The evaluation framework is being tested at a representative group of Alzheimer Society pilot sites. The outcomes of this initiative will provide data to support the Alzheimer Societies' efforts to build a national case for ongoing, sustainable funding for First Link®, and will provide ongoing surveillance data for care partners of persons living with dementia across Canada.

461

Promoting Brain Health among Older Michiganians via Technology: A quasi-experimental Design

Dr Fei Sun, Ms Haneul Kim, Mr Lucas Prieto, Dr Heer Rin Lee, Dr Paul Freddolino

Michigan State University, East Lansing, USA

Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Fei Sun, HaNeul Kim, Lucas Prieto,Hee Rin Leeand Paul Freddolino

Aims: Limited studies have tested psychosocial educational interventions to promote brain health among elders who are concerned about cognitive decline. This study aimed to explore the effectiveness of an 8-week intervention that teaches lifestyle and cognitive strategies via Zoom among older adults in Michigan of the U.S.A.

Methods: A one-group design was used to test and evaluate the effectiveness of the pilot program. Participants (n=27) included male = 4, female = 23; Caucasian = 10, African American = 17) that were 60 or older(*M* = 71.3, *SD* = 6.14). Participants' MoCA score ranged from 18 to 29 (*M* = 26.15, *SD* = 2.51). Paired t-tests were used to compare the differences on the brain health knowledge, dementia beliefs, confidence of managing cognitive changes, and fear of dementia.

Results: At post test, participants reported decreased their biased beliefs toward dementia (p=0.05), increased dementia knowledge (*p*= .028) and confidence to managing cognitive changes (*p*= .000) compared their baseline scores. However, no statistical differences were found regarding fear of dementia, social isolation, and depressive symptoms.

Discussion: The 8-week psychosocial educational brain health intervention has shown acceptability among participants, and made a positive impact on their dementia knowledge, beliefs and confidence. Though this study provides a promising direction, future studies with a large sample size and randomized control trial design are needed to examine the effects of psychosocial educational models in promoting brain health.



462

Web-based communication guidelines to support people living with dementia and their care partners – a scoping review

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University College London, London, United Kingdom

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: Communication difficulties impact on people living with dementia and their overall well-being. Many family and paid carers seek advice about how best to support communication, and may access the internet to find guidance. It is unclear what advice is given on websites and if it is consistent, comprehensive and based on evidence.

Aim: This scoping review aims to identify the communication strategies on the internet, to compare this advice to the evidence of what works, and to develop a conceptual framework of communication strategies.

Method: We searched Google, Yahoo and Bing for dementia-focused websites containing communication strategies, and screened the first 50 results from each search engine for inclusion. The Discern tool was used to evaluate the quality of information on included sites and advice about supporting communication was extracted. Strategy data was collated to identify commonalities and contradictions and a reflexive thematic analysis of strategy content will be undertaken. We are working with our research network of people living with dementia and care partners to understand the relevance and accessibility of the websites and extracted strategies.

Results: 32 websites met inclusion criteria and detailed results will be presented, including mapping of strategy content and a summary of thematic concepts generated.

Conclusions: This review will advance understanding of effective communication strategies for people living with dementia, and enable care partners to identify which strategies may be most beneficial. Findings will guide future analysis of interactions in dementia, with a view to adding to evidence about effectiveness of strategies used.

463

Mild Traumatic Brain Injuries and future risk of developing Alzheimer's disease. SystematicReview and Meta-Analysis

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Topic

Dementia risk reduction: Risk factors

Abstract

Background: Traumatic brain injury (TBI) increases the risk of future dementia and Alzheimer's disease (AD). However, it is unclear whether this is true for mild TBI (mTBI).

Aim: This systematic review and meta-analysis examined the evidence for an association between mild TBI and subsequent risk of developing AD.

Methods: Following PRISMA systematic review guidelines, wesearchedfour electronic databases from January 1954 to April 2020. We included studies reporting primary data and where mTBI preceded AD by ≥ 5 years, and conducted random-effects meta-analyses.

Results: 5 of the10,435 results met the inclusion criteria.

Results: The meta-analysis found that a history of mTBI increased risk of AD (pooled relative risk=1.18, 95% CI 1.11–1.25, N=3,149,740). A sensitivity analysis including only high quality studies revealed almost identical results, however a sensitivity analysis including only studies with a follow up time of > 10 years demonstrated a pooled relative risk of2.02 (95% CI 0.66- 6.21, p=0.22).

Conclusion: There is an increased risk of AD following mTBI.Our findings of increased risk even with mTBI means it cannot be assumed that mild head injuries from sports are harmless. Implementation of policy to reduce mTBIs, including in children and sportsmen, are urgently needed. Further research is needed on the effect of frequency and age at injury of mTBIs.



464

The Effects of Pomegranate Seed Oil on Mild Cognitive Impairment

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Greek Association of Alzheimer's Disease and Related Disorders, Thessaloniki, Greece

Topic

Dementia research and innovation: Clinical trials

Abstract

In recent years, there has been a growing interest, supported by a large number of experimental, epidemiological and clinical studies, about the beneficial effects of pomegranate in preventing various pathologic conditions, including brain neurodegeneration. Specifically, the Pomegranate Seed Oil (PSO) contains high level phytosterols and vitamin C. Its antioxidant and antiapoptotic properties are helpful in the treatment of neuroinflammation.

For this reason, the Greek Association of Alzheimer's Disease and Related Disorders is conducting research on the effects of PSO on cognition and mental health of patients with Mild Cognitive Impairment (MCI). The rigor methodological plan of the present randomized clinical trial will cover every aspect of the disease and eliminate possible limitations with careful selection of inclusion and exclusion criteria, with randomization of the sample and with the use of all the contemporary means and measures, such as neuropsychological assessment, MRI and analysis of blood biomarkers. The effects of PSO will be compared with the effects of Mediterranean Diet and the participants will be divided further into Apolipoprotein ε3 carriers and Apolipoprotein ε4 carriers in order to clarify the role of this specific allele in the treatment.

So, the present study is going to be the first in vivo clinical trial internationally which will examine thoroughly the effects of PSO on MCI patients. However, this study is ongoing and by now the treatment is at the third month. For this reason, the results from the neuropsychological assessment after six months of treatment will be presented.

465

STRiDE PAR Mapping Indonesia's Dementia Care Services

Dr Tara Puspitarini Sani[1,2], Ms Imelda Theresia[2], Dr Eric Arija Artha Santawi[1], Dr Yuda Turana[1,2], Ms Adelina Comas-Herrera[3], Dr Klara Lorenz-Dant[3]

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Topic

Dementia as a public health priority: Healthcare system readiness

Abstract

Background: In 2050, 68% people with dementia will live in low-and-middle income countries (LMICs). It is essential that countries build an adequate response towards dementia. In Strengthening Responses to Dementia (STRiDE-Dementia) project, we analysed the dementia situation in several LMICs including Indonesia. To fill out the gap for information that we could not identify through literature review, we conducted interviews with stakeholders and used case vignettes to better describe the dementia situation in Indonesia.

Methods: A desk review on literature regarding dementia situation in Indonesia up to December 2020 was done and analysed qualitatively using Strength-Weakness-Opportunity-Threats (SWOT). An interview topic guide was then developed based on the areas where information is lacking and potential stakeholder respondents identified. Separately, five case vignettes were used to simulate typical scenarios faced by persons with dementia and their families in Indonesia. These scenarios are then presented to stakeholders to be reviewed.

Results: Although Indonesia already has a National Dementia Plan, dementia services still differ across regions, depending on regional and hospital budget allocation of the national health insurance coverage. The Ministry of Health issued a regulation on annual cognitive screening for older people in primary care, but training has just started in 2021, partly due to pandemic.

Conclusion: Capacity building training and clear guidelines to implement standardized dementia services across the country are needed. The COVID-19 pandemic calls for more online and home-based post-diagnostic and long-term care services.



466

Preventing cognitive decline by adopting healthy lifestyle habits - contribute to creating age-friendly communities

Miss Marie Christine Le Bourdais
Alzheimer Society of Montreal, Montreal, Canada

Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

My Cognitive Health is an innovative program of the Alzheimer Society of Montreal. Its objectives are to raise awareness among the general public and people with Alzheimer's disease about the importance of healthy lifestyle habits in maintaining good cognitive health. This program also presents the modifiable risk factors of Alzheimer's disease, promotes the importance of early diagnosis and how to empower oneself to take action on one's cognitive health.

We will present how this program allows our clients and the general public to quickly obtain accessible information on the protective factors of cognitive health in addition to providing tools for people recently diagnosed with a neurocognitive disorder (NCD). We will make the population aware of the warning signs for NCDs - and encourage them to take action - through conferences, literacy, video capsules, partnerships with different networks and early management of people with an NCD.

We have also developed the Mon milieu de vie project, which will provide stakeholders and managers with the tools they need to adapt their living environments to people living with an NCD. The project aims to help community workers better understand the symptoms of NCDs so that they can make judicious choices in their interventions. Among other things, they will learn the principles and basics of person-centred communication as well as learn and implement intervention strategies using this same approach that meet the specific needs of people living with an NCD.



467

Successful ways to express the person-centred approach

Miss Marie Christine Le Bourdais
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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

At the Alzheimer Society of Montreal, a person-centred approach to care is at the heart of our mission and forms the basis of our programs and services. This approach allows us to establish a path for our clients within our organization: a path that is adapted, relevant and personalized. All of our clients can thus obtain this personalized support, the many impacts of which we will demonstrate.

The context of the COVID-19 pandemic has not dampened our resolve to provide support in a variety of ways - and some, boldly implemented. Among the range of our programs and services, we will present two unique and distinctive offers: individual psychosocial support and art therapy for people living with a neurocognitive disorder (NCD).

The individualized psychosocial consultations help by first establishing a trusting relationship with the client and then proceeding to an evaluation of their need, in order to propose an adapted intervention plan. These meetings allow clients to discuss and express themselves confidentially about their reality and the impact of the diagnosis on their daily lives. In addition, they can obtain information and referrals to resources available in the Montreal area.

The feedback from our in-person art therapy groups made clear our clients' needs to maintain this therapeutic connection and opportunity for artistic expression in a virtual format. These sessions also allowed participants to create a «Village to stay connected», a virtual vernissage of their works, some excerpts of which will be presented along with the benefits for participants.



468

Engaging care partners of persons with dementia and reducing barriers to support through virtual dementia care navigation: Description of the "GLENNERCARE™" program and its impacts

Mrs Shannon Patel, Mr Scott Tarde

George G. Glenner Alzheimer's Family Centers, Inc., Chula Vista, USA

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background and objectives: We describe GLENNERCARE™, as an innovative virtual dementia care navigation service that focuses on engagement and rapport building with care partners of persons living with dementia by providing proactive professional recommendations, support, and referrals from the privacy and safety of their home. Care partners of persons living with dementia are often engaged at a much higher level than other diseases and as such, reducing unnecessary emergency room visits and hospitalizations, are main goals of GLENNERCARE™.

Methods: Upon enrollment, a Hospital Risk Assessment (HRA) is conducted with each care partner to determine how frequently the GLENNERCARE™ team will initiate a Meaningful Check-in (MC) call, email or text message to the care partner.

Results: Outbound communication from care partners accounts for a majority of the total interactions between GLENNERCARE™ team and care partners, supporting the importance of the utilization of HRA scores to determine regular MC communication with care partners as opposed to waiting for the care partner to initiate contact.

Discussion/Conclusion/Implications: GLENNERCARE™ can improve outcomes for persons living with dementia by engaging with their care partners to reduce risks of caregiver burnout, adverse health related events, costly and often unnecessary emergency room visits and hospitalizations and making decisions from a place of crisis, while also increasing quality of life through care partner education, connection to resources, and professional recommendations.

469

STATE OF DEMENTIA CARE IN BENIN (WEST AFRICA)

Ms Angeladine Kenne Malaha[1], Dr Clémence Thébaut[1], Dr Salimanou Ariyoh Amidou[2], Prof Dismand Stephan Houinato[2,1], Prof Pierre-Marie Preux[1], Dr Maëlenn Guerchet[1]

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Topic

Dementia as a public health priority: Healthcare system readiness

Abstract

Aims: To appraise the dementia policies and plans available, and describe the healthcare facilities for people living with dementia (PWD) in Benin.

Methods: First, we searched online and in public health institutions for all available dementia policy and plans documents. Then interviewed health system stakeholders. The summary of the 'Global action plan on the public health response to dementia 2017 – 2025' and the STRIDE situational analysis guide were used to retrieve information from documents and guide interviews. A snowball sampling finally was applied to identify hospitals and other facilities taking care of PWD. These structures were visited and described.

Results: We found no dementia action plan available in the country, neither existing nor in preparation. Dementia falls into the portfolio of the non-communicable disease control programme, under the topic of mental health, which focuses mainly on activities related to alcohol, tobacco and drugs use. Nevertheless, many older people's exist which sometimes offer education on chronic diseases. About ten neurologists and five psychiatrists work full time in five main public and one confessional hospitals across the country. Specialties' residents assist them in the two main public hospitals. Additionally, ten liberal neurologists work part-time in private and other public hospitals. We identified one private organization that provides residential care to elders. They also offer at-home care by specialised caregivers trained through their organization.

Conclusion: Even though no dementia plan or formal long-term care system exist for PWD in Benin, many actions are ongoing which deserve to be organized and scaled-up.



470

Results of a Low-Cost Dance Intervention for Cognitive Reablement in Dementia

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

We demonstrated that a 30-minute dance intervention three times per week over a thirty-day period to four residents living in dedicated memory care assisted living facility improved MMSE (Mini-Mental State Exam) scores by an average of 3.375 points. No adverse effects were observed. This small, retrospective review lends credence to the theory that dance therapy may be an effective, low-cost cognitive reablement intervention for those with dementia and ADL impairments significant enough to warrant long-term care placement.

471

Digital technologies to support social isolation in cognitive impairment and dementia: a systematic review

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Introduction: It has been estimated that half a million people in the UK go without seeing or speaking to anyone at all for up to 6 days a week. This issue of social isolation is particularly prevalent in dementia communities. Despite recent advances, we remain without accessible disease modifying therapy for dementia and there is a need to ensure high quality post diagnostic support is in place not just in clinical settings but also in our communities. Such approaches align well with concepts of healthy ageing including a need to maximise functional abilities. While the use of technology holds much promise for supporting social connections, there are key questions around both the quality and quantity of existing research and how accessible such solutions are to the general population.

Methods: To address the question above, we conducted a systematic review of online databases fordigital technologies (e.g. mHealth, eHealth, apps, online interventions) developed for people with mild cognitive impairments and dementia. Our inclusion criteria includedthat interventions needed to be designed for, or have a strong rationale for hypothesisedimpact upon isolation/loneliness. We used a number of key search terms to form our searches and appraised the study quality of such studies using the mixed methods appraisal tool (MMAT). We included studies with outcomes regarding quality of life/ loneliness.

Results/Discussion: Our search identified 1,329 potential articles of interest where 10 met our inclusion criteria. This work will provide a number of important recommendations for future global research and practice.



472

Cognitive decline and mental health among independent older adults living alone in an urban area: a cross-sectional study in Tokyo

Dr Shuji Tsuda, Dr Hiroki Inagaki, Dr Mika Sugiyama, Dr Tsuyoshi Okamura, Dr Fumiko Miyamae, Dr Chiaki Ura, Dr Ayako Edahiro, Dr Hiroshi Murayama, Dr Keiko Motokawa, Dr Shuichi Awata

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aims: This study examined whether living alone modifies the correlation between cognitive decline and mental health among independent older men and women.

Methods: We conducted a cross-sectional, self-administered questionnaire survey from community-dwelling older adults in the Tokyo metropolitan area, who were aged ≥65 and not on long-term care. The questionnaire included the 10-item self-administered dementia checklist, the WHO-5 psychological wellbeing scale, a question on living arrangements, and other participant's characteristics. The analyses were stratified by sex and fitted with linear regression models.

Results: Totals of 33,179 men and 41,243 women participated. Their mean ages were 73.5 (SD 5.98) and 73.6 (SD 5.79), and 18.4% and 25.9% lived alone. The dementia checklist scores indicate that the cognitive status of 95.9% of men and 97.0% of women varied from intact to possible mild dementia. For both sexes, cognitive decline showed a linear correlation with lower psychological wellbeing after adjusting for their characteristics (men, beta -0.378, 95% CI -0.396, -0.361; women, beta -0.395, 95% CI -0.413, -0.377). When the interaction between living arrangement and cognitive decline was added in the model, men who lived alone showed lower psychological wellbeing than men who lived with others (slopes, -0.472 vs -0.360, p for interaction<0.001), but the interaction was not significant among women.

Conclusion: The findings suggest that when faced with cognitive decline, older men living alone in an urban area are vulnerable to mental health issues. It is important to consider how this high-risk group can be supported to have more favorable mental health.

473

Memory Strategies as Conversational Techniques for Hidden Victims of Alzheimer's Disease

Dr Kasper Bormans, Prof Keith Roe, Prof Dirk De Wachter

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Aims: Alzheimer's Disease is the most common form of dementia, characterized by a lingering process of deterioration for the patient and the environment ('caregiver burden'). More than 70% of dementia patients are still living at home, taken care of by a family member. Thus, the number of people affected by dementia is trice the number of patients. The primary objective of this study is to examine how the addition of (augmented) reality to mnemonic strategies can transform the 'hidden victims of dementia' into 'hidden resources'.

Method: We developed a mobile application ('MemoryHome') based on the ancient mnemonic strategy 'the method of loci' (MoL). Previous research solely focused on the MoL as a solitary activity for Alzheimer patients to delay memory problems. The novelty of our study is to use the mnemonic strategy as a dyadic intervention to increase well-being by introducing the concept of a 'co-walker'. The digital instrument stimulates positive conversation between patients and caregivers.

Results: The impact of our psychosocial intervention was evaluated (week 0-4-8) in homecare (n=19 dyads) and in the residential setting (n=22 dyads) on quality of life (QOL-AD), feelings of depression (GDS-15) and connectedness of subjects in the early phase of AD and their significant others (QCPR). Participants reported to feel more cheerful, more physically active and socially connected.

Conclusion: The mobile application MemoryHome is an efficient tool to reinforce the dialogue between patients and their environment. Translating mnemonic strategies into dyadic interventions can turn 'hidden victims' in 'hidden resources' in future Alzheimer research.



474

The art of caring for self and others four-month creative learning programme

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

People with unpaid caring roles often give more than they realised was possible. Carer assessment forms identify needs, but the reality is that many informal carers still find themselves isolated, exhausted, and emotionally unsupported.

The ART of Caring for Self and Others was developed to be an uplifting and useful four-month learning programme to prevent carer breakdown. It provides highly reactive, emotional support, whilst linking people to available community services. Funding partners over the years include NHS, local councils and third sector funders.

Each programme is different as topics are raised by participants, but typically include the following:

- Understanding and responding to different symptoms of dementia.
- Alleviating stresses caused by changes in cognitive function.
- Increasing positive interactions.
- Celebrating life through mindful and creative activities.
- Gaining clarity for end of life wishes for self and others.
- Planning for dying and death.
- Enhancing and maintaining self-care strategies.
- Practicing assertiveness for asking for what we want from services
- Navigating moral and ethical dilemmas
- Who and when to contact for different situations.

The group sessions run in person or online, with additional one-to-one sessions for more sensitive conversations. Care partners quickly form strong bonds with one another and offer compassionate safe space. Mental wellbeing meaningfully improves over the course of the programmes (measured via Warwick and Edinburgh Mental Well Being Scale), and feedback often shows the positive impact and 'life changing' effects experienced by participants.

This presentation will share main points about the process, the education and practice research involved in developing the programme.

475

Implementing psychosocial interventions in Alzheimer's Research through compliance-without-pressure-techniques

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KULeuven, Leuven, Belgium

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aims: Over the past 30 years, more than 200 interventions have been examined, targeting the caregivers of dementia patients, and found to be effective within randomized clinical trials. Only 3% of this large collection of psychosocial interventions was translated into daily practice. The primary objective is to determine facilitators and barriers for implementing psychosocial interventions in Alzheimer's research.

Method: We recruited professional caregivers in homecare (n=14) and the residential setting (n=24). Both groups were enrolled in a similar intervention trajectory of 36 weeks to assist people with dementia and their loved ones using a mobile health application ('MemoryHome'). Caregivers received communicational training based on social influence and compliance-without-pressure-techniques to increase ecological validity.

Results: The implementation of psychosocial interventions in Alzheimer's research can be enhanced through communicational training focusing on compliance-without-pressure-techniques (e.g. foot-in-the-door, illusion of choice and positive reinforcement). The condition of homecare and residential setting had specific facilitators (e.g. more involved family members in homecare) and barriers (e.g. decreased health conditions in the residential care setting).

Conclusion: The challenge for the future of psychosocial interventions is not so much to come up with new inventions, but to motivate people to actually use existing instruments. Stimulating significant others to collaborate by means of compliance-without-pressure techniques, can provide a crucial added value for upcoming Alzheimer's treatments.



476

Reaching Back To Our Childhood Selves: Understanding The Benefits of Caregiving Youth

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Topic

Support for dementia carers: Young carers

Abstract

There are many reasons that young caregivers could decline an offer to care for a loved one, but despite those hurdles, many take the leap. According to a 2005 report by the National Alliance for Caregiving, 1.3 million (and potentially many more) children between the ages of 8 and 18 are taking care of a relative.

Most legislation and conversations around caregiving are directed toward adults using adult terms, explicit language, and no pictures. Most caregiver depictions on TV, marketing collateral, and on websites are female, this discourages male caregivers.

Additionally, adults have the ability to lean on a spouse and their own children for emotional support. Caregiving wasn't designed with young adults and children in mind.

With dementia added into the equation, young adults don't need a full understanding of dementia in order to understand how to interact with a loved one. Naïveté and other positive qualities of development are extremely beneficial for younger caregivers and their loved ones who need their support.

In this presentation, I will explore the ways that we can rely on young caregivers to advance dementia care, and help older caregivers lean on youth, to inform their dementia caregiving processes. I found immense success taking care of my grandmother with dementia when I was 12, relying on simple childhood lessons and I want to share that knowledge with others.

477

Review of Mild Cognitive Impairment and Dementia Concept. New Rationales Diagnostic Proposal for these Terms

Dr Roberto Leonel Ventura Brignoli
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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

The mild cognitive impairment represents a diagnostic category that is a category in itself situated between the normal performance and the dementia.

It has been up to now referred as a single or multi dominion of mnestic and non mnestic kind .As soon as the sum of the cognitive deficits arrive to a degree where normal life activities are not able to be fulfilled, this can often be considered "dementia".

The problem nowadays is that the up to now classification doesn't also consider many other cognitive syndromes that are belonging to bigger degrees of impairment, but cannot be considered as "dementia". Said other ways, nowadays there are no categories that include other cognitive syndromes of impairment of single or multi dominion kind that reduce the abilities needed for the daily life, but cannot be considered as dementia.

This paper explains the real problem and proposes an alternative solution where all existing impairments can be considered. In this way, there is no problem to arrive at a conclusion if that impairment can be classified as dementia or not. Our proposal bases on a reformulation of the diagnosis scheme, focusing on patient executive dysfunction.



478

CRITICAL REVIEW OF THE DSM V MANUALIN THE DIAGNOSIS OF COGNITIVE IMPAIRMENT.(Medico-legal implications of a midway taxonomy)- DIAGNOSTIC REFORMULATION PROPOSAL -

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

It is clear that there is a discrepancy between the international manuals regarding the condition that should be called “dementia”. Clearly the DSM V Manual no longer uses it. It is important to note that in any case this difference generates medical-legal problems when defining in a trial or litigation whether or not the person suffers from said condition since both manuals request different domains as mandatory to be able to define it. In the present work, the discrepancy with the DSM V manual is reviewed, criticized and substantiated, it is clarified because its taxonomy is halfway there and generates inconveniences and another form of taxonomic presentation is proposed that ends up harmonizing both manuals.

1) Dr. Roberto L. Ventura: Critical analysis of the disagreement between both manuals. The medical-legal implications and the proposal for a new taxonomic reformulation in DSM V.

Summary: The current discrepancy between international manuals about what should be called “dementia” is very clear. DSM V homologates all cognitive domains that can significantly interfere with daily living under the concept of Dementia referred to in DSM IV-TR. It has gone further, making the term “dementia” disappear.

If we extrapolate this discrepancy to a criminal court where it is intended to establish whether the patient suffers from a specific disability, a legal expert can rely on one or another manual drawing different

Conclusions: The discrepancy between these manuals is analyzed, the discussion is established and a new taxonomic form is proposed for the DSM V.

479

CRITICAL REVIEW OF HOW TO MAKE THE DIAGNOSIS OF DEMENTIA IN NON-HISPANICIZED INDIGENOUS POPULATIONS OF IBERO-AMERICA (The construction of a diagnosis based on different activities of daily life) -- PROPOSAL OF DIAGNOSTIC FORMULATION --

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

It is clear that a diagnostic manual can be used to systematize a state of cognitive-behavioral impairment in any part of our planet. But when we go on to consider the diagnostic tools to measure performance in daily living activities, we realize that they may not be useful or the most appropriate for the approach in native populations of Hispano-America that are not Hispanized and that live with very customs. different from those of the Hispanic world. We refer to populations that inhabit the deep jungle such as the Amazon jungle. Although we consider that the cognitive capacities to explore are the same in any human being (language, memory, executive capacities, etc.), the tools that should be used could be very different from those used in the Hispanic world. It is necessary to first make a survey of how many indigenous communities exist in Hispanic-America, which are capable of being studied and later to make a survey of their daily activities to understand how a cognitive-behavioral impairment manifests itself.

The present work exposes the different steps to follow to discover the steps to make a diagnosis of the demential condition in an aborigine who lives in the deep jungle of the Amazon.



480

Living with Dementia in Aotearoa (LiDiA): Carer experiences and roles in a multi-ethnic dementia prevalence feasibility study in Aotearoa New Zealand

Dr Susan Yates[1], Dr Adrian Martinez-Ruiz[1,2], Dr Gary Cheung[1], Dr Makarena Dudley[1], Dr Rita Krishnamurthi[3], Miss Fuafiva Fa'alau[1], Dr Claudia Rivera Rodriguez[1], Dr Ngaire Kerse[1], Dr Sarah Cullum[1]

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Introduction: Estimates suggest there are 70,000 people living with dementia in Aotearoa New Zealand (NZ), however to date there has been no dementia prevalence study in NZ. There is also limited information on carer experiences in NZ, although overseas research indicates high rates of carer burden and psychological distress.

Methods: As part of a dementia prevalence feasibility study, people aged≥65 from both Māori and Non-Māori (NZ European, Chinese, Indian, Fijian-Indian, Samoan, Tongan) were interviewed using the 10/66 dementia assessment tool. In addition, an informant or family member who knew the participant well were also interviewed.

Results: Seventy-eight interviews were conducted in the targeted ethnic groups. Analysis of the informant/family member interviews is currently being conducted, including information on care arrangements, service utilization, and caregiver strain. The results of this analysis will be discussed.

Conclusions: This research provides a starting point for understanding carer experiences across the major ethnic groups in NZ. It is hoped that future research will build on this knowledge base.

481

INTERDISCIPLINARY DIVORCES IN THECLINICAL APPROACH TO DEMENTIAL PATHOLOGY (ABOUT THE DISCUSSION OF WHICH MEDICAL SPECIALTY IS RIGHT FOR THEFOLLOW-UP OF PATIENTS WITH DEMENTIAL ILLNESS) - PROPOSAL FOR TEACHING REFORMULATION--

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

For a long time we have conceived the approach to mental health faced with the challenge of understanding the Cartesian dichotomy about the existence of one pathology that is organic and another that is non-organic or one is organic and another is functional. It is here that we remember Eric Kandel (Nobel Prize in Neurophysiology) when he expressed that all mental processes are the consequence of operations carried out at the brain level and that the mind is a set of functions carried out by the brain. We also remember a phrase by Karl Popper (Nobel Prize in Philosophy) when he stated that "absence of evidence is not evidence of absence". Clearly, a dementing disease such as Alzheimer's disease shows a clear affectation of a biological structure such as the human brain. Analyzing its complex symptoms is that we realize that there are symptoms and signs addressed by the psychiatrist, others addressed by the Neuropsychologist and others by the Neurologist. We also include the action of the Psychologist.

We believe that those responsible for these problems of the clinical approach are the teaching programs of the Faculties of Medicine that educate us in a divorced way from the beginning, training Neurologists, Psychiatrists and Neuropsychologists as different specialties when all are specialties that are supported by the study of the nervous system central and its operation. In this paper, this situation is analyzed and changes in teaching programs are proposed.



482

Addressing stigma through shared activities and events: A mixed methods participatory, ethnographic project for building an intersectoral community for persons living with Alzheimer's and their carers

Prof Melissa Park[1,2], Mr Christian Sénéchal[3], Ms Marilyn Lajeunesse[4], Ms Anna Aglietta[5], Mr Philip Silverberg[6], Mr Andrès Solis[7], Ms Marie Christine Le Bourdais[8]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

The aim of our multi-pronged participatory project, funded by a Public Health Agency of Canada Dementia Community Investment grant (2019-2023), is to cultivate social and cultural environments worth living in by expanding existing arts-related activities. In this presentation, we describe how we modified activities during the pandemic context: Art Links (Montreal Museum of Fine Arts), Au Contraire Community Screenings (Urban Pardes), and creative movement/dance (National Center for Dance Therapy) and report on a unique question of our project : Can engagement in shared expressive aesthetic forms change « us » by shifting the stories we tell about "dementia" and ourselves?

Methods: To conduct process evaluation of any transformative processes, we used longitudinal ethnographic

Methods: narrative interviews, participant observation with film and binaural recordings, and audit trails. Narrative and critical phenomenological analyses of data, including and other artifacts (e.g., word clouds generated during community film screenings) are ongoing and anchored in new conceptual work on stigma.

Emerging Results: Arts/culture interventions promote reciprocity between persons living with Alzheimer's, their carers, and intervention facilitators and provide a foundation for working relationships across different social sectors (community-based, arts/culture, academic, mental health, general public). Further, shared activities are helping open conversations across linguistic and other long-held markers of difference. Currently, we are analyzing longtudinal data to understand the impact (or not) of shared activities on changes in stigmatizing discourses.

Conclusion: Arts/culture activities and events can fill a critical gap between sectors that support community-based health at individual and societal levels.

484

Do community-dwelling Māori and Pacific Islanders diagnosed with dementia at a memory service have better outcomes than NZ Europeans?

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Aim: To investigate whether ethnicity predicts mortality and institutionalisation among people who received a new diagnosis of dementia at a NZ memory service.

Method: This cohort study used routinely collected clinical data gathered on assessments at the memory service at Middlemore Hospital in South Auckland between 2013 and 2019. Baseline sociodemographic and clinical data from 14/06/13 to 14/12/19 were linked with administrative mortality data and long-term care (LTC) admission data up to 24/1/2020. Survival analyses were carried out using multivariate Cox regression models to determine significant risk factors and their association with mortality and with LTC placement.

Results: 657 NZ European, Māori and Pacific patients were included.Adjusted analyses showed that risk of mortality was increased by older age and greater cognitive impairment, but reduced by cholinesterase inhibitors (HR 0.54, 95%CI:0.34-0.86). Compared to NZ Europeans, there was reduced risk of death in Māori (HR:0.40, 95%CI:0.14-1.17) and Pacific patients (HR:0.42, 95%CI: 0.22-0.80).

LTC placement was independently increased by older age (HR 1.02 per year, 95%CI:1.00-1.05), moderate dementia (HR 1.45, 95%CI:1.05-1.99), severe dementia (HR 2.25, 95%CI:1.33-3.81), and antipsychotics dispensed prior to placement (HR 1.55, 95%CI:1.04-2.32) but, even after adjustment, was reduced in Māori (HR 0.35, 95%CI:0.18-0.68) and Pacific patients (HR 0.32, 95%CI:0.20-0.51).

Conclusion: Despite having more severe dementia and higher comorbidity, Māori and Pacific Islanders had reduced risks of mortality and LTC placement. The possible reasons will be discussed. This highlights the need to better understand dementia in non-European cultures and to ensure culturally safe and responsive dementia services are accessible to all.



486

Utilization of Online Survey to Understand the Behavioural and Psychological Symptoms of Dementia (BPSD) among Family Member of Webinar Attendees.

Ms Noveline Sagita[1,2], Mrs Yustiani Dikot[3], Mrs Sari Wulan[4], Ms Febby Rosa Annisafitrie[5], Mrs Chandra Calista[6], Mrs Lusiana Darsono[7], Mr Alvin Wiharja[8]

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Background (Aims): The COVID-19 Pandemic force dementia support group to make a change. We must try to grasp the needs and problems faced by care person in daily live using online platform. This study intended to utilize an online survey from one session of Dementia Webinar conducted by Alzheimer's Indonesia (ALZI) Bandung Chapter, to have the profile of the behavioural and psychological symptoms of dementia (BPSD) among family of attendees.

Methods: All webinar attendees were asked to fill in an online survey consists of demographic data and the profile of BPSD experienced by their family member with dementia diagnosis.

Result: From 90 webinar participants, 79 attendees (87,77% participation rate) are willing to fill in the online survey. Most of the participants are women (n = 57, 59%). About 22 percent attendees are having family diagnosed with dementia, and act as the primary care person. Most common BPSD complaints are agitation (16%) and depression (16%), followed by sadness (14%) and sleep disorders (14%).

Conclusion: The online survey is a useful tool to evaluate the needs of the attendees, for example in choosing the next topic of webinar. Online survey can also become the basic to separate the webinars for dementia care person with specific needs and webinar for dementia public awareness raising.

487

Strategies to Expand Dementia Care in the COVID-19 Era.

Dr Tolulola O Taiwo
Red Deer Regional Hospital Centre, Red Deer, Canada

Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Clinical diagnosis of Alzheimer's Dementia and other neurocognitive disorders usually involves direct interactions.

Ensuring that patients and their care partners have access to timely assessments is imperative. The restrictions on direct evaluations following the global COVID-19 pandemic has placed some constraints on the ability to consistently conduct in-person assessments.

We also developed a framework (attached) which we have used for our assessments.

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 challenges are:

1. Inability to make new diagnosis

2. Inability to conduct Capacity assessments – need direct patient assessment.

3. Ensuring confidentiality – CPSA, AHS guidelines are used to ensure that patient confidentiality, autonomy and other ethical principles are recognized and maintained as much as possible.



488

Ultrastructural analysis of PDE4D and HCN1 in entorhinal cortex: Relevance for Alzheimer's Disease pathogenesis

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Tau pathology emerges in a distinct spatial and temporal pattern in Alzheimer's Disease (AD). Anatomical studies in AD patients show earliest signs of tau pathology in the stellate cell islands in entorhinal cortex (ERC) layer II. However, the molecular mechanisms that confer vulnerability to ERC layer II cells early in AD is unknown. cAMP-PKA magnification of calcium release has been seen in prefrontal cortex, associated with HCN channel opening to dynamically regulate synaptic strength. This process is regulated by phosphodiesterases (PDE), regulation that is lost with advancing age. The current study examined whether this "signature of flexibility" could also be seen in layer II ERC, underlying vulnerability to tau pathology with aging.We used high-spatial resolution immunoEM to localize PDE4D and HCN1 in primate ERC layer II. Our results suggest that PDE4D was concentrated on the smooth endoplasmic reticulum (SER)-spine apparatus and in postsynaptic density, and HCN1 expressed in the membrane near excitatory synapses in dendritic spines. Within dendritic shafts, PDE4D labeling was observed along microtubules and near mitochondria, whereas HCN1 was organized in discrete clusters along the plasma membrane.These data suggest that PDE4D is optimally positioned to modulate cAMP microdomains and control calcium extrusion from the SER. HCN1 channels are localized in subcompartments to facilitate dynamic physiological representation of sensory experience and visual space governed by cAMP-PKA signaling. The anatomical patterns in ERC layer II corroborate our findings in vulnerable glutamatergic circuits in prefrontal cortex, suggesting conserved molecular features in association cortices most susceptible in AD.



489

Social health and progression of MCI to dementia: The significance of having 'someone to confide in'

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Aims: Social health is hypothesized to prevent cognitive decline, with possible pathways including bridging (weak ties providing cognitive stimulation) and bonding (close relationships protecting against stress). We investigated the social health variables associated with progression from mild cognitive impairment (MCI) to dementia.

Method: We harmonised data from 12 population-based longitudinal studies of ageing (11 COSMIC consortium studies and ELSA). Participants were categorised into 2 groups: people with MCI who remained stable (n = 5706) and those who progressed to dementia (n = 659). Generalised linear mixed models compared the groups on both bridging (social network size, interactions, group activities) and bonding social health variables (relationship status, having 'someone to confide in', and loneliness).

Results: After controlling for age, sex, education, baseline global cognition, APOE e4 carrier status, and physical health factors, only one social health variable was associated with MCI progression. Compared to people with MCI who remained stable, those who progressed to dementia were less likely to have 'someone to confide in' (OR = 0.70 [95% CI: 0.50, 0.99], p = 0.044). Higher baseline global cognition was associated with being more likely to have 'someone to confide in' (OR = 1.19 [95% CI: 1.03, 1.35], p



= 0.02).

Conclusions: Harmonised longitudinal data demonstrated support for the bonding, but not bridging, pathway from social health to cognitive health, prompting further research into the mediating variables. Reverse causality could not be ruled out, suggesting that bidirectional pathways between cognitive and social health require further exploration.

490

Co-design element of WEAVE: Weaving Evidence into Action for Veterans with dementia

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Aim: Veterans with dementia have unique needs, resulting from the poorly understood connection between dementia and effects of trauma, with experiences often distressing and challenging for veterans, and for those caring for them. Best practice dementia care is critical to ensure that symptoms associated with dementia are manageable for the individual, their families and their formal carers, of which non-pharmacological interventions should be at the forefront. This paper describes the first phase (co-design) of an implementation/evaluation study that aims to embed four evidence-based, non-pharmacological interventions for veterans with dementia.

Methods: A co-design approach, based upon the Double Diamond model, was used to understand the needs and preferences of veterans with dementia, their families, staff, and volunteers within an Australian residential care home. Several co-design sessions (in person and online) were undertaken to explore barriers, enablers, and context of implementing four interventions: exercise; reminiscence therapy; sensory modulation; and music therapy.

Results: Co-design sessions revealed valuable ideas and insights related to: (1) reasons for participating in activities (or not); (2) methods of engaging veterans in activities; (3) structure and type of activities, including length of sessions and practical support required; (4) assisting with data collection for outcome measures related to behavioural and psychological symptoms of dementia, physical/cognitive capacity, and symptoms of depression; and (5) the specific needs of veterans (e.g. understanding triggers related to past trauma).

Conclusion: Co-design is a critical component of implementation studies, ensuring that interventions are fit-for-purpose, adapted for the unique needs and preferences of all stakeholders.



491

The effects of stepping exercise on stepping performance, muscle strength and balance of people living with mild to moderate dementia: a report on preliminary Results: Dr Wayne Chan

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Aims: To examine the effects of a 12-week step exercise program on the stepping performance, lower limb muscle strength and balance of people living with mild to moderate dementia.

Method: Community-dwelling individuals who are (1) 65 years or older; (2) able to walk independently indoor and outdoor without any walking aid or with walking stick; and (3) diagnosed with mild to moderate dementia were recruited. During each 30-minute exercise session, the participants were asked to take forward, sideway and backward steps on target panels while avoiding other distracting panels on the floor repeatedly followingthe instructions of an exercise instructor. Their stepping performance, muscle strength and balance were evaluated at week 0, 12, 24 and 36 weeks, and the program was conducted between week 24 and 36.

Results: Fifteen participants (mean age: 81.0 ± 7.1; mean MoCA: 13.5 ± 5.1) have been recruited so far. Up to mid-November 2021, these participants have finished 8 weeks of the program. Their attendance so far is 63%. No drop-out and adverse event has been reported. We expect that 60 participants will be recruited for this study, and we will be able to evaluate the effects of this program on the participants.

Conclusion: The step exercise program seems to be feasible and acceptable for people living with mild to moderate dementia. More data about the effects of this program on the stepping performance, lower limb muscle strength and balance will be available in mid-2022.

492

Inequalities in cognitive limitations and coexisting diabetes among Arab American immigrants and non-Hispanic whites living in the United States

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aims: Arab Americans are often absent in discourse on racial and ethnic health inequities in the United States because they are classified as non-Hispanic whites by the government. There remains a gap in the literature on inequalities in the prevalence of cognitive limitations, and other coexisting conditions, specifically diabetes. Our aims are to 1) estimate and compare the prevalence of cognitive limitations with and without diabetes among Arab American immigrants compared to US- and foreign-born non-Hispanic whites and 2) examine differences after controlling for demographics and potentially modifiable risk factors across the life course.

Method: Cross-sectional data using linked 2000-2017 National Health Interview Survey and 2001-2018 Medical Expenditure Panel Survey data (ages >=45 years, n=86,882) were analysed. Bivariate and multivariable logistic regressions were conducted.

Results: The prevalence of cognitive limitations was 7.3% among Arab American immigrants, which was higher than US-born (6.7%) but lower than foreign-born (8.1%) non-Hispanic whites. In our fully adjusted regression model, Arab American immigrants had higher odds (OR=1.24; 95% CI=0.67-2.27) of reporting a cognitive limitation than US-born non-Hispanic Whites. Among adults with cognitive limitations, the age- and sex-adjusted prevalence of diabetes was higher among Arab American immigrants (27.7%) than US- (25.1%) and foreign-born (24.3%) non-Hispanic whites, However, results were not statistically significant in crude and adjusted regression models.

Conclusions: To further examine cognitive health and coexisting conditions among the growing Arab American aging population, policy changes are needed to include an ethnic identifier for this group as part of minimum reporting standards.



493

Advanced care planning in dementia - discussion from an Islamic perspective

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Topic

Dementia diagnosis, treatment, care and support: Dementia and spirituality

Abstract

The number of people living with dementia is projected to increase to almost 132 million by 2050. Human dignity is an unconditional value for every human being. However, preservation of dignity in dementia may be challenged by progressive cognitive decline, especially in advanced stages. Person-centered care (PCC) aims to promote the personhood of those living with dementia through existentialist and humanistic considerations of their needs, values and beliefs. Advanced care planning (ACP) is an essential component of PCC. ACP enables the implementation of a person's individual values and preferences regarding possible therapeutic decisions for future health conditions. However, the challenge is often deciding on the optimal time to initiate these discussions.

Spirituality and religion appear to help people cope with their condition, promoting a better quality of life. A PhD study by Husaini (2018) on advanced cancer patients in Brunei found that patients who used spirituality to cope with their conditions were more likely to experience acceptance. This acceptance allowed them to plan for their end-of-life care with their healthcare providers and families.

To date, there are no studies published on the integration of Islamic religious practice in promoting PCC and ACP to people living with dementia and their families. We discuss the applicability of lessons from the local study on palliative care and the potential benefit of integrating religious practices in Islam in easing patients and families into initiating advanced care planning and maintaining their dignity in the journey during the advanced stages of dementia.

494

Melody Memory Project: Increasing Dementia Awareness through Traditional Gamelan Music

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Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Background: Gamelan, a traditional music ensemble has become the most popular traditional music played by Balinese people for decades, both as leisure and religious activities. Musical activity can enhance cognitive function. However, there are limited activities for retired musicians.

Aim: Alzheimer Indonesia Nederland Foundation (ALZI Ned) initiated the "Melody Memory Project" which aimed to increase the quality of life and dementia awareness of the retired Balinese elderly musician through gamelan practice.

Methods: This project started in July 2021 and was planned to last 6 months. A weekly gamelan practice was conducted at the Pinda village community center, Gianyar, Bali Indonesia.Each session is preceded with dementia awareness session (e.g. sharing the 10 early signs of Alzheimer's, brain gym) by ALZI Ned volunteers. There were health screenings once every two weeks (i.e. blood pressure/ blood sugar check, hearing problem). Cognitive assessment was conducted using Mini Mental State Examination (MMSE).

Results: Thirty participants (age 58-77 yo) were registered in this program. From July to October 2021, 6 practice sessions (each for 2 hrs), 2 performances and 3 health screening sessions were conducted in cooperation with the local government authorities. This activity has recently been approved as part of the Village program and further continuity will be supported by the government.

Conclusion: Gamelan practice has proven to be an interesting activity that increased dementia awareness among the elderly. This project has enabled community partnership between ALZI Ned, local government authorities and the elderly community in Pinda Village resulting in a sustainable program.



495

Learning to Change: Family Caregivers of People With Dementia: Positive Experience Approaches

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

In contrast to the general assumptions that people with dementia are a physical, psychological, and financial burden, recent studies have demonstrated that family caregivers can benefit and experience personal growth when caring for a family member with dementia. This study investigates the transformation of family caregivers when caring for a family member with dementia. This study first examined the negative experiences of family caregivers of people with dementia and then explored the triggers that helped change their experiences from negative to positive during caregiving. In-depth interviews were conducted with 18 participants. The participants were recruited from two local care associations and one medical centre in central and southern Taiwan. Each interview was audio-recorded and data were transcribed verbatim. A thematic analysis was performed to analyze the themes and subthemes related to the triggers. The findings revealed that optimistic characteristics, mutuality, spirituality, and coping abilities and skills are important triggers for developing a positive caregiving experience model. This study is intended to help family caregivers, who may often feel pessimistic, to have positive daily caregiving experiences. Moreover, the study provides government long-term care policymakers, scholars, and healthcare professionals and practitioners with a more comprehensive understanding of the caregiving challenges and needs of family caregivers.

Above abstract is retrieved from "Models of Transformative Learning Among Family Caregivers of People With Dementia: Positive Experience Approaches", Journal of Research in Education Sciences, 2018, 63(2), 187-218.

496

A Spatial Dashboard of Dementia in Australia

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Aims: Population aging is a driver for change across healthcare and related services with dementia and co-morbidities presenting a significant challenge for local service providers and communities. Policy and funding changes need to be informed by high quality information about the impact these changes have at the local level. One tailored strategy is the concept of a visuospatial approach, both data-informed and spatially analysed to identify dementia clusters across communities, drawn in this case from the Australian health and ageing contexts.

Method: Maptitude geographic information system (GIS) software package was utilised to apply estimates of dementia types to projected demographic data at the small area geographic level for Australia. These data were then transferred to a Power BI dashboard for user interaction and inquiry.

Results: The outcome of this approach is a spatial model of dementia for Australia at the small area level. The dashboard output involves an interactive data visualisation environment for engagement and application by service providers. Results include topographic analysis of dementia types, forward projections, mapping of dementia, and associated cost components, in relation to local healthcare services and communities.

Conclusion: This is an innovative spatial data approach for Australia, and other countries, facing the challenges of population ageing and increased dementia rates. There is potential for GIS and related data visualisation technologies in supporting individuals living with dementia and care partners. The granular identification of emerging dementia patterns across communities enables policy makers, funders, and service providers to target prevention, management, and treatment resources more effectively.



497

Developing a Patient and Public Voice program with global impact.

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Background: Patient & public voice (PPV) fosters meaningful and active partnership between the public and researchers. At Global Brain Health Institute (GBHI), which trains international fellows to be brain-health leaders, a new 24-month PPV program for dementia is being developed.

Design:

- *Recruiting*: Developing an international panel of people with lived experience of dementia to inform & guide GBHI's work.
- *Educating*: Designing and implementing dementia-specific PPV training program for Fellows & awareness-raising program for GBHI faculty & staff.
- *Creating & disseminating*: GBHI Fellows from 8 countries are developing Global PPV Toolkit, fostering a global PPV dementia network. Pilot sites in Peru, Egypt, & Brazil.

Results: *12-month outputs:*

- PPV Panel of 20 people with lived experiences formed ('Dementia Community Research Advisory Panel'; DC-RAP) to inform GBHI activities by: (1) educating fellows in PPV; (2) advising appropriate language use; (3) training lay summary writing for research proposals; (4) advising pilot research grants.
- 28 Fellows (57% female) from 22 countries & 6 disciplines attended training in PPV basics; 11 volunteered further training.
- Global Toolkit outline completed - key domains & principles agreed ensure cultural and language relevance.

Impact:

- PPV Panel developeddementia-specific language guide & lay summary guidelines, leading to awareness workshops.
- 43% of Fellows encountered PPV for the first time.

Training feedback survey: 75% response rate - 91% 'Satisfied' or 'Very satisfied'

Knowledge-Attitude-Practice survey of Toolkit group revealed significant impact on perceived importance of & improved capability to work with PPV.

Conclusion: Embedding dementia-relevant PPV in GBHI provides the potential to disseminate PPV

principles globally, fostering meaningful public engagement to advance dementia understanding worldwide.



498

Challenges and potential solutions for cultural adaptation, translation and validation of Alzheimer's Disease Assessment Scale – Cognitive sub-scale (ADAS-Cog) for use in a low- and middle-income country setting (India)

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Adaptation and validation of ADAS-Cog in India; report challenges with possible solutions.

Methods: We adapted, translated, and validated ADAS-Cog in Tamil and Kannada by:

1. Engaging stakeholders to discuss cultural and linguistic appropriateness of items, including persons with dementia and family members, dementia care professionals, experts with experience translating and adapting ADAS-Cog, and language experts.
2. Translating ADAS-Cog to Tamil and Kannada, and 'back-translating' to English.
3. Administering ADAS-Cog-Tamil and Kannada to five participants without dementia, each, exploring appropriateness and cultural relevance.

Administering: ADAS-Cog-Tamil to 53 participants with dementia and 54 healthy controls aged 60+; ADAS-Cog Kannada to 50 participants with dementia and 60 without.

Results: ADAS-Cog-Tamil: Internal consistency (α=0.91); concurrent validity [Vellore Screening Instrument for Dementia (VSID)-Patient version: r –0.84; VSID-Caregiver version: r –0.79]; Cut-off score 13: specificity 89%, sensitivity 90% for dementia diagnosis. ADAS-Cog-Kannada: Internal consistency (α=0.92); concurrent validity (with 10/66 dementia diagnosis kappa value 0.8). Cut-off score 13: specificity 90%, sensitivity 96% for dementia diagnosis.

Challenges	Solutions
Conserving complexities of test items while ensuring cultural and linguistical appropriateness	Consulting stakeholders
Identifying and engaging stakeholders	Establishing networks
Varying literacy levels influencing test results	Incorporating tests relatively unaffected by literacy levels
Identifying persons with mild to moderate dementia - those recruited in clinical settings are often diagnosed late in India	Building a service caseload of people with mild to moderate dementia, offering appropriate interventions

Conclusions: Following a rigorous, replicable linguistic and cultural adaptation process, managing the challenges by involving stakeholders, ADAS-Cog-Tamil and Kannada showed good psychometric properties.



499

To develop, conduct and evaluate a sustainable multi-modal 6-month online dementia training course for Bangladeshi Clinicians.

Prof Iracema Leroi[1], Ms Abhisweta Bhattacharjee[1], Dr Sanjib Saha[2], Dr Raisul Islam Khan[3], Dr Badrul Islam[4], Dr Shahriar Faruque[5], Dr Sridhar Vaitheswaran[6]

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Topic

Dementia awareness and friendliness: Community partnerships / Public-Private-People partnerships

Abstract

Background: Prevalence of people living with dementia in Bangladesh is 3.6% (population - 165 million), but healthcare professionals lack up-to-date knowledge regarding dementia identification, treatment and management.

Design: A 6-month online training course developed and delivered with 29 step-wise pre-recorded lectures, 4 live interactive case-based discussions, suggested reading, quizzes and an online chat forum. Lectures delivered by international experts from 9 countries. Delegates invited to develop a Quality Improvement (QI) proposal for dementia in Bangladesh context. Evaluation is based on New World Kirkpatrick Four-Level Training Evaluation Model.

Results: Twenty-seven healthcare professionals from Bangladesh participated in the course.

Level 1 (Reaction) evaluation - high satisfaction with course content, delivery and utility. 80% attended live interactive sessions and 90% participated in online group chat.

Level 2 (Learning) feedback - significant impact on Delegates' Knowledge-Attitudes-Practices of dementia post-course compared to baseline.

Level 3 (Behaviour) - most delegates prepared an individual or team QI proposal for dementia fostering further networking. Positive delegate feedback received on changing practice to include dementia care by implementing learning in clinical settings, and development of professional networks around dementia.

Level 4 (Results), referring to longer-term impact on Bangladeshi dementia care and services, will be evaluated over time. Further funding obtained for modified course in 2022.

https://neurologyacademy.org/events/course/dementia-masterclass-bangladesh

Conclusion: This course increased dementia Knowledge-Attitude-Practice among Bangladeshi clinicians, empowered them to network and spread best practice knowledge, and fill the gap in local dementia resources, thus contributing to improving the quality of life of people living with dementia in Bangladesh.

501

Post stroke cognitive impairments and associated factors among Ethiopian stroke survivors

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Recently sub-Saharan Africa faces a surge of non-communicable diseases including stroke and dementia, but data is scarce on the cognitive outcome of stroke survivors in the region. This study aims to describe the prevalence, severity, and predictors of post stroke cognitive impairment (PSCI) among Ethiopian stroke survivors.

Method: A prospective, cross-sectional study was conducted among adult stroke survivors who visited the outpatient stroke clinic of Tikur Anbessa Specialized Teaching Hospital in Addis Ababa University, Addis Ababa, Ethiopia. Study period was from March 01 to July 30, 2021. Adults (> 18 years) patients who survived for at least 3 months after the stroke ictus and gave consent were enrolled consecutively. Demographic and clinical data were obtained, and cognitive function was assessed the using Montreal Cognitive Assessment-Basic (MOCA-B). Post stroke functional recovery and depression were measured using modified Rankin Scale (mRS) and Patient Health Questionnaire (PHQ-9).

Results: Among the 67 stroke survivors (mean age: 52.1 ± 12.7 years, 37.3% stoke onset < 45-year, 40.3 % female, 25.3% illiterate, rural dwellers 32.8%), 46 (68.7%) had cognitive impairment in at least one domain and 17 (25.3%) had dementia. On multivariate regression analysis, older age [OR= 0.22 (0.06-0.74)], right hemisphere stroke [OR = 0.21 (0.06-0.77)] and poor function recovery of mRS >3 [OR= 1.4 (1.06-1.74)] were independently associated with post stroke cognitive impairment and dementia.

Conclusion: This study suggests a high prevalence of PSCI among Ethiopian stroke survivors. In addition to physical therapy, cognitive rehabilitation measures will likely improve the neuropsychology outcomes of stroke survivors.



502

Care home attributes supporting relational, person-centred care for residents living with dementia

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Topic

Dementia diagnosis, treatment, care and support: Models of care

Abstract

Aim: Identify factors that support relational, person-centred care for people living with dementia in aged care homes.

Methods: This mixed-method study comprised: interviews and assessments regarding the person-centredness of the care home environment and care delivery; structured observations of interactions between residents with dementia and others; and social network methods regarding collaboration in the care home. Descriptive quantitative and social network data were collected; qualitative data were analysed thematically.

Results: The study occurred in five Sydney aged care homes, with 14 people living with dementia and 139 of their formal and informal care partners. Four core factors emerged as associated with delivering relational, person-centred care: staffing and management attributes; the care home's physical environment, and prioritising the discovery, and development of a resident's story.

Staffing attributes were prominent, including: staff rosters and roles being informed by holistic (biopsychosocial) resident needs; a higher than recommended staff to resident ratio; a broad staff mix, incorporating a good proportion of lifestyle-oriented staff; and an initial grounding in and ongoing person-centred care training focused on quality of relating for personal care workers.

The manager's longevity and empowerment from their parent organisation, were associated with their ability to innovate, empower their staff and promote ongoing affirming interactions among all care partners, including residents. Social network analysis demonstrated that relational, person-centred care was associated with greater collaboration among care partners.

Conclusion: Aged care home manager and staff attributes play a prominent role in provision of relational, person-centred care for residents living with dementia.

503

TasTest: Developing an online screening test for pre-clinical Alzheimer's disease

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Aims: There is urgent needfor population-level biomarkers that candetectpre-clinicalAlzheimer's disease. Motor function declines in the pre-clinical phase but there has been little exploration of digital motor biomarkers. We have developed 'TasTest', an online test ofcognitionandmovement. Here weassessTasTest'suseabilityandcomparehowTasTestitems are associated withtheCambridge Neuropsychological Test Battery(CANTAB)andage.

Methods: TasTest items include measures of motor control (keyboard tapping), processing speed, attention and visual perception, and visuospatial memory. A community sample of 2466 adults aged over 50 years (30% male; mean 65 years), performed both TasTest and CANTAB online. We compared performance on TasTest items to performance on the Paired Associates Learning (PAL) CANTAB task, which has been validated as predictive of accelerated cognitive decline (Barnett et al. 2015, Current Topics inBehavioralNeurosciences, vol 28, Springer, Cham).

Results: 90%ratedTasTestas easy to use and >95% stated they would prefer to do the test at home. Most TasTest items were significantly associated withPALand somehad stronger correlations with age than PAL,including keyboard tapping tasks,visual perception and simple and choice reaction times.

Conclusions: Older people were able to complete TasTest tasks from their homes, and performance on most items was significantly associated withage and PAL. TasTest shows potential as a non-invasive, scalable dementia screening tool.

LINKED IMAGE MISSING



504

Profiles of social, cultural, and economic resources and quality of life among people living with dementia

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Everyone has different sets of resources: social (e.g. friends), cultural (e.g. educational attainment) and financial (e.g. a pension). We wanted to find out which of these types of resources people living with dementia in Britain have, whether these change over time, and whether people with more resources have a better quality of life.

Between 2014 and 2016, 1537 people with mild-to-moderate dementiatold us about the resources they had and rated their quality of life. They answered the same questions again 12-months and 24-months later.

Overall, people living with dementia had similar social, cultural, and economic resources to other people of their age in Britain, and these were largely stable over the two years of the study. However, older people in Britain typically have relatively low levels of resources.

We found that the people with dementia could be divided into four groups, each with similar levels of resources.The first group had high social and economic resources and low cultural resources (18% of participants). The second group had very high economic resources and low social and cultural resources (21% of participants). The third group had low social, cultural, and economic resources (37% of participants). The fourth group had very low social, cultural, and economic resources (24% of participants).

The two groups with lower resources reported poorer quality of life over time.

These findings highlight the need for policies that promote social, cultural, and economic resources among people with dementia, such as making social and cultural activities more affordable and accessible.

506

Unusual reaction to Covid-19 by caregivers of persons living with dementia attending a memory clinic in Southwest Nigeria

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Objective: The lockdown that accompanied Covid-19 infection was a monumental event. This study examined the effect of the restriction and lockdown on the mental health of the caregivers of persons diagnosed with dementia attending a memory clinic in Nigeria as well as its effect on the quality of care they provided.

Method: We selected 46 dyads of persons diagnosed with dementia and their caregivers. These caregivers were administered a semi-structured questionnaire that collected demographic information and asked questions on effect of Covid-19 on caregiving. PHQ-9 and GAD-7 were administered and participants were interviewed by telephone.

Result: Caregivers expressed little worry about Covid-19; more importantly, 97.8% and 95.7% had neither depressive nor anxiety symptoms. About 70% of the caregivers were not afraid of getting infected should there be need for hospital consultations for the person living with dementia and 30% of the caregivers opined that the lockdown afforded them more time to provide care.

Conclusion: The lockdown during the pandemic produced little distress to caregivers. Reasons for this are unclear, but it is reasonable to speculate that ignorance of the consequence of infection, more children as caregivers rather than spousal caregivers, low infectivity and mortality from Covid-19 as well as filial obligation contributed to the outcome of this study. Moreover, this unusual response might be due to the myths and misconceptions about the pandemic because many in our country believed that it was not a disease for Africans, and an unproven claim about natural immunity due to the temperate climate.



507

Healthcare utilization and costs associated with multiple long-term conditions in people living with dementia, 2010-2019: A population-based cohort study

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aims: People living with dementia often have multiple long-term conditions (or multimorbidity), which may complicate the management and care of dementia. This study aimed to quantify healthcare utilization and costs associated with the number of long-term conditions and specific conditions that are common in people with dementia.

Method: This is a retrospective cohort study using population-based electronic health records retrieved fromthe Hong Kong Clinical Data Analysis and Reporting System. All individuals aged 35+ with a dementia diagnosis between 2010 and 2019 were included. Outcomes were measured by rates of all-cause healthcare utilization, consisting of hospitalizations, Accident & Emergency (A&E) department visits, and outpatient visits, and their associated costs.

Results: We identified 88,151 individuals (mean [SD] age, 82.9[8.6] years; 59.3% were women) with a median follow-up time of 2.5 years (interquartile range: 1.0-4.7 years). Individuals who had diseases in at least 2 and 8 chronic condition categories in addition to dementia accounted for 81.8% and 18.0% of the total sample, respectively. Healthcare utilization and costs increased monotonically as the number of co-occurring long-term conditions increased. In individuals with eight or more conditions, adjusted rate ratios of hospitalization, A&E visit, outpatient visit, and healthcare cost rates were 2.05 (95% CI, 1.98-2.12), 1.67 (1.58-1.75), 1.62 (1.45-1.80), and 1.99 (1.89-2.09), respectively, compared to those without comorbid long-term condition.

Conclusions: Healthcare utilization and costs differed substantially by the number of long-term conditions. These findings highlight the need for developing atailored approach to care for this clinically complex population.

508

COGNISANCE: Co-designing hope. Involving people living with dementia, carers and health professionals in developing a post-diagnostic support website and campaign brand

Prof Lee-Fay Low[1], Dr Meredith Gresham[2], Dr Lyn Phillipson[3], Prof Yun-Hee Jeon[1], Prof Joanna Rymaszewska[4], Dr Carrie McAiney[5], Dr Isabelle Vedel[6], Prof Shelly Doucet[7], Dr Alison Luke[7], Prof Greta Rait[8], Prof Louise Robinson[9], Dr Jane Wilcock[8], Prof Frans Verhey[10], Miss Maud Hevink[10], Prof Henry Brodaty[2]

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

COGNISANCE is a five-country research project aiming to improve communication of dementia diagnoses and post-diagnostic support.

Four online workshops were held in each country (20 workshops in total) to co-design a website and campaign brand and messages involving people with dementia, carers and health and social care professionals. Probes around motivations, abilities, objections and triggers for information-seeking, draft brands and website mock-ups were presented for input. Content analyses was undertaken of workshop notes collected on structured feedback templates.

Across the five countries there was general agreement that the website needed to be a) in everyday language; b) provide practical, localised information to help people and their carers live well with dementia; c) be trustworthy, accurate, up-to-date, and comprehensive; d) include stories and perspectives of people with dementia and carers; e) account for the different circumstances and preferences for information of individuals with dementia and carers; and f) be easy to navigate in terms of fonts, layout and icons.

Language was perceived as critical. The brand needed to a) instil hope and be positive but realistic; b) counteract stigma by including the diverse voices and images of people with dementia; and c) help people feel less alone and supported. There were differences between countries and stakeholder groups in the priorities of these requirements, in brand preferences, and in the project name that had to be compatible with four languages. Our final product is www.forwardwithdementia.org which is currently being promoted and evaluated.



509

Dementia Research in Indonesian Older Adults: Challenges amidst COVID-19 Pandemic

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Introduction: Indonesia is one of the countries experiencing the highest mortality and morbidity rates of COVID-19, with the highest number of deaths being in older people. Almost two years into the pandemic, new challenges not previously found in the pre-pandemic era have emerged in health research. Adjustments in research activities have to be made to allow scientific progress to continue.

Methods: Population-based research to establish prevalence and cost of care is done in 2 provinces: Jakarta and North Sumatera, with researcher teams in each site. We analysed meeting notes from both sites to evaluate challenges in the research process.

Results: Considering the government's large-scale social restrictions during the pandemic, fieldworkers are recruited locally. Fieldworker trainings were done online and offline. Specific precautions in response to pandemic were strict health protocols, regular weekly antigen swabs of the fieldworkers, and mask distribution to respondents. Prior to data collection, engagement with local leaders is essential to secure respondents' trust.

Challenges on the researcher side are the high turnover of fieldworkers and difficulties in operating the data collection platform. There were instances of respondent withdrawal, though a rationale was often not given.

Conclusion: Comprehensive preparation and coordination with relevant parties are required in research during a pandemic. Regular observations, evaluations and re-training during data collection need to be carried out on an ongoing basis to ensure common understanding and uniform implementation of data collection protocol to obtain accurate and credible data.



510

Markers of cognitive reserve and early life events among older people in Central Africa – association with dementia (EPIDEMCA & EPIDEMCA-FU studies).

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Topic

Dementia risk reduction: Risk factors

Abstract

Introduction: Markers of cognitive reserve and early life events are potential modifiable factors that may contribute to reducing the occurrence of dementia. Despite a predicted increase in the number of older people living in sub-Saharan Africa, evidence on the relationship between these markers and dementia is lacking. Our study aimed at investigating the association between markers of cognitive reserve, early life events and dementia among older people in Central Africa.

Method: Data from the EPIDEMCA programme, a multicentre population-based study carried out between 2011-2015 among people aged ≥65 years and living in the Central African Republic and in the Republic of Congo, were analyzed. Participants with dementia were diagnosed following DSM-IV-TR criteria and 12 markers of cognitive reserve and 9 early life events were investigated. Cross-sectional and longitudinal analyses were conducted using multivariable logistic regression models.

Results: A total of 2002 (median age 72 [Interquartile range:68-78] years; 61.8% female) participants, including 135 living with dementia (7.6%, 95%CI=6.5%-8.8%), were included in our cross-sectional analyses. Having friends (adjusted Odds Ratio=0.46, 95%CI=0.25-0.82) and occupational status (aOR=0.28, 95%CI=0.13-0.56) were associated with low probability to present dementia. Longitudinal analyses confirmed that having friends (aOR=0.39, 95%CI=0.19-0.85) and a high number of markers of cognitive reserve markers (aOR=0.79, 95%CI=0.64-0.99) were associated with a reduced probability of developing dementia.

Conclusions: Certain markers of cognitive reserve are associated with a low probability of having or developing dementia in older in Central Africa, highlighting the importance of social support for older people and of stimulating activities to improve their well-being.



511

Dementia Prevalence in Jakarta and North Sumatra, Indonesia: data from the STRiDE project

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Topic

Dementia research and innovation: Epidemiology

Abstract

Background: Indonesia currently does not have national dementia prevalence data. Previous research taking place in Yogyakarta and Bali provinces showed a high prevalence of probable dementia. As part of the Strengthening Responses to Dementia in Developing Countries (STRiDE) prgramme, we are conducting household survey to establish dementia prevalence, impact and cost of care in two provinces in Indonesia.

Methods: We are conducting household surveys in Jakarta and North Sumatra provinces (n≈2,200 households). Households with an older person (aged 65+) were selected at random. The older person and an informant (i.e., an adult family member, neighbour, or friend) were asked to participate in the survey.

All participants are asked to complete a comprehensive set of questionnaires on cognition and functional status alongside a broader set of comprehensive outcome measures. Older adults with probable dementia are identified using the 10/66 short schedule.

Results: We will present findings about the prevalence of dementia in Indonesia from this novel dataset. Prevalence rates will be reported for each province, split by age and sex. We will explore other potential risk factors of dementia in the region.

Conclusion: This prevalence study is important to provide empirical on the magnitude of the problem of dementia to help formulate national policies in Indonesia.

512

A Lifeline for Elderly Care In Qatar- Teleconsultation during COVID -19 pandemic

Dr Pravija Talapan Manikoth, Dr Hanadi Khamis Al Hamad, Dr Mani Chandran, Dr Irshad Badarudeen, Dr Maryam Yousef Alobaidli, Dr Mahmoud Ahmed Refaee, Ms Vimala Yesurethnam, Ms Marwa Awad El Orrabi, Dr Nuseiba Mahgoub

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Background: World Health Organisation declared the COVID -19 pandemic in March 2020[1], and the elderly population was deemed high risk for severe illness. A reorganization of health care services took place globally to reduce the rates of transmission. In Qatar, the Department of Geriatrics and Long-Term Care launched the first teleconsultation "Vsee" Clinic in Hamad Medical Corporation, to ensure that the older adults continue to receive health care input during this pandemic without the risk of exposure.

Aim:

- Analyze the impact of use of teleconsultation services on the new cases waiting time in the Geriatric Outpatient Clinics during the COVID-19 era
- Compare with the data during pre-COVID-19 era

Methods/Case presentation: Retrospective analysis of the electronic health records to obtain the number of new cases seen during the COVID-19 era from April 2020 to October 2020 and identify the waiting time during this period and compare this with the pre-COVID-19 era from April 2019 -October 2019.

Results: The number of patients seen in the pre-COVID 19 era was 516 and during the COVID-19 era using teleconsultation was 762. The average waiting time period for clinic appointments between April 2019 and October 2019 was 23.6 days and between April 2020 to October 2020 was 12.37 days which shows a marked reduction

Conclusion: This data highlights that teleconsultation is a way forward to continue to provide health care input to patients were clinically appropriate during this COVID-19 pandemic, whilst keeping them safe in the comfort of their homes.



513

Translation and adaptation of the WHO iSupport Manual in Bahasa

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Background: WHO iSupport is a self-administered training manual for care partners of persons with dementia, which is adaptable to local culture. Translation and adaptation of this manual is needed to produce a culturally appropriate version for use in Indonesia. This study aims to identify the challenges in adapting and translating iSupport/module content into Bahasa.

Method: Online Focus Group Discussion (FGDs) were conducted with 3 participant groups separately: 1) members of organisations working on dementia, 2) care partners (n=8), 3) care professionals (n=10) to obtain input for the adaptation process. The FGDs have followed the WHO iSupport Adaptation and Implementation Guidelines accordingly. Materials to be discussed were sent a month before the FGD meetings in electronic format. Inputs from the FGD results informed the translation and adaptation process of this manual.

Results: Several challenges identified in conducting the FGDs are: care partners are not comfortable in reading online materials, online interaction between participants and facilitators requires more effort to dig up information and liven up the atmosphere. Several suggestions identified are the needs to: 1) find terms familiar to general public, 2) provide examples applicable at each stage of disease change, 3) provide more comprehensive material on bio-psycho-socio-cultural and spiritual aspects

Conclusion: Participants lacked of accessing online materials and platforms, internet network and infrastructure, are challenges in implementing the online translation and adaptation process FGDs. Input related to content and language in the FGDs were very beneficial in translating and adapting the WHO iSupport guidebook according to local culture.

514

Creation and Utilization of "Dementia Care Path"- Importance of Gathering and Providing Information of Social Resources to Persons Living with Dementia

Ms Yumi SHINDO, Dr Kentaro HORIBE, Dr Akinori TAKEDA, Dr Yukihiko WASHIMI

National Center for Geriatrics and Gerontology, Obu city, Japan

Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Being diagnosed with dementia is a tough experience. Therefore, it is important for the person living with dementia to have useful information such as how to meet others who experience similar situations and what kinds of activities/services are available in the community in order to consider their future life.

In Japan, when the Five-Year Plan for the Promotion of Dementia Policies (Orange Plan) was announced in 2014, the creation of a "dementia care path" was positioned as its first pillar.

The term "Dementia Care Path" has two meanings: one is "Community Dementia Care Path," which is outlines of what kinds of social resources, such as not only medical/care services, but also housing, dementia café, dementia-friendly shops and even volunteers, are available in order to support persons living with dementia in the community.

The other one is "Individual Dementia Care Path," which is created by individual's wishes. Based on the Community Dementia Care Path, each person is able to choose which service he/she is going to use and/or ask.

Before creating Dementia Care Path, even professionals in medical and nursing care fields were not fully aware of the social resources in the community because they are changing year by year. But the Dementia Care Path has made it possible for families, residents, and professionals to know social resources and consider how to support people living with dementia with other resources.

In my presentation, the possibilities and limitations of Dementia Care Path will be presented by using data.



515

A new architecture award to encourage and recognise architectural exemplars of enabling and universal design. The Western Australia Institute of Architect's Enabling Architecture Committee has created a new annual architecture award The Brian Kidd Enabling Architecture Prize.

Mr Todd Paterson[1], Ms Toni Neck[1], Ms Ash Osborne[2,1], Ms Sarah Corderoy[1], Ms Thea McClelland[1], Mr Mike Collett[1]

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Topic

Dementia awareness and friendliness: Dementia and design

Abstract

Recognition of the environment as having a direct impact on the experience of disability is an important conceptual and practical step on the road to improving participation and the quality of life of people with disabilities, including those living with dementia. Australia has a well established regulatory and legislative framework to encourage the design and construction of a built environment that is supportive of Australians living with a disability, these are minimum standards, and compliance does not guarantee excellence.

The Western Australia Institute of Architect's Enabling Architecture Committee has created a new annual architecture award to encourage and recognise WA architecture that exceeds these minimum requirements and creates exemplars of enabling and universal design.

The purpose of the award is to encourage and recognise excellence in universal Architecture for projects and to encourage Architects to push the boundaries of accessibility beyond the requirements of the Australian Standards. It recognises built environments that will enable West Australians living with disability to participate equally in social and economic life through thoughtful and informed architectural design.

The award has been named in honour of Brian Kidd,(1936 – 2017) a highly respected architect, teacher and access consultant, who is remembered as a guiding spirit for the architectural community through his tireless campaign for accessible environments for all, and homelike environments for people living with dementia in residential aged care.

This presentation will provide brief dementia-focussed case-studies of the inaugural 2022 award entries including feedback from users on how their lives have been impacted.

516

The Impact of Online Caregivers Meeting Services in Indonesia through ALZI Talk Show and Caregivers Counseling Sessions

Mr Michael Dirk Roelof Maitimoe
Alzheimer's Indonesia, Jakarta, Indonesia

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: In 2021, ALZI has been improving the main services on Online Caregivers Meeting with ALZI Talk Show and Caregivers Counseling that are held alternately every month. The difference that ALZI Talk show can open for general public and Caregivers Counseling are specifically for the family caregivers who are providing care of People with Dementia.

Objective: ALZI Talk Show and Caregivers Counseling aim to deliver social and enrichment activities during the pandemic to provide better understanding on dementia, increased opportunity for sharing and peer support, reduce the burden for caregivers and to improve the quality of life for caregivers and People with Dementia.

Methods: Post-session surveys were given to participants with the link survey that the tools will track percentage of participants demonstrating reduced burden, percentage of participants demonstrating better understanding of dementia and comments from caregivers about how they feel after the support.

Results: In total there are 385 participants who filled in the survey, 44.68% are family caregivers, 28.05% are professionals, 25.71% are public and 1.56% are People with Dementia. 51.69% feel opportunity for peer sharing and support, 46.23% stated it helps them to feel less stressed, 31.17% admitted they made new connection with other caregivers and 21.3% claimed better understanding of dementia.

Conclusions: The Online Caregivers Meeting played big impact on all participants. Most of them feel the opportunity for peer sharing and support as an important needed during the pandemic. A hybrid session is being considered in the future to bring greater experience for the participants.



517

Virtual Cognitive Stimulation Therapy (CST): A new normal? The impact of the COVID-19 pandemic on implementation in UK memory clinics.

Ms Emily Fisher[1], Ms Danielle Proctor[1], Dr Cerne Felstead[1], Ms Ellen Holden[1], Dr Luke Perkins[1], Dr Joshua Stott[1], Dr Charlotte R Stoner[2], Prof Aimee Spector[1]

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Background and aims: Cognitive Stimulation Therapy (CST) is a post-diagnostic intervention for people with mild to moderate dementia. Before the pandemic, our service audit found that in-person CST was offered by 87.7% of National Health Service (NHS) memory clinics. We aim to summarise the impact of COVID-19 on CST provision in the NHS and how this may shape future care.

Methods: We shared a survey with NHS memory clinic mailing lists to explore provision of virtual CST during the pandemic and investigate the perceived benefits and challenges of virtual delivery.

Results: Thirty-three memory clinics responded to the survey. During the pandemic, 55% of respondents delivered CST virtually, whereas 45% stopped provision and did not offer face-to-face or virtual CST. Staff reported that virtual CST helped them to overcome longstanding barriers to face-to-face delivery, including lack of transport and reduced mobility. Virtual groups also led to a perceived improvement in participants' digital confidence. Barriers to participation included digital exclusion and low digital literacy, sensory impairment, and staff time commitment. Of those offering virtual CST, 80% plan to continue with a hybrid face-to-face and virtual delivery model, whilst 20% intend to revert to face-to-face CST only.

Conclusion: CST is offered by the majority of UK memory clinics, with many now offering CST virtually. Virtual sessions should not completely replace in-person groups due to the risk of exclusion. A hybrid approach, however, can increase access to those with reduced mobility, without access to transport, and those living in rural communities.

518

The Impact of Dementia Care Skills Training in Indonesia with 6-hours Online Based Programme

Mr Michael Dirk Roelof Maitimoe
Alzheimer's Indonesia, Jakarta, Indonesia

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: An understanding of the journey of caring for people with dementia is a major need for caregivers.Alzheimer's Indonesia (ALZI) has provided 6-hours dementia care skills training since 2017. Despite the high demand for trainings from caregivers, the COVID-19 pandemic has posed limitations to the delivery of offline trainings. Therefore,ALZI has taken the initiativein transforming thetrainingprogram into an online format.

Objective: The online training was conducted to continue providing services and support for the caregivers during the pandemic.

Methods: A post evaluation survey was conducted in evaluating the online version of the training. Three training sessions have been held in October 2020, June 2021 and November 2021 with 63 participants in total. An online survey was used in evaluating the overall satisfaction of the training, topic delivery, and identifying three new things participants learnt.

Results: There are 89% women and 11% men of participants. The average total score for all the training is 4,5 of 5. The top three new things the participants have learnt are BPSD, communication and creating meaningful activity for people with dementia.

Conclusions: The online version of 6-hour dementia care skills training for caregiver has been able to meet participants expectation.BPSD and communication are the new topics for the caregivershavelearntwhich isone ofthe most challenging in the journey of caring for People with Dementia. Further evaluation of other training modules in ALZI is essential tocreate a range of effective support forthe caregivers.



519

Apathy in UK care home residents with dementia: longitudinal course and determinants

Dr Andrew Sommerlad[1,2], Dr Hee Kyung Park[1,3], Dr Louise Marston[1], Prof Gill Livingston[1,2]

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Aims: Apathy in dementia is a common and troubling symptom associated with worse disease outcomes. We aimed to describe the longitudinal course of apathy in dementia, and identify associated sociodemographic and disease related factors.

Methods: Prospective cohort study of UK care home residents with dementia. At baseline, and 4, 8, 12, and 16 months, care home staff rated apathy using the Neuropsychiatric Inventory (clinically-significant apathy if score ≥4), dementia severity using the Clinical Dementia Rating scale, and provided other sociodemographic information about each participating resident. We examined the prevalence and persistence of apathy and, in mixed linear models, its association with time, age, sex, dementia severity, antipsychotic use, and baseline apathy and other neuropsychiatric symptoms.

Results: Of 1419 included participants (mean age 85 years (SD 8.5)), 30% had mild dementia, 33% moderate, and 37% severe. The point prevalence of clinically-significant apathy was 21.4% (n=304) and the period prevalence during 16 months follow-up was 47.3% (n=671). Of participants who had follow-up data, 45 (3.8%) were always clinically-significantly apathetic, 3 (0.3%) were always sub-clinically apathetic, and 420 (36.2%) were never apathetic until death or end of follow-up. In adjusted models, apathy increased over time and was associated with having more severe dementia, worse baseline apathy and other neuropsychiatric symptoms.

Conclusions: Most people with dementia are not apathetic but it is common, and fluctuates in its course. It is important for clinicians to know that most people with dementia do not develop apathy and it is not an inevitable symptom and often remits.

520

If "a picture paints a thousand words," what can a movie say to us? Exploring dementia through contemporary cinema.

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Have you ever watched a movie that evoked strong emotions or inspiring memories or thoughts? If you have, your heartfelt responses are prompting unconsciously forgotten memories andunlocking pathways to your unconscious brain. Sparking an awareness of deeply buried feelings in your mind. When intentionally watching a movie, Cinematherapy can help you explore these reactions to the themes within the film gaining an expanded self-awareness and understanding behind your triggered reactions.

Many books have been written that directly and indirectly deal with the topic of people living with dementia. Psychotherapists have long used a book method of helping people confront and understand their life journey after reading a book and reflecting on its message, called Bibliotherapy. Now, the use of films is considered a better alternative because people are more likely to watch a film than read a book. And, while viewing a movie by itself does not appear to produce change, viewing a movie and then participating in a therapeutic discussion afterwards does appear to help to produce positive change in people. Using a reflective process to stimulate thoughts, emotions, and actions to enhance learning and facilitate positive transformational change. As Dewey (1933) said, "we do not learn from experience, we learn from reflecting on our experience.

Research shows that film, music, or books can "talk" directly to our unconscious self. This session introduces the concept and process for facilitating Cinematherapy with a focus on films depicting dementia. With a practical exercise from one of seven dementia focused films.



521

The Impact of ALZI Care Navigator (NARAZI) Services in Indonesia in The Pandemic COVID-19 Era

Mr Michael Dirk Roelof Maitimoe
Alzheimer's Indonesia, Jakarta, Indonesia

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Background: In the pandemic Covid-19 Era, there were limited services to get consultation due to hospital services full of Covid-19 patients. ALZI has taken the initiative of services called NARAZI (ALZI Care Navigator) since April 2020 to help the family caregivers in the journey of caring People with Dementia supported by a doctor, psychologist, or therapist accompanied by an experienced ALZI's care navigator.

Objective: To continue providing services and navigating the family caregivers in the journey of caring for People with Dementia through online services.

Methods: Post-session surveys were given to participants with the link survey that will track percentage of participants demonstrating better understanding of dementia after the support, comments from caregivers about how they feel after the support, reflections from clients how the support helped them increase their empathy/patience.

Results: More than 112 online sessions have been held with 36 participants who filled the survey. 100% of clients reporting increased understanding and help them how to take care People with Dementia, 97.2% claimed the support helped them to increase their empathy. 76.2% admitted they are very satisfied with the services of ALZI's Care Navigator, 19% satisfied and others are quite satisfied.

Conclusions: Most of the clients understand and help them to provide care of People with Dementia. We do need some data to evaluate what is working and what is not for NARAZI in the future. The next step, ALZI has a plan to launch a website application to facilitate users with more convenient services.

522

Women's experiences of sport reminiscence: The gendered context, the female paradox, the tea makers, and the motor racing champion.

Dr Rebecca Oatley
University of Worcester, Worcester, United Kingdom

Topic

Dementia research and innovation: Sex and gender - impact, research, policy

Abstract

Sport reminiscence is a reportedly popular activity for men living with dementia that tackles loneliness, supports wellbeing and upholds masculinity. However, sport reminiscence has remained rooted in a traditional masculine hegemony dominant in sport. Such a context neglects to consider the diversity of people living with dementia. Women's voices, thus far, have been notable by their absence.

This ethnographic-style research is the first to explore women's experiences of sport reminiscence activities for people living with dementia. Ethnographic observations of four sport reminiscence groups, alongside in-depth interviews with different women living with dementia, demonstrated that sport reminiscence could be a meaningful activity for some women. A critical constructionist analysis revealed that the context of the sport reminiscence group promoted rigid binary gendered norms that impacted how women saw, engaged, and were interpreted to benefit from the activity. However, women had vibrant and varied connections to sport that both reflected typical gendered stereotypes, and challenged stereotypes of femininity and female sporting history, demonstrating the context to be one apt for renegotiating identity.

This research draws attention to the impact of gender and adds to a growing call for more feminist research into the impact of gender on the lived experience. Findings draw attention to the underpinning assumptions upon which sport reminiscence (and other community group activities) for people living with dementia might be based and, in turn, demonstrate ways in which a limited construction of gender can be unhelpful to both men and women affected by dementia.



523

"DELIRIUM - CLINICAL ORPHAN - TIME TO OWN IT" -A National Education Drive in Qatar

Dr Hanadi Khamis Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, Dr Irshad Badarudeen, Dr Haroon Ahmed Saleh, Dr Mahmoud Ahmed Refaee, Dr Wasim Akram, Dr Sameer Acharath Valappil

Hamad Medical Corporation, Doha, Qatar

Topic

Dementia risk reduction: Public health campaigning

Abstract

Introduction: Delirium is a life-threatening medical emergency. Delirium is commonly seen in the acute hospital setting, occurring in 18%–35% of patients on general medical wards and upto 80% in Intensive care settings. Delirium often is misdiagnosed as depression/dementia.Delirium, recently also known as Dementia factory, studies show delirium as a major risk factor for Dementia. Lack of clinical ownership amongst disciplines taking care of patients with delirium remains an ongoing concern. The awareness and detection of delirium have been shown to improve significantly with targeted education of healthcare professionals and focused care pathways.

Methods: Structured National delirium education drive with multimodal learning methods tailored to both healthcare staff and community, educational drive incorporated train the trainer system with focused workshop-based teaching.

Intervention: This National educational drive achieved its objectives through 55 Educational Events and activities across the state of Qatar through HMC and community facilities, training 3840 health care staff, and raising awareness in 4500 people in the community over the Year.

Results:

1. This project highlighted the dearth of delirium recognition and diagnosis in an acute care setting
2. InitiatedWork on Hospital Wide Delirium clinical practice guidelines further advocating Ownership.

Conclusions: This project has Initiated the Process of Increased awareness and better Recognition of Delirium. Initiated work on getting systems in place for better awareness better recognition and prompt and effective care both in hospital and community.

524

Practice makes life perfect – Holistic activation with DIGITAAL life

Mrs Gloria Pötz, Ms Maria Fellner

digitAAL Life GmbH, Graz, Austria

Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

DIGITAAL life is a tablet-based serious game for multimodal activation of cognitive performance. The daily training can be carried out with supervision or independently. Each training session of about 45 minutes has a specific theme and contains a sequence of exercise tasks that stimulate the various senses of the human body. Movement and perception exercises are followed by knowledge questions, math problems, gap words, puzzles, troubleshooting pictures, songs and more. All training units are available in four levels of difficulty. Each task can be done at your own pace, you can always take a break or talk about the content shown. The important thing is to enjoy the workout and have social interaction while doing it.

The tablet app was developed and scientifically evaluated as part of several research projects together with JOANNEUM RESEARCH, Medical University Graz and application partners.

The training can be used by individuals at home alone or with relatives. In the context of mobile services, it can be used for supervised training with professionals or with trained volunteers. In residential facilities and practices, it can be used not only for individuals but also in group settings. People are at the center of technological innovation: technology meets elderly or cognitively impaired users and relatives. They are trained and guided, as this is a critical success factor in the introduction of such a digital application. The goal is for older people to use the technology under guidance or even independently.

A free trial version is available at www.DIGITAAL.life/test.



526

How an assistance dog supports me living with a dementia

Mrs Eileen Mary Taylor
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Topic

Dementia diagnosis, treatment, care and support: Importance of peer supporting and living well with dementia

Abstract

Dogs are helpful in many settings and how they help will be explored.

It is known that assistance dogs are helpful for many people with a disability. Firstly with the use of seeing-eye dogs for the blind. In recent years they are now used with children with a disability. Therapy dogs are now popular in many settings as a means of support and will be explored Other speciality trained dogs are used in the military and in the police force in different ways too than that of an assistance dog.

This presentation will give a brief overview of the history of assistance dogs in general (for instance seeing eye dogs) as well as discuss the development of using dogs in Australia for helping people living with dementia. These dementia dogs are in Australia and were run by DOGS 4 Dementia out of a university

Minddog is another accredited Australian national dog training service for people with a psychiatric disorder of which I was able to join. It is an Australian national organization that focuses on self training your own dog.

In conclusion I'll share my own experience of training my own dog Hamish as an Minddog , with the ups and downs of the process culminating in him passing the Public Access Test (for assistance dogs) .I will explain the benefits of having my own Minddog helping me to cope with my own reality of living with a diagnosis of Dementia at home and out in the community.

527

Online Educational Intervention for Carers of People Living with Dementia in Low-middle Income Countries: Preliminary results of a feasibility study

Mr Azam David Saifullah[1,2], Dr Gillian Carter[1], Prof Kevin Brazil[1], Prof Christine Brown Wilson[1]

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: Approximately 60% of dementia cases in 2020arereported to be in low-middle income countries (LMICs). People living with dementia in LMICs generally live with their families which may create an additional exacerbated strain due to pandemic. Therefore, it is important to find cost effective ways to support dementia caregivers in LMICs in this era of a pandemic.

Aim: To explore the feasibility of an online educational intervention for caregivers of people living with dementia in LMICs.

Method: A sequential mixed methods study was undertaken to investigate the feasibility of 12-hour Dementia Care Skills online training for caregivers in Indonesia. The quantitative phase measured the outcomes at three time points, including knowledge, self-efficacy, and general mental distress. The qualitative phase consisted of two focus groups with eight participants.

Result: The intervention was delivered to 25 participants across 6 weeks. The data showed a statistically significant improvement in knowledge (t = 4.73; p =.000), anxiety ($\chi 2$ = 4.20, p =. *040)*and stress ($\chi 2$ = 14.34, p <. *00),*but not with the self-efficacy (t =0.32; p =. 751) and depression *(*$\chi 2$ =. 65; p =.419*).* Qualitative findings suggest that participants felt they had benefited greatly from the training and its delivery, including benefits for the caregiver, family, the person living with dementia and the community.

Conclusion: An online educational intervention is feasible to be implemented and investigated on a larger scale in LMICs with the potential to improve knowledge and reduce stress and anxiety for dementia caregivers.

528

Do Nurses need Dementia skill Training in Qatar?: A Survey Report

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Introduction: The intensity of prevalence of Dementia is rising rapidly. Every3 sec. new case of dementia is diagnosed in world. the number of people with dementia in Qatar is more than 4400 persons over 60 years. Dementia care is still under priority in health care setting compare to other diseases. There are care challenges for nurses when they encounter person with dementia.

Aim: to analyses the need of initiation of training & education in Dementia care for nurses.

Setting: Elderly settingincluding community settings like home care across Qatar. Total 865 registered licensed nurses were participated.

Method: 4 weeks online survey was conducted (structured questionnaire). Average time to complete the survey was 8 minutes 04 sec. 366 nurses were involved in daily private home nursing care almost 8 to 12 hrs are spend in elderly care. with the help of literature review the questionnaire were formed; components like Knowledge regarding dementia, communication skill, confidence in caring, involvement of family members in dementia care.

Findings: Nurses in elderly facility find challenge in communication, Total 406 nurses rated 4.05 average number of their confidence in providing elderly care.

Nurses face difficulty in caring persons with dementia, delirium, and depression{3Ds) in hospital & in home care. barriers to care: difficulty in communication. Time, lack of involvement of family members in care, stressful environment.

Majority nurses are involved in care of patients with 3Ds need care specific skilled training to meet the care expectations.

Face to face is recommended for training and educationfor nurses

LINKED IMAGES MISSING

529

Association between dietary salt intake and cognition in middle-aged and older Malaysian adults with elevated blood pressure

Ms Yee Chang Soh[1,2], Dr Andrea McGrattan[3], Dr Siew Siew Lee[1], Ms Mawada Alawad[1,2], Prof Shajahan Yasin[4], Prof Tin Tin Su[1,2], Dr Azizah Mat Hussin[5], Dr Zaid bin Kassim[6], Dr Ahmad Nizal bin Mohd Ghazali[6], Prof Blossom CM Stephan[7], Prof Pascale Allotey[8], Prof Daniel D Reidpath[9,2], Prof Louise Robinson[10], Dr Mario Siervo[11], Dr Devi Mohan[1]

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Topic

Dementia risk reduction: Risk factors

Abstract

Background: There is mixed evidence that high dietary salt (sodium) intake is associated with poor cognition independent of its effect on blood pressure.

Objective: This study analyzed the baseline data of participants recruited for the DePEC-Nutrition study. It was a randomized, controlled 2*2 factorial trial piloting a nutritional intervention to reduce dementia among middle-aged and older adults with elevated blood pressure in a semirural population in Malaysia. This paper aimed to examine the association between dietary sodium intake and cognitive function among these participants.

Methods: Sixty-fourparticipants aged 50-75 years resided in Segamat, Malaysia, completed socio-demographic and health questionnaires, and underwent blood pressure and anthropometric measurements. Dietary sodium intake was estimated by 24-hour urine collection and 24-hour dietary recall. Cognitive function was assessed using Mini-Mental State Examination (MMSE), Montreal Cognitive Assessment (MoCA), Auditory Verbal Learning Test (AVLT) and Trail Making Test B (TMT- B).

Results: The median (Q1, Q3) daily sodium intake of the participants (59.4 % female; mean ± SD age = 61.8 ± 6.6 years) was 2595 (1738, 3923) mg/day, which was higher than the WHO recommendation. There was a negative correlation between daily sodium intake and cognitive scores (MMSE: r = -0.068; MoCA: r = -0.027). The mean cognitive scores were lower for participants with daily sodium intake above recommendations. However, these associations were not statistically significant.

Conclusion: Morelarge-scale prospective studies and clinical trials examining the effect of salt reduction



on cognition in hypertensive adults are needed.



530

The Global Brain Health Institute: Five Years of Advocacy, Education and Research

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Background: Established in 2015, the GBHI set out to reduce the scale and impact of dementia globally by training the next generation of diverse leaders through the Atlantic Fellows for Equity in Brain Health program. Foundational elements included enrolling trainees from diverse professional disciplines, providing training that included the fundamentals of dementia neuroscience and value-based leadership.

Methods: We completed a systematic review of years 1-5 using surveys, database searches, and informal data collection approaches to categorize the number of publications, new positions, media events and research dollars raised across these cohorts.

Results: Between 2015 and 2021, GBHI enrolled 146 Atlantic Fellows from 42 different countries, all completing a 12-month in residence experience at the University of California San Francisco or Trinity College Dublin. 29% of these Fellows were from Latin American Countries and 19% from the Mediterranean region. Broad diversity of discipline is noted with 49% clinicians/clinical researchers, 12% working in policy or health economics, 11% in public health or epidemiology, and the remainder in advocacy, education, arts, humanities, and technology. Among these trainees, we count over 700 publications in scientific journals, 220 media events and nearly 400 conference presentations. Collectively, this group has raised $47,000 in research funding for their work.

Conclusion: Examination of metrics indicate success in meeting anticipated goals in professional diversity and regional representation. Reducing the frequency and burden of dementia globally will require diverse disciplines to engage. GBHI demonstrates a model for such collaborative work to reduce the scale and impact of dementia globally.



531

Ethical issues during COVID-19 necessitated virtual adaptation of Cognitive Stimulation Therapy (CST) in a LMIC: CST-International study

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Topic

Dementia research and innovation: Clinical trials

Abstract

Background: The COVID-19 pandemic necessitated the adaptation of Cognitive Stimulation Therapy for virtual platforms (vCST), as persons with dementia (PwD) are a high-risk group. The paper focuses on ethical issues encountered during delivery of vCST in New Delhi, India, in the CST-International implementation study.

Methodology: A record of challenges encountered during adaptation and implementation of vCST during the pandemic was kept. Thematic analysis was performed to yield ethical issues.

Results: The first challenge was obtaining fast-track approval from the Institutional Ethics Committee, which prioritized COVID-19 research proposals over pandemic necessitated protocol modifications for ongoing research.

The informed consent process was challenging due to difficulty in reaching out to PwD and carers through tele-communication due to isolation and lockdowns. This adversely impacted the shared decision making, often practiced in traditional societies. The participants were also concerned about confidentiality and privacy on virtual platforms,

Other ethical issues included fidelity of e-consent processes (as e-participant information sheets and e-consenting protocols were created without any prior template), difficulty in judging the comprehension and voluntariness of participants during e-consent, and the need for re-consent and deferred consent.

In addition, there were ethical concerns related to technical issues with virtual platforms, possible diminished participation in a virtual intervention due to lack of familiarity and limited accessibility to technology in a resource-constrained Low- and Middle-Income Country (LMIC).

Conclusion: Ethical issues encountered in the CST-International Study in a LMIC during the COVID-19 pandemic can inform further development of ethical guidelines for research conducted in pandemics and other disasters.

532

Mapping healthcare utilization of stroke survivors with behavioural and cognitive symptoms: ethnographic insights.

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Our ethnographic research on stroke recovery in rural Malaysia found that no stroke survivors(n=18) experienced formal assessments or diagnosis of cognitive health from a healthcare provider at any point post-stroke, regardless of the severity of their experienced cognitive symptoms. This is concerning given the high risk of cognitive impairment (CI) and dementia afterstroke.

Andersen(1995) posited that healthcare utilization is determined by predisposing factors, enabling factors, and need and the interaction of these. We drew on the experiences of three stroke survivors with salient behavioural and cognitive symptoms and mapped their health care seeking experiences using Andersen's model. They had follow-up care from healthcare providers throughout the one-year observationperiod but none utilized services specifically to support behavioural and cognitive symptoms.

Family networks were involved in all aspects of the stroke survivors' healthcare, influencing the predisposing factors, enabling resources and perceived needs that impacted how participants accessed care. The need for services were often not recognised by family/survivors. Healthcare providers did not recognise the impact of behavioural issues and distress, even when caregivers tried to seek help for those issues. Caregivers and survivors became stuck in a state of distress, with no support in coping with cognitive and behavioural issues, which led to poorer outcomes.

The need for health care services begins at the recognition by family and healthcare providers. Early recognition of symptoms can alleviate the suffering of individuals and caregivers. Interventions should target the predisposing factors and enabling resources that shape the need for health services.



533

How might patterns of unplanned hospital admissions among people with dementia change from diagnosis to the end of life?

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Background: People with dementia frequently experience unplanned hospital admissions.

Aim: To describe patterns of unplanned hospital admissions of people with dementia from diagnosis until death/study end.

Methods: Retrospective cohort study using mental healthcare provider data of people diagnosed with dementia (1995-2017), linked to mortality and hospital data.The primary outcome was the rate of unplanned hospital admissions after diagnosis until death/study end. We calculated the cumulative incidence of unplanned hospital admissions. The rates of unplanned hospital admissions and the percentage of time spent as an inpatient were stratified by time from first dementia diagnosis.

Results: For19,221 people with dementia (61.4% female, mean age at diagnosis 81.0 years (SD 8.5)), the cumulative incidence of unplanned hospital admissions (n=14,759) was 76.8% (95% CI 76.3% - 77.3%). Individuals remained in the study for mean 3.0(SD 2.6) years, and 12,667(65.9%) died. Rates and lengths of unplanned hospital admissions remained relatively low and short in the months after the dementia diagnosis, increasing only as people approached the end of life. Percentage of time spent as an inpatient was <3% for people who were alive at the study end but was on average 6.5% and 10.4% for the decedents in the last six and twelve months of life, respectively.

Conclusions: Rates of unplanned hospital admissions remain relatively low and stable after a dementia diagnosis and only increase as people with dementia approach the end of life. Investing in resources for dementia end-of-life care may help with reducing the negative impact of unplanned hospital admissions.

534

DePEC-Nutrition trial: feasibility and adaptions during the COVID-19 pandemic

Dr Siew Siew Lee[1,2], Dr Andrea McGrattan[3], Ms Yee Chang Soh[1], Ms Mawada Alawad[1], Prof Tin Tin Su[1], Prof Uma Devi Palanisamy[4], Dr Azizah Mat Hussin[5], Dr Zaid bin Kassim[6], Dr Ahmad Nizal bin Mohd Ghazali[6], Prof Blossom Stephan[7], Prof Pascale Allotey[8], Prof Daniel D Reidpath[9], Prof Louise Robinson[10], Dr Devi Mohan[1], Dr Mario Siervo[11]

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Introduction: The DePEC (Dementia Prevention and Enhanced Care)-Nutrition trial is a feasibility nutritional intervention study of reduced salt intake and increased high-nitrate vegetable consumption to prevent cognitive decline. This paper presents the feasibility and acceptability of recruitment, retention and data collection of the trial during the COVID-19 pandemic.

Methods: Participants aged 50-75 years with elevated blood pressure were recruited from the South East Asia Community Observatory (SEACO) health and demographic surveillance system in Malaysia. The study was conducted between June 2019 and December 2020. The intervention included a combination of group counselling, information booklets, reinforcement videos and text messages. Except for the baseline data collection and counselling, all other intervention components and follow up were carried out through distant

Methods: The acceptability and feasibility were assessed during the 2 month, 4 months and end of the study follow up interviews.

Results: The recruitment had to cease prematurelydue to the restrictions caused by the pandemic; butmore than 60% (74/120) of our target sample size were recruited. The adaptation of data collection method had caused the extension of study duration from 6 months to 10-months, but the retention rate was reasonably high at 73 %. All the intervention strategies were feasible and acceptable, with group counselling being the most acceptable strategy.

Conclusion: Our adaptations have enabled successful delivery of the feasibility trial in spite of the challenges posed by COVID-19 pandemic. The study provides important insights to inform the design of



a dementia prevention intervention in crisis like COVID-19 pandemic.





535

How to advocate for carers' human rights for living well with dementia ~ Challenges and the search for solutions in the super-aged society of Japan~

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aslong-term care needs related to the aging society and changes in the family structure increased, the Long-Term Care Insurance was established in Japan in 2000.

It was the official start of the socialization of care, and the care service for people in need improved drastically. However, the Long-Term Care Insurance is set for only people who need care and does not include services for family carers. Moreover, there is no legal advocacy for the carers' human rights. Presently it is estimated that 75% of PLWD live at home, and most of them are cared for by their family members, who also assume many other roles. With further aging in Japanese society and the implementation of community care by the Government, the family carers' role is getting more and more significant. This presentation reviews the concept of care in Japan historically and culturally compared with other countries and introduces the present challenges and approaches to the issue of carers. In conclusion, I explain a proposition to advocate for the human rights of both carers as well as people with dementia to realize a holistic vision of "living well with dementia in the super-aged society."



536

MISBAH - PRAYER BEADS , CAN THEY HELP IN BEHAVIORAL AND PSYCHOLOGICAL SYMPTOMS IN DEMENTIA?

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Topic

Dementia diagnosis, treatment, care and support: Dementia and spirituality

Abstract

Background: Since the very first transcript of Clinical Profile of Auguste D in Nov 4, 1906, by Alois Alzheimer, Behavioral issues have remained an integral phenomenon in Alzheimer's and Related Dementia's as condition Progresses. BPSD -Behavioral and Psychological Symptoms in Dementia as they are called carries quite concerning impact related to Dementia both in Person with Dementia leading to high risk of Institutionalization, and increase Carer Burden. Existing Pharmacological agents have limited efficacy and more risks related to their use in the management of these symptoms. Non Pharmacological strategies remain the preferred mainstay of management of these symptoms in the Long Term. Studies have highlighted the Positive Role of Spirituality and its Impact on Dementia.

Vance et al (2008) identified that Therapeutic activity and practices that Integrated spiritual and religious elements decreased agitation and increased Quality of Life in people with Alzheimer's Disease.

Prayer enables one to connect to one's spiritual being. Prayer beads are a form of beadwork used to count the repetitions of prayer, Islamic Prayer Beads are called Misbaha.

Aim: Share a Clinical Observation highlighting Impact of spirituality in Dementia Care

Method /Case presentation: The authors will present a Clinical Scenario they encountered where Careful observation prompted considering the use of Misbah which led to minimizing Restlessness and agitation in a person with Dementia.

Conclusion: Authors through this presentation raise the Question on Therapeutic Role of Misbah -Prayer Beads in Dementia care

537

Monitoring daily activity of people living with cognitive impairment using wearable sensors and a tailored platform for health-care professionals: A long-term observational study

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aims: To investigate the potential of long-term monitoring daily functionality in people with cognitive impairment across the Alzheimer's Disease (AD) spectrum using and maintaining a system based on wearable sensors.

Method: An eHealth monitoring platform was developed to collect health and lifestyle data from wearable sensors, which are analyzed, transformed, and presented in visual analytics dashboards to enable clinicians to observe changes over time and adapt interventional programs. 41 participants (16 with mild cognitive impairment, 13 with subjective cognitive decline, 7 with AD, and 5 healthy controls) used the platform at home for 4 to 12 months, while clinicians periodically observed changes in the dashboards and provided feedback about the system usage.

Results: After continuous monitoring, the participants showed statistically significant improvement in sleep patterns and physical activity. These results support the notion that monitoring of physical health and providing feedback to people with cognitive impairment, who received the sensor-based system, have shown improvement in domains such as sleep quality and daily activity.Overall, paired-sample t-test analysis revealed significant improvement ($p<0.05$) from the beginning to the end of the trial, in physical condition, and in the domains of sleep.Meanwhile, clinicians found the eHealth system extremely helpful and beneficial for receiving objective information about the participants' status.

Conclusion: Deploying a sensor-based system in real home settings of people with cognitive limitations living alone and maintaining its long-term use is not only possible, but also beneficial for clinical decision making in order to tackle cognitive, functional, and behavioral problems.

This study has been financed by the Greek national funds through the Operational Program "Competiveness, Entrepreneurship and Innovation, under the call RESEARCH-CREATE-INNOVATE (project code: T1EDK-02668).



538

Dementia-friendly innovative way to keep families connected

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Famileo, St Malo, France

Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Geographical distance, technological gap, dementia... make it harder for different generations in the same family to keep in touch. Older adults, especially when living with dementia do not have access to all the information we share on our social media.

Famileo developed a bridge between generations communicating on social media and their older relative who grew up receiving postcards and letters. Each family member upload content on the Famileo app. Once a week, these messages are turned into a personalized gazette which is printed and posted or brought to the older relative. Famileo succeeded in putting back the older relative at the center of the family interactions.

Receiving something tangible from their family make the person feel: loved, valued and part of a wider family.

“Doing the gazette does not only help my mother (who has dementia) in seeing old and new pictures of the family but it also helps me in sending them. It is as if she can remember when I write a piece about each photograph and share those with her, each bringing back a memory of an event that we had shared. It is a way of talking to my mother although miles apart and knowing that she will be able to see what I am sending in printed form, to look through over and over again.”

Famileo is used across Europe and North America by occupational therapists,dementia therapists,care home professionals; and counts 160 000 families using it to keep memories alive.

LINKED IMAGES MISSING



539

Resources and impediments for influencing one's own life when living with younger onset dementia

Dr Mervi Issakainen[1], Prof Anna Mäki-Petäjä-Leinonen[2], Dr Sirkkaliisa Heimonen[3], Dr Ann-Charlotte Nedlund[4], Prof Arlene Astell[5,6,7], Dr Jennifer Boger[8,9], Prof Sari Rissanen[1], Prof Louise Nygård[10]

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Understanding the different factors that enhance opportunities to make decisions and choices regarding one's life when living with dementia is highly important. This inter-disciplinary study combined social psychological and legal viewpoints to explore how people living with younger onset dementia seek to influence their lives, and what makes it easier or more difficult for them in their everyday life. The concept of relational autonomy was utilised to analyse three focus group discussions with 12 persons living with younger onset dementia. In this presentation, we describe different resources and impediments for handling challenges at work and their consequences with dignity, managing daily tasks and living a fulfilling life, as well as fighting the stigma attached to dementia. The results highlight the need for 1) workplace education for different stakeholders i.a. about signs of cognitive impairment in general and the legal rights of individuals living with younger onset dementia, 2) equal and ongoing access to guidance and counselling to provide adequate post-diagnostic support that meets their individual needs, and 3) an effort by society as a whole to eradicate stigma. This study is a part of an international multi-disciplinary research project scrutinising what happens when people develop dementia while still working (´Dementia or mild cognitive impairment: @ Work in Progress´) and the Finnish project ´Working Life and Memory Impairment – Mental Wellbeing, Legal Security and Occupational Capacity of People with Early Onset Dementia´(WoLMI).



540

STRIDE PAR: Towards prevalence and impact of dementia in South Africa: Findings from the STRiDE household survey

Mrs Roxanne Jacobs[1], Dr Sumaiyah Docrat[1], Prof Marguerite Schneider[1], Dr Nicolas Farina[2], Prof Sube Bannerjee[3]

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Topic

Dementia research and innovation: Epidemiology

Abstract

With increasing prevalence of dementia particularly in low-and middle income countries, health care systems are ill-equipped to respond to treatment, care and support of people living with dementia and their families. With very little data available on prevalence of dementia in South Africa, the STRIDE project (i.e. Strengthening responses to dementia in developing countries), in part, aims to address this gap by generating new evidence across two provinces in South Africa: (1) urban Cape Town, Western Cape province and (2) the rural Dikgale area, Limpopo province. The aim of this presentation is to present the preliminary findings on estimating the prevalence, care needs, social impact and cost of dementia in South Africa. A total of 800 households with a person 65 years and older were randomly selected in 8 selected wards in the Cape Town area and 11 villages in the Dikgale area between October and December 2021 (400 in each site). Within each household a person aged 65 years and older and an informant (18 years and older, who knows the older adult the best) were recruited. Toolkits were culturally adapted and translated, and administered in 4 languages (English, Afrikaans, isiXhosa and Sepedi) to assess neuro-cognitive function, care needs, household expenses, caregiver experiences and the impact of COVID-19. This presentation will present findings on costs and service use, needs and support received, as well a preliminary estimate of the prevalence of dementia in South Africa.

541

Inequalities in diagnosed Alzheimer's disease and related dementias among minority groups in the United States

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Topic

Dementia research and innovation: Epidemiology

Abstract

Aim: Alzheimer's disease and related dementia (ADRD) inequalities exist by race, ethnicity, and place of birth in the United States (US). The aim of this study was to estimate and compare the prevalence of diagnosed ADRD among US-born and foreign-born non-Hispanic white, non-Hispanic black, Hispanic, Asian and Arab American adults.

Methods: Cross-sectional data from the 2000-2017 National Health Interview Survey (NHIS) and 2001-2018 Medical Expenditure Panel Survey (MEPS) were linked (ages >=45 years, n=116,556). Race, ethnicity, and place of birth were measured using NHIS. Diagnosed ADRD was measured using ICD-9 (290/294/331/797) and ICD-10 (F03/G30) codes from MEPS. Preliminary analyses included bivariate statistics.

Results: The overall prevalence of diagnosed ADRD was 1.4%. Among US-born adults, prevalence was highest among US-born non-Hispanic blacks (1.7%), which was notably higher than the prevalence among foreign-born non-Hispanic blacks (0.7%) and marginally higher than that of US-born non-Hispanic whites (1.4%). Among foreign-born adults, prevalence was highest among foreign-born non-Hispanic whites (1.7%), which was marginally higher than that of US-born non-Hispanic whites (1.4%). US-born Hispanics and Asians has a prevalence of 1.5%, which was higher than their foreign-born counterparts (1.3% and 0.9%, respectively). Arab American results are not reported due to small samples.

Conclusions: Results are consistent with previous studies highlighting inequalities in diagnosed ADRD by race, ethnicity, and place of birth. Findings add to the literature by using two nationally representative data sources. Further analyses will use multivariable regressions, explore inequalities among adults ages 65 and older, and evaluate the prevalence of undiagnosed ADRD.



542

Barriers and facilitators to virtual Cognitive Stimulation Therapy in LMIC settings: Findings from CST-International Study in India and Brazil

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Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Aims: Cognitive Stimulation Therapy (CST) is a group intervention for persons with dementia (PwD) demonstrated to improve cognition. Virtual CST (vCST) was developed to overcome the constraints posed by the COVID-19 pandemic on face-to-face interventions. However, low- and middle-income countries may face unique challenges in adapting an intervention for virtual delivery. This study describes barriers and facilitators to virtual CST (vCST) groups in Brazil and India.

Method: Six vCST groups (four in Brazil, two in India) were conducted from April-November 2021. vCST sessions were delivered using Zoom, an online video conferencing platform following adaptation for virtual delivery. After completion of each vCST group, we obtained feedback from PwD and their caregivers through semi-structured interviews and reports from vCST facilitators.

Results: An important facilitator was the availability of vCST in the safety of one's home. We also identified the following barriers: poor digital literacy, slow internet connection, lack of dedicated space at home, non-availability of a caregiver to assist the PwD and low socioeconomic status (SES). To manage several of these barriers and improve participation, we offered training for caregivers on setting up Zoom, provided tablet computers for persons from low SES (India only) and when slow internet connection interrupted participation, the coordinator phoned the caregiver and sent backup activities while the vCST facilitator continued with the session.

Conclusion: The use of technology enhanced participation of PwD. Despite the barriers, vCST was a feasible alternative to face-to-face groups, and the overall experience of PwD and their caregivers was positive.

543

Citizenship for employees living with dementia – how agents in the welfare system reason and act in the transition from work

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

A goal of welfare systems is to provide social security and to ensure safety for the citizens by enacting different policies. Transition from work is commonly experienced as a critical milestone in life – a situational event that is shaped by the social context. This study focuses on citizens who develop dementia while they are still working and how agents in the welfare system reason and act in the transition from work.

The study followed a qualitative exploratory design using focus-group discussions with key agents in the Swedish welfare system to cover a wide range of experiences, e.g. worklife, sickleave, unemployment, role of advocacies. The discussions evolved around how laws and policies are understood, experienced and enacted.

The analysis resulted in a conceptual framework that unfolds the interfaces of employees living with dementia and welfare policies and practices. These concepts are: (1) blockage, i.e. a hindrance or an obstruction between agencies which makes an action difficult, (2) gap, i.e. a break in a linkage between agencies; and (3) void, i.e. emptiness, an unfilled empty space between agencies.

The study shows that transition from work for citizens living with dementia is to a large extent an overlooked topic in the welfare system. The agents aimed to be supportive by enabling the agency of the citizen, but their discretion could often be limiting due to laws and policies that incapsulate current structural norms. These norms have to be challenged in order to increase awareness and to secure citizenship for employees living with dementia.



544

The potential of 'brain health' to reframe the conversation around dementia risk reduction in the UK.

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aims: The latest evidence suggests that up to 40% of global dementias could potentially be preventable. Alzheimer's Research UK (ARUK) led an initiative to explore whether reframing the conversation from dementia risk reduction to brain health could raise the low levels of public awareness of dementia prevention and modifiable risk factors.

Methods: In January 2021, ARUK published a joint policy report with the Royal Society for Public Health on public attitudes towards brain health. This accompanied a new digital awareness campaign – Think Brain Health – to empower people to keep their brain healthy, thereby reducing their risk of dementia.

The report drew on externally commissioned public polling of a representative sample of UK adults (n=2,080), four focus groups and 18 semi-structured interviews with a cross-section of prevention-related experts. The campaign was co-designed with individuals representing the targeted audience, midlife adults (aged 40-60) with experience of dementia.

Results: The report found 69% of UK adults believe they can influence their brain health, surpassing the 34% who believed they could influence their risk of developing dementia. Brain health also resonated across age groups, showing potential to overcome some lasting misconceptions. In a post-campaign survey (n=360), 79% felt it was possible to reduce one's risk of dementia and 61% said they were 'much more likely' to take steps towards a brain healthier lifestyle.

Conclusion: After successfully demonstrating considerable public appetite and messaging potential for brain health, a forthcoming cross-sector consensus will build further engagement, call for policy action and help change the narrative.

545

Local Terms Used in Jakarta to Describe Dementia

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Background: Awareness of dementia in Indonesia is still low. Using the appropriate term to describe dementia can help to reduce stigma and improve how a person living with dementia is treated in society. As part of the Strengthening Responses to Dementia in Developing countries (STRiDE) project, we identified locally culture-specific terms regarding dementia within a population-based survey.

Methods: We conducted a population-based survey on 1,100 dyads in Jakarta, Indonesia, each consisting of an older adult (≥ 65 years old) and an informant (friend or family member). Respondents were asked to respond to a set of questionnaires, including questions on whether they have heard the word 'dementia' or 'Alzheimer's disease, and if not: the word(s) used to describe "an older adult experiencing memory loss and difficulties with thinking, problem-solving, and language, so much so it affects their ability to perform everyday activities".

Results: The majority of older person respondents had never heard the words "Alzheimer's Disease" or "Dementia". Most of the respondents use the word "*pikun (*a forgetful older person*)*" and other less accurate words/local terms were used are "*pelupa (*forgetful*)*", "*linglung (*absentminded*)*", or "amnesia". Identifying local terms that are commonly used in society will help us to know more about how society perceives a person living with dementia.

Conclusion: The term "*pikun*" is the most popularly used word to describe dementia in Indonesia. Using the appropriate local term along with the correct medical term (dementia) when raising awareness can improve knowledge and subsequently attitudes in reducing stigma.



546

The supportive influence of pet ownership on the quality of life in home-dwelling people with Alzheimer's Disease

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aim: Human-animal interactions have positive psychosocial and psychophysiological effects on well-being. We examined the impact of pets on the quality of life (QoL) and general well-being during a 5-year follow-up in the home-dwelling persons with AD.

Method:A prospective, follow-up study including 223 persons with very mild (CDR 0.5) or mild (CDR 1) AD at the baseline who participated in the ALSOVA study. Altogether 17.9% of study participants had a pet. Self- and proxy-rated Quality of Life in Alzheimer's disease scale (QoL-AD), self-rated visual analogic scale (VAS) and 15D were assessed annually for three years and after five years. Also, the status of Alzheimer's disease was evaluated annually using MMSE, Neuropsychiatric Inventory (NPI), and CDR sum of boxes (CDR-SOB).

Results: We found asignificant positive effect of pet ownership (p=0.003, the proxy-rated QoL-AD) on QoL in persons with AD over the whole follow-up time. However, there was no effect in self-rated QoL-AD, 15D or VAS between the groups.

Conclusion: The pets' significant positive effect on the QoL was noticed over the 5-year follow-up, suggesting that having a pet can support QoL in home-dwelling persons with AD. The divergence between self-and caregiver-rated QoL may be related to a lack of insight and difficulty understanding the questionnaire as AD progresses.



547

Gender differences in dementia, cognition and health in the Cognitive Function and Ageing Studies (CFAS)

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Topic

Dementia research and innovation: Sex and gender - impact, research, policy

Abstract

The question of whether gender differences in dementia risk exist, and what influence social and biological factors have, is receiving renewed interest. Bringing these domains together has been rare, as has reviewing all findings from individual cohort studies. This synthetic review examined all published research from the Cognitive Function and Ageing Studies (CFAS), a long-running multi-centre population-representative cohort study in the UK. Of 337 publications reviewed, 94 report results by gender (including null findings) from primary analyses of CFAS data. Results are summarised by theme: dementia epidemiology, cognition, mental health, health expectancy, social context and biological resource (including neuropathology). Where differences are found they most commonly favour men; however, greater mortality in men may confound associations with age-related outcomes. This 'survival bias' may explain findings of greater odds of dementia and faster cognitive decline in women. Age-specific dementia incidence was similar between genders, although reduced incidence across study generations was more pronounced in men. Mood disorders were more prevalent in women, but adjusting for disability and deprivation attenuated the association. Prominent neuropathology findings from other cohorts that women have more Alzheimer's disease pathology and greater risk of dementia from the APOE 4 allele are not observed, warranting further investigation including selection differences across cohorts. The 'male-female health-survival paradox' is demonstrated whereby women live longer but with more comorbidity and disability. Examining why health expectancies changed differently over two decades for each gender (interacting with deprivation) may inform population interventions to improve cognitive, mental and physical health in old age.



548

Based on a Danish Lifelong learning Model, a new and unique Lifelong learning service called the Brain Gym has been established in the UK. Brain Gym is a teacher-led service, which provides tailor-made CST informed individual programmes of activities for people in the early stages of dementia.

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Lifelong learning refers to learning undertaken throughout life. Learning is associated with change and growth that can help to manage and cope with positive/negative life situations, including ill health. People with dementia can continue to learn and develop and so benefit from lifelong learning but are often excluded from its access. Emerging evidence shows it could promote regeneration of neural networks, that it can be used to train and retrain existing skills, and skills, and support memory. Furthermore, lifelong learning has been advocated as a key Public Health agenda to protect brain health.

Brain Gym believes that people with dementia can continue to learn, develop, and grow. It provides an individual education-led programme of activity. This aims to support its members to maintain or develop skills. These skills are designed to help to maintain people's independence and quality of life at home.

Potential Brain Gym students are assessed for suitability by the Project Manager. Each group consists of six people who engage in teacher-led activities for up to four hours per week. A carefully designed schedule has been developed to maximize brain stimulation, and enjoyment of the members while building on their strengths to preserve skills and knowledge and improve confidence and performance. It uses repetition and contains activities to preserve/build transferable skills including; memory, visual recognition, orientation, aural memory, fine/gross motor skills, and communication. Each group's programme is evaluated 6-monthly to document effects of the group's cognitive performance and attitudes.

549

ADRD care partner experiences and health by race, ethnicity and care recipient geographic context in the United States

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Few studies have examined how the intersectionality of geographic context and race/ethnicity influences Alzheimer's disease and related dementia (ADRD) caregiving. Our aims were to determine whether 1) care partner experiences and health differed across metro and non-metro areas and 2) these links were moderated by race/ethnicity.

Methods: We used 2017 National Health and Aging Trends Study and National Study of Caregiving data. The sample included care partners (n=808) of care recipients ages 65+ living with 'probable' ADRD (n=482). Geographic context was defined as care recipient's residence in metro or non-metro counties. Outcomes included care partner experiences (effects, gains, life impacts, services/resources) and health (anxiety, depression, chronic conditions).

Results: Non-metro ADRD care partners were less racially/ethnically diverse (82.7% white) and more were spouses/partners (20.2%). Among racial/ethnic minority ADRD care partners, non-metro context was associated with having more chronic conditions (p<.01), providing less care (p<.01), and not co-residing with care recipients (p<.001). Amid white ADRD caregivers, non-metro context was associated with not reporting caregiving was more than they could handle (p<.05) and finding financial assistance for caregiving (p<.05). In multivariate regression analyses, non-metro minority ADRD care partners had 3.09 times higher odds (95% CI=1,02-9.36) of anxiety in comparison to metro minority care partners.

Conclusions: Geographic context shapes ADRD care partner experiences and health differently across races/ethnicities. Despite higher ADRD rates and ADRD-related mortality in non-metro areas, findings suggest both positive and negative aspects of supporting someone with ADRD among minority care partners.



550

Dementia and Stigma: What is our social responsibility?

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

The word dementia, by definition, means "to be mindless". Dementia is not just an unpleasant word,it is the epitome of "madness" in our performance-oriented society.Most people living with dementia don't use the word dementia because this topic is a big taboo. By keeping this taboo, care partners protect themselves from the danger that comes when their loved ones are referred to as "senile":no longer normal is synonymous with no longer belonging to society. Therefore, dementia is not just a health condition or medical diagnosis, it's also a stigma. It's a sign of otherness that goes hand in hand with the loss of one's social position and has a degrading effect. This is why it arouses fear and horror in people. Social conditions are the result of constantly renewed and changing cultural practices. So,socially valid images, preferences, and attitudes are variable and can be redesigned to benefit everyone. In order to achieve this, that is, to reduce the fear of dementia in society,it should reduce the resistance and reservations against aging; We must increase the acceptance that mental deterioration is "normal" among those affected and in society.Regarding dementia, the structures of our personality that make us who we are constantly are dissolved; self-perception, self-reflection, self-knowledge, and self-expression are increasingly lost. So,we are in danger of losing everything we have acquired during our personal growth.Family members state that the disorders in the social structure, which can be summarized as stigmatization,are much more severe than the disease itself.

551

Multilingualism and cognitive performance in a multi-language country

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

AIM: We aimed to explore the association between multilingualism and cognitive function in Switzerland. We hypothesized that multilingualism may contribute to acquire and maintain high levels of cognitive reserve across the life course, and lessen associated age cognitive decline.

Methods: We conducted a population-based, cross-sectional study on a representative sample of older adults, aged 65 years or older, living in the Canton of Zurich, Switzerland. We collected sociodemographic information and enquired about the number of spoken languages and the respective proficiency in in-person interviews. We assessed cognitive function using the locally tested and validated REDcap electronic version of the 10/66 short schedule, which includes the CSI "D", the CERAD animal verbal fluency and ten-word list learning tasks.

Results: The study sample comprised 652 participants (68% response rate) aged 65 to 93 years (mean age =73.0 y; SD=6.1; 47.5% female, and 36.8% with a university degree). Of these, 91.9% spoke at least two languages. In age- and education-adjusted regression models, language proficiency (0 to 50 self-reported score) and multilingualism were associated with higher overall cognitive function (β=0.16; 95% CI -0.06 to -0.19), with memory (β=0.19 95% CI 0.13 to 0.31), and verbal fluency (β=0.15; 95% CI 0 to 0.02) scores, but not with orientation or language (p>0.05).

Conclusion: Multilingualism was the norm and was significantly associated with better cognitive function in a representative sample of community dwelling older adults in Zurich, Switzerland. The observed effect sizes are similar to those associated with worse cardiovascular profiles and to age-associated cognitive decline.



552

The effects of SUDOKU Mind Activation and Revitalizing Training (SMART) Program on cognitive function among people with mild cognitive impairment

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Topic

Dementia risk reduction: Risk reduction and prevention (including clinical trials)

Abstract

Aim: The high conversion rate to dementia among persons with mild cognitive impairment (PwMCI)calls for effective and sustainable intervention to deter their cognitive decline. With the advanced knowledge in cognitive benefits of word puzzle, a novel cognitive training program based on unique solving algorithm of SUDUKU puzzle was developed for PwMCI, with the sake to enhance attention and logical reasoning. The paper reports the interim analysis on its effect on objective and subjective cognitive function.

Method: This waitlist randomized controlled trial recruited 83 PwMCI from Sept 2020 to Oct 2021. They were randomized to receive a 12 weekly face-to-face training session and 12-week facilitated self-practice on this unique SUDOKU-resolving method (N=41) or the waitlist intervention (N=42). A battery of neuropsychological tests and Memory Inventory were used to measure objective and subjective cognitive function at baseline and post-test respectively.

Results: Following the intention-to-treat principle, the linear mixed model analysis indicated the SUDOKU group has significantly greater improvements in global cognition measured byAlzheimer's Disease Assessment Scale - Cognitive subscale ($p < 0.001$), total learning ability on the Hong Kong List Learning Test ($p = 0.023$) and subjective memory ($p<0.001$) than the waitlist control. However, there was no significant difference in the executive function as measured by the Color Trail Test (CTT).

Conclusion: The interim analysis demonstrated the cognitive benefits of a specially designed SUDOKU among PwMCI. The high engagement rate (93%) in the facilitated self-practice implies its high potential to be a sustainable lifestyle strategy to prevent dementia.

553

Participatory Design of a Spatial Processing Intervention for People Living With Preclinical and Mild Dementia

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Introduction: Promoting spatial processing has the potential to facilitate cognition for people living with dementia (PLwD), yet current non-pharmacological interventions have not focused on spatial cognition. We developed a prototypical spatial processing intervention with seven themes of activities for people with preclinical or mild dementia. To better incorporate users' ideas, we invited a group of people with mild cognitive impairment (MCI) or mild dementia to co-design the activities. The present study aims to test the prototype, refine the activities, and examine the feasibility and acceptability of the intervention using a participatory design.

Methods: This study involves prototype testing with observation method, qualitative focus groups, and intervention modification. Eleven participants with MCI or mild dementia, and their carers, joined a total of 7 themed sessions. Participants first engaged in group activities, then provided feedback on the design and operation flow in focus group discussions. Finally, we modified the design based on the feedback collected.

Results: Findings here are preliminary as data collection is still on-going.Participants reported 1) fun and enjoyment; 2) improved logical thinking, memory, and creativity; 3) sense of accomplishment; 4) hand exercise; 5) novelty, 6) enhanced motivation to try new things, and 7) high acceptance of the design. These preliminary findings suggest that the intervention is not only feasible and acceptable, but also perceived as beneficial and exciting to PLwDs and their carers.

Conclusion: This study provides preliminary evidence on the feasibility and potential of the spatial processing intervention as a novel non-pharmacological treatment for preclinical and mild dementia.



554

Social Cognition in Alzheimer Disease: patterns of impairment and different predictors

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Social cognition (SC) impairments contributes to the dependence of people with AD, influencing the functional disability and caregiver burden.Our goal was to longitudinally evaluate the associations between SC, global cognition, and other clinical variables in people with AD and their caregivers. We also investigated the different SC predictors according to three perspectives: people with AD, caregiver about people with AD, and the discrepancy analysis.

Methods: We recruited 137 dyadsof people with mild and moderate AD and their caregivers. The dyads realized two assessments: M1 and, afterthe period of one year, M2.In the two moments, the same instruments were applied, and we investigatedcognition, SC, quality of life, functionality, neuropsychiatric symptoms, and caregiver burden. During the follow up 58 people with AD were excluded.

Results: Longitudinal analysis showed consistent results with a disease progression such as cognitive decline, deficits in awareness of disease and impaired functionality. In opposite the SC presented a more stable pattern.Regarding predictors, SC was associated with cognition by people with AD and their caregivers in both moments of evaluation. The predictors of the discrepancy were in line with caregivers point of view associating the SC impairment to decreased quality of life.

Conclusion: SC stable pattern of functioning over the 12 months in AD shed light about the possibility of this neurocognitive domainto be more influenced by emotional processing than the cognitive functioning impairment.In addition, the SC predictors showed that theinvestigation of different points of view enables a more global understanding contributing for a better and directive treatment.

555

COGNISANCE: Design of a co-developed evidence-based online toolkit for people living with dementia and carers in the first twelve months post diagnosis.

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Background: *COGNISANCE* is an international research programme (Australia, UK, Canada, Netherlands, Poland) in partnership with people living with dementia, carers, healthcare professionals and key dementia organisations. Together we co-designed an online supportive dementia guide and toolkit to support people in the first 12 months following diagnosis when people often feel overwhelmed and under-supported.

Methods: Four co-design workshops were run with local user groups in each partner country. Consensus was reached on core elements of the intervention content, design and functionality. The developed resource went through an iterative period of translation, international user testing, refinement and cultural adaptation.

Results: An online dementia guide was produced, which comprises an information website and interactive toolkit (https://www.forwardwithdementia.org). People wanted online support that was relevant at an individual level. Personalisation through the ability to select and save information and tools relevant at any given time was key. As was the importance of acting in the first twelve-months, for example by planning ahead. The toolkit prompts users to take action to manage their dementia through a series of to-dos. Users can create and edit a shareable action plan to take them positively forward with a dementia diagnosis.

Conclusion: We identified the need and content for a practical and individually tailorable resource. The dementia guide has a planning toolkit for the first twelve months following a diagnosis. We will present the personalisable toolkit functionality focussing on how each element reflects what people informed us they would find useful to help plan for a life with dementia.



556

Innovative formal-informal care interfacing in dementia intervention delivery: A qualitative descriptive study in Hong Kong

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Professionalization and over-reliance on formal care is a challenge in ageing society. Group interventions for people living with dementia (PLwD) can be delivered by informal carers, although the limited evidence casted doubts on feasibility. We observed a naturally occurring, informal carer-initiated and delivered Cognitive Stimulation Therapy, with formal care support in a community social care setting. This study explores the evolvement of this formal-informal interface.

Method: We recruited the complete sample of the informal carer-initiated intervention, including 7 informal carers of PLwD and 2 formal carers and conducted individual in-depth interviews. Thematic analysis following a descriptive approach was used to identify themes in the evolvement of the informal carer team and intervention delivery.

Results: Five themes and 14 subthemes were identified, representing a five-stage evolvement of seven informal carers from individual service users to a team who delivered group intervention to PLwD: (1) individual learning; (2) connected by formal care; (3) triggering of team formation; (4) team formation and preparation with formal care support; and (5) delivering intervention as a team. A conceptual framework for developing formal-informal interface for dementia intervention delivery is proposed. Relationship and role are two important aspects in the formation of this informal carer-initiated and delivered intervention

Conclusion: Observing formal practice allows informal carers to learn and form connections. With recognition, consensus and proper role alignment, informal carers may assume a more leading role in delivering intervention and form a new mode of formal-informal care interface that requires future validation and testing.

557

National Dementia Support Doctors Programme in Japan and how it has changed from the original concept.

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Back in 2004, the Japan Government newly designed the official term for dementia, "Ninchisho".

It was because the formerly used word had stigmatizing connotations, which had to be wiped out.

In need of avoiding the new word to be stigmatized again, the Government launched a series of programmes to raise public awareness and to better improve dementia care.

Dementia Support Doctors (DSD) Programme is one of those programmes.

DSDs are designed to serve as tutors at the national dementia education programme for home doctors and non-specialists, which may be one of the first of its kind in the world and their advisers in daily dementia practice.

They are also expected to play a crucial role in assisting regional liaison among related specialists, care service providers, and local government authorities.

We, the National Center for Geriatrics and Gerontology (NCGG), have been responsible for the DSD education programme since its launch in 2005.

As of 2021, over twelve thousand doctors have attended our education programme nationwide and are functioning as DSDs in their communities.

However, the surrounding environments have changed, such as governmental dementia policies including the successive National Dementia Strategies, and the COVID-19 pandemic. Accordingly, the roles of DSDs were obliged to be rearranged.

We will look back at the story of how the dementia policies and other surroundings have altered during the 16-year history of the DSD programme, and therefore affected its figure.



558

What factors can influence the social participation of older adults with dementia outside home?

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Topic

Dementia diagnosis, treatment, care and support: Social isolation, loneliness, depression and the consequences for people with dementia and carers

Abstract

Background: People with dementia who live in the community tend to participate less in activities for social participation outside home, for example visiting friends. This decline in social participation can negatively affect health and well-being. For the purpose of tailoring interventions that target their social participation, more research is needed to understand influencing factors.

Methods: A mixed methods study aimed to gain insight into factors that can influence social participation, including taking part in activities for social participation outside home, and getting to these activities and related places. Data of people with dementia living in Swedish communities (n=35) were collected using the Participation in Activities and Places Outside Home Questionnaire (ACT-OUT). Quantitative data were analyzed using Spearman's rank correlations, while free text comments were analyzed using a thematic analysis approach.

Results and conclusion: No statistically significant associations were found between the number of places visited for social participation and the four risk elements of getting lost, being afraid to fall, being stressed when going out, and being embarrassed when going out. Preliminary findings revealed that the following factors possibly influence the social participation of people with dementia who live in the community: (1) personal factors (e.g. being afraid to fall); (2) activity-related factors (e.g. familiarity of activity); (3) the social environment (e.g. social support); and (4) the physical environment (e.g. not adjusted places, traffic). It is anticipated that further analyses will reveal how different factors might interact with each other and influence their overall levels of social participation.

559

Human Rights, Adult Safeguarding And People Living With Dementia In Nursing Homes in Ireland- Giving Voice to the Issues.

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

People living with dementia (PLWD) innursing homeshave the right to be safe and to live a life free from harm and abuse; all persons are entitled to this right, regardless of their circumstances or where they live. Research shows however that people living with dementia are at greater risk of abuse and neglect than those without a diagnosis (Fang and Yan, 2018). Such abuse often goes unnoticed, because dementia may affect a person's ability to recognise abuse or to report it (Dixon et al., 2021). In 2021, the Alzheimer Society of Ireland's Irish Dementia Working Group (IDGW) commissioned the development of a briefing paper that would outline the key issues relating to upholding the human rights and safeguarding of PLWD in nursing homes including concrete recommendations for policy and practice.

This presentation reports on the co-development of the briefing paper between a safeguarding academic and the IDWG including the process of engagement in relation to the content, and reaching an agreement on recommendations and dissemination strategies. The briefing paper outlines what is adult safeguarding and abuse and explores some of the specific issues relating to abuse for PLWD in nursing homes. It examines the issue of human rights of nursing home residents, the specific impact of Covid19 on PLWD in nursing homes and current challenges to the protection of PLWD who may be experiencing harm, neglect, or abuse in nursing home care in Ireland including information on where to access access and support.



560

Let's Connect to challenge stigma and social isolation in dementia with touchscreen games

Prof Arlene Astell[1,2,3], Ms Erica Dove[3,1], Ms Maria Acenas[1], Mrs Teresa Shearer[4], Mrs Karen Cotnam[4], Mr Paul Gural[4], Ms Elicia Chamoun[3]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Introduction. Stigma contributes to social isolation experienced by people living with dementia. Touchscreen games are a meaningful and engaging pastime that people with dementia can enjoy playing solo or with others. We examined the impact on social isolation and stigma of training staff and volunteers in community programs, to introduce and play touchscreen games with people with dementia. Method. Thirty staff and volunteers (mean age 46.33 years) and 44 clients living with dementia (mean age 81.9 years; mean MoCA 9.18/30) participated in the 8 session Let's Connect touchscreen tablet program. Staff and volunteers completed the Dementia Attitudes Scale (DAS), while clients completed the Social Provisions Scale (SPS-10) and Quality of Life in Alzheimer's Disease Scale (QoL-AD) before and after. All participants completed a post-study interview regarding the tablet program.

Results: Pre- and post- comparison of staff and volunteer DAS total scores revealed a significant improvement (p=0.037), while there was no change in client's SPS-10 (p=0.950) or QoL-AD (p=0.122) scores. Thematic analysis of post-study interviews identified key benefits and challenges of the touchscreen tablet program experienced by staff, volunteers, and clients. Discussion.The results highlight the potential for training staff and volunteers to introduce and play touchscreen games with people with dementia. Although the scores of people living with dementia did not change significantly, thematic analysis highlighted the social aspect of learning and playing together. Additionally, seeing people with dementia learn to play and improve over time, challenged misconceptions and stigma held by staff and volunteers about their abilities.

561

Benefits and challenges of peer support online: experiences of people with Young Onset Dementia

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Topic

Dementia diagnosis, treatment, care and support: Importance of peer supporting and living well with dementia

Abstract

Aims: People with Young Onset Dementia (YOD) are at a high risk of stigmatization and social isolation. Peer support provides an opportunity for social connection and support. Research shows that people with YOD use online platforms for peer support. However, little is known about people's experiences with peer support in online settings. This study aims to explore how people with YOD experience online peer support, and what the barriers are.

Methods: An online survey was developed about people's experiences with online peer support, and for those who do not engage in online peer support, why this is and what barriers they face. Participants were people living with a YOD diagnosis. The survey was developed together with two people living with YOD and one carer.

Preliminary Results: 45 people took part in the survey. More than half never engaged in online peer support. The main reasons were not knowing about online peer support or where to look for support, and difficulties using technology was a barrier. Those who engaged in online peer support mainly used Zoom, social media, and email. Positive experiences included meeting new people and sharing experiences. Challenges included difficulties to keep up with the conversation and missing in-person interaction.

Conclusions: Online peer support can help people to stay socially connected and share experiences. However, many people did not know about online peer support or where to look for support. This indicates a need for more signposting and information about online peer support for people with YOD.



562

Dementia and elder abuse: Findings from a household survey in South Africa

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[1]University of Cape Town, Cape Town, South Africa. [2]Brighton and Sussex Medical School, Sussex, United Kingdom

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Abuse of older adults is a global public health and human rights concern and considered a hidden pandemic. Globally, one in every six people 60 years and older are said to have experienced some form of abuse, and for people living with dementia that figure is estimated at two in every three older adults. Elder abuse is a neglected public mental health challenge, with a lack of evidence in low-and middle-income countries like South Africa. This study will therefore be a first step towards understanding elder abuse from both older adult and carer experiences in South Africa, using the culturally adapted Elder abuse Screening Tool (EAST) and the Caregiver abuse screen (CASE) to assess risk of abuse. A household survey was conducted with older adults 65 years and older and household informants/ carers in an urban Cape Town and a rural Dikgale area, randomly selecting 800 households (400 in each site). We will present findings on risk of elder abuse for both older adults and carers and describe these findings in the context of those older adults who showed neurocognitive impairment suggestive of dementia (using the 10/66 short algorithm). Limitations to measuring elder abuse in South Africa as well as the support needs of carers, older adults and specifically persons living with dementia will be discussed.

563

A neighborhood volunteer-supported exercise intervention to promote brain health in persons with mild cognitive impairment: A waitlist randomized controlled trial

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Topic

Dementia research and innovation: Mild Cognitive Impairment (MCI)

Abstract

Aims: Physical inactivity is a salient risk factor for cognitive decline in persons with mild cognitive impairment (PwMCI). However, enabling them to adopt and maintain regular physical activity is challenging. This study evaluated the effects of a neighborhood volunteer-supported exercise intervention on cognitive function and health-related quality of life (HRQoL) in PwMCI.

Method: This randomized controlled trial recruited 208 PwMCI from April 2019 to October 2021 in the community setting and were randomized to either the volunteer-supported exercise intervention (n = 105), attending a 10-week multifaceted intervention to integrate exercise into lifestyle through neighborhood volunteering, or the waitlist control (n = 103). A battery of neuropsychological tests, including the Alzheimer's Disease Assessment Scale - Cognitive subscale (ADAS-cog), Digit Span Test (DST) and Color Trails Test (CTT) were used to evaluate different cognitive domains, and the Short Form 36 (SF-36) was used to measure HRQoL at baseline and post-intervention.

Results: Following the intention-to-treat principle, the linear mixed model analysis indicated significantly greater improvements in global cognition measured by ADAS-cog ($p = 0.024$), executive function measured by CTT ($p = 0.019$) and working memory measured by DST-backward ($p = 0.041$) in the intervention group as compared to those in the control group. However, no significant between-group differences were found in short-term memory and HRQoL.

Conclusion: This study demonstrated favorable effects of the neighborhood volunteer-supported exercise intervention in improving the global cognition, working memory and executive function among PwMCI. Longer term follow-up is required to reveal the sustained effects of this intervention.



564

Living with Dementia in Jordan: The Forgotten Battle of Alzheimers Disease

Dr Suha Al Ghoul
Al Oun for Alzheimer's Patient Care Association, Amman, Jordan. Doctor Suha Al Ghoul, Amman, Jordan. Hamza Nouri, Amman, Jordan

Topic

Dementia risk reduction: Public health campaigning

Abstract

Background: There are 2.3 million people living with dementia in the Eastern Mediterranean region out of 55 million people worldwide.

There is underreporting and low detection of the numbers for people living with dementia in Jordan. In addition, the support and facilities are scarce and not only show geographic variation but there are major differences in attitudes.

We describe the experience of a grass-root organization AACA formed to help DEMENTIA patients and their caregivers. It aims to raise awareness and improve the quality of life for people living with Dementia.

Methodology: The non-for-profit organization launched a community outreach project in collaboration with a group of healthcare providers from all Jordanian health sectors targeting marginalized communities in underserved and rural areas in Jordan.

The project organized community educational days to raise awareness on "Living with Dementia, diagnosis, and support". Participants include primary healthcare physicians, medical students, social workers, and nurses. The team assessed the visitor's needs and answered caregivers' questions. In addition, referrals were organized if needed.

Results: The outreach project captured national media recognition with positive feedback. One of the main critical findings was the knowledge gap amongst primary healthcare providers. In addition, caregivers voiced out concerns about social stigma.

Conclusion: Community involvement in Dementia awareness is the key to overcoming the challenges and obstacles facing people living with dementia and their caregivers.



565

Are we on the same page? Priorities for dementia care and policy from the perspectives of multiple stakeholders and service users

Dr Cheng Shi, Dr Gloria Wong, Dr Jacky Choy, Ms Kayla Wong, Prof Terry Lum, Prof Doris Yu

The University of Hong Kong, Hong Kong SAR, China

Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Aims: This study aimed to identify and compare the consensus-based priorities for dementia care and policy of the multiple stakeholders (including care professionals, policymakers, academicians, and the general public) and the service users (including persons living with dementia and family caregivers).

Method: Two Delphi studies were conducted using online survey with multiple stakeholders (n=79) and phone interviews with service users (n=100). The statements generated from the two panels were critically compared in terms of the contents and consensus level.

Results: 32 statements from the stakeholder panel and 25 statements from the user panel were identified, with the majority achieving moderate to high level of consensus. After consistent comparison, those statements were converged into six themes, including (1)early prevention, detection and referral system for dementia, (2)care and intervention services, (3)manpower capacity building for service providers within and across sectors, (4)supportive services for family caregivers, (5)development of longer-term dementia service planning and policy framework, and (6)promotion of dementia-friendly community. Despite similar priorities under each theme from the two panels observed, the stakeholders covered wider perspectives from a macro-level consideration. Meanwhile, the user panel achieved more high-level consensuses and focused on the microscopic unmet needs of persons with dementia.

Conclusion: Discrepancies between the two panels reflect the distinctive value of the engagement of service users in policy-making process. The findings provide implications for direction to promote integrated person-centered care for dementia and development of long-term dementia policy better tailored to the needs of various stakeholders.



566

Feasibility of a Dietary Intervention Using Coconut Oil to improve Cognition and Quality of Life in Older-Adults: Randomised Controlled Pilot study

Ms Raysa El Zein, Prof Jane Murphy, Dr Shanti Shanker

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Topic

Dementia risk reduction: Dementia and nutrition

Abstract

Background: Research has demonstrated associations between nutrition and cognitive impairments in older-adults specifically for the relation between glucose hypo-metabolism and neurodegeneration. Therefore, providing ketones as an alternative source of neuronal energy could reduce neurodegeneration and consequently, risk of dementia. Coconut oil (CO), rich in medium chain fatty acids (MCFA) can induce ketosis and potentially reduce neurodegeneration. The aim of the study was to evaluate the feasibility of a food-based intervention using CO to improve cognition and quality of life (QOL) in older-adults.

Methods and analysis: Thirty-one older-adults (mean age 74 ± 5.6 years, 17 women; 14 men) were randomised to receive either 30 ml/day of coconut oil (n= 18) or sunflower oil (n= 13) for 6 months. Recruitment, retention, adherence and fidelity were monitored. Quantitative data consisted of anthropometric, dietary, QOL, cognitive and blood ketone measures at baseline, three and 6 months.

Results: Ninety-one percent of participants completed the study (n=28/31). At 3 months, 13/15 (87%) participants adhered to CO and 11/15 (73%) participants for 6 months. Participants reported no issues with the study processes and procedures after 6 months. The intervention was positively received by participants and were able to incorporate the oil into their diet. Cohen d analysis on cognitive measures demonstrated a small effect size for the direction of benefit in the CO group.

Conclusion: Recruitment, retention, indicative results and participant acceptability data suggest the intervention is feasible for older-adults and support the development of a future fully powered RCT to measure long term effects.



568

Developing an Immersive Gamification Technology System (ImGTS) for the Management of Behavioral and Psychological Symptoms among Persons with Dementia (Phase 1 Trial)

Dr Veeda Michelle Anlacan[1,2], Mr Angelo Cedric Panganiban[3], Dr Roland Dominic Jamora[1,2], Ms Isabel Teresa Salido[4], Dr Michael Tee[5], Mr Gregg Lloren[6,7], Mr Francis Joseph Serina[8], Dr Jaime Caro[3]

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Background - Behavioral and psychological symptoms of dementia (BPSD) refer to a range of signs and symptoms of disturbed perception, thought content, mood, and behavior in persons with dementia. Despite being commonly observed, current pharmacologic and non-pharmacologic interventions addressing BPSD are limited in effectiveness. Virtual reality (VR) applications have shown promise in alleviating BPSD, but there are currently no applications specific to the Philippine culture, customs and lifestyle. Hence, this project embarked on the development of an immersive gamification technology system using VR for Filipino persons with dementia with the aim of managing their BPSD and improving their quality of life.

Aims: This ongoing Phase I trial aims to create a VR application for the management of BPSD in persons with dementia, and to determine its acceptability, usability, and safety.

Methods: The VR application will be developed and delivered through a head-mounted display system and/or a semi-CAVE system. Currently, the project has completed alpha testing of an initial prototype of the VR application. Participants of the alpha test included a select number of health professionals and experts in game development. Focus group discussions were also held where participants described and evaluated their experience with the application. Current efforts of the research team are focused on developing a beta version of the application for testing among the clinical trial participants.



569

Non-medical care costs of cognitive impairment and its association with dementia diagnosis in long-term care settings

Dr Cheng Shi[1], **Dr Gloria Wong**[1], Dr Jacky Choy[1], Dr Jennifer Tang[1], Dr Hao Luo[1], Dr Shiyu Lu[2], Ms Adelina Comas-Herrera[3], Prof Martin Knapp[3], Prof Terry Lum[1]

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Topic

Dementia as a public health priority: Economics of dementia

Abstract

Aims: This study aims to examine the association between non-medical care costs (i.e., social care and informal care) and dementia diagnosis among people living with cognitive impairment in long-term care settings.

Methods: We used staff time measurement to capture utilisation of service provided by formal and informal carers for public-funded service users in Hong Kong (n=1,518). Controlling for demographics, clinical characteristics and functional status, generalized linear models were employed to examine the incremental costs associated with dementia diagnosis among people with different levels of cognitive impairment.

Results: Mean annual non-medical costs for people presenting cognitive impairment with dementia diagnosis were most expensive, followed by those without dementia diagnosis and then the cognitively intact group (community: $17,792, $13,857 and $7,342, P= .000; care homes: $32,799, $28,019 and $16,524, P = .000). Compared with the cognitively intact group, an additional non-medical care cost of 39.4% and 83.0% were significantly observed among community-dwelling participants who were cognitively impaired without and those with dementia diagnosis respectively (18.4% and 38.5% for care home residents). Among people presenting mild to moderate cognitive impairment, dementia diagnosis predicted an increase of care costs by 25.3%, higher than those with severe cognitive impairment (11.5%).

Conclusions: Formal dementia diagnosis is associated with significant increases in non-medical care costs of cognitive impairment, particularly beneficial in community care setting and among those presenting mild to moderate cognitive impairment. Resources allocation to support dementia in long-term care settings should consider the presence of cognitive and functional impairment regardless of having dementia diagnosis.

570

A feasibility study of a decision aid to support family carers of people with severe dementia or those towards the end of life

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UCL, London, United Kingdom

Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

Aims: Family carers often make decisions about the health and wellbeing of their relative with dementia when the individual no longer has capacity.We developed and aimed to test the acceptability and feasibility of a decision aid for family carers of people with severe dementia or those towards the end of life.

Method: Feasibility study using a before-after design with a target of 30 family carers of people with severe dementia or towards the end of life.Family carers received a paper-based decision aid to be used whilst making decisions about care towards the end-of-life. Quantitative outcome measures were completed at baseline, 3 months, and 6 months, including the Decisional Conflict scale, and analysed using descriptive statistics. We conducted semi-structured interviews with family carers to explore acceptability, purposively sampling carers to gain a range of views, analysed using thematic analysis.

Results: 26 family carers (87% of target) completed baseline assessment and 20 (77%) of those were followed-up at 6 months. Almost all quantitative outcomes changed in a direction indicating improvement over 6 months, including the decisional conflict scale reduced by 4.14 [95% CI (-0.52, 8.80)]. Carers found the decision aid acceptable, explaining the decision aid as comprehensive, accessible with good engagement and breaking down the complexity of decisions.

Conclusion: The study met the success criteria to proceed to a larger evaluation study. In this presentation we will discuss the options for future evaluation beyond the traditional randomised controlled trial, and highlight aspects of the decision aid positively reviewed by carers.



571

How can technology support people with young onset dementia in the workplace?

Prof Arlene Astell[1,2,3], Dr Jen Boger[4], Mr Karan Shastri[4], Dr Kristina Kokorelias[1], Ms Sheida Marashi[4], Dr Charlotta Ryd[5], Dr Mervi Issakainen[6], Prof Anna Mäki-Petäjä-Leinonen[6], Dr Ann-Charlotte Nedlund[7], Prof Louise Nygård[5]

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Introduction: People who develop young onset dementia while they are working face multiple challenges staying in employment. Technology could provide some support for scheduling, tracking and completing tasks, depending on occupation and environment. We set out to examine existing research on this topic alongside the experiences of people with young onset dementia.

Method: A scoping review of the literature was conducted to identify existing technologies for people with young onset dementia in the workplace. We also interviewed 23 people with young onset dementia in three countries (7 Canada, 11 Finland, 5 Sweden) as part of a larger study into their experiences in the workplace, including the use of technology.

Results: The literature search was run three times over a 12 month period and returned no results, i.e. a null review. The interviews revealed a number of barriers and facilitators to workplace technology as well as adaptations individuals made using everyday technologies across the three countries.

Discussion: The needs of individuals with young onset dementia for technology in the workplace has so far been unrecognised in terms of research. Much can be learnt from the workplace experiences of people with young onset dementia to promote development of technological supports alongside other accommodations.

572

"Then they went to A&E. It just seemed to be the policy": Findings of an interview study involving bereaved relatives about emergency department visits by people living with dementia.

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Aims: Emergency department (ED) visits can be distressing for people living with dementia and risk several complications. A recent systematic review found specific patient and service-related characteristics associated with ED attendance towards the end of life. The aim of this study was to explore the mechanisms behind these associations, specifically the experiences of using health and social care services, including the ED, by people living with dementia and their relatives.

Method: Relatives of people living with dementia were involved in the planning of this study. Using purposive sampling, people with dementia and relatives were invited to interview. Topic guides for semi-structured interviews were informed by Thomas and Penchansky's (1981) five domains of access to healthcare. Interview transcripts were analysed using reflective thematic analysis.

Results: Fourteen interviews were completed with bereaved relatives. Relatives describe the ED as a 'last resort' for people with dementia and expect that calling for help will result in a non-negotiable automatic transfer to the ED. Relatives describe this automation being driven by the defensive practice of healthcare professionals, a blanket approach to care, and an inequity of accessible community support suited to the medical and emotional needs of the person living with dementia.

Conclusions: These findings from bereaved relatives implicate wider systemic influences on ED attendance for people living with dementia. They call for a single point of access to more integrated, personalised community services that operate in collaboration with relatives.



573

Rights Made Real; how the Irish Dementia Working Group led education sessions on human rights for their peers living with dementia.

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The Alzheimer Society of Ireland, Dublin, Ireland

Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

The Irish Dementia Working Group (IDWG) recieved funding from the Irish Human Rights and Equality Commission to create a course called Rights Made Real.

The course aims to empower people living with dementia to understand what their human rights are and to make those rights real and applicable in their lives.

The group worked with Professor Suzanne Cahill who developed the course to create 4 modules tomove human rights from something intangible that exists on paper to something that can impact the lives of people with dementia in a positive manner.

The course was delivered to people living with dementia and co-facilitated by a person living with dementia.

This presentation will chart the evolution of the Rights Made Real course

- the initial idea
- funding application
- collaboration with Professor Cahill
- course delivery (and the impact of COVID-19)
- course evaluation.

This is an important innovation from The Alzheimer Society of Ireland which has traditionally delivered training for informal caregivers and the organisation's staff. Rights Made Real offers a practical course for people living with dementia, and as one member of the Irish Dementia Working Group said '*our rights are everything, we must understand how to make sure they are protected'.*

574

The Greek Dementia Helpline: experience and impact

Mrs Patra Blekou, Dr Paraskevi Sakka, Mrs Antigoni Athina Leonti, Mrs Sotiria Megagianni, Mrs Panagiota Zoi

Athens Alzheimer Association, Athens, Greece

Topic

Support for dementia carers: Education and training for informal carers

Abstract

During the Covid-19 pandemic in Greece, quality and quantity of support for people with dementia and their family carers varies widely and depends on the availability of resourses in different areas. The pandemic forced an urgent transition from face-to-face to telehealth services.

The Greek Dementia Helpline 1102 was launched on February 2021, as a telephone service staffed by psychologists, neurologists and social workers with expertise in dementia care and is provided by Athens Alzheimer Association. The aim of the helpline is to offer counseling about dementia, to support and guide family carers and link them with community support services and programs. Between February 2021 and October 2021, more than 8000 people have called Helpline 1102 and more than 2500 people have contacted the line via email or live webchat (68% women and 32% men). The beneficiaries of the helpline were family carers (75%), health professionals (15%) and lay people requesting information on dementia prevention, care and treatment. Especially, carers were interested in availability of dementia services in different areas of Greece, disability allowances, legal issues, and how to choose residential homes or paid caregivers.

After using the Dementia Helpline, carers have reported increased sensitivity to the challenges faced by their loved ones with dementia, and more able to make the needed adjustments to their care-giving task.

Dementia Helpline 1102 provides dementia carers with a reliable a framework through the implementation of appropriate counseling by trustworthy healthcare professionals.Athens Alzheimer Association offers this service free of charge.



575

National Support Service - Pre Diagnosis and Beyond

Mrs Lorna Hart-Thomson
Alzheimer Scotland, Glasgow, United Kingdom

Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Purpose: People with dementia and their carers have arguably been the hardest hit population of the Covid-19 Pandemic. This presentation will share the work of Alzheimer Scotland's National Support Services, how we maintained contact with our community and evolved to meet the changing needs of people living with Dementia and their carers in Scotland.

What we did: The demand on Alzheimer Scotland's 24hr Dementia Helpline identified the need for the National Counselling Service and Action on Rights team to be established. These dedicated teams are providing critical support to people living with dementia and their carers. The evidence captured by our National Support Services are linking quieter voices in our localities to our national Active Voice through the National Dementia Carer Action Network and Scottish Dementia Working Group. By utilising these campaigning networks and support services we are mobilising peoples lived experience which is shaping dementia policy and legislation in Scotland.

Aims and Objectives:

- Provide information to empower people with dementia and their families
- Keep families informed of dementia policies and guidance
- Ensure families are engaged with local and national policy
- People with dementia and their carers feel better supported to make informed decisions
- Access practical and emotional support needed to address their anxieties and emotional needs arising from the pandemic

Obtain support to address the trauma and distress of the pandemic and restrictions'

Conclusion: To ensure nobody faces dementia alone by providing specialist services from pre diagnosis and beyond.

576

Constipation- A Hidden Etiology in BPSD

Dr Irshad Badarudeen, Dr Hanadi Khamis Al Hamad, Dr Mani Chandran, Dr Pravija Manikoth, **Dr Haajra Fatima**

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

Background: Among the multiple causes and risk factors forbehavioural and psychological symptoms of dementia(BPSD), physical ailment is a central variable thereby warranting thorough evaluation and elimination of the trigger factor.Constipation is one of the most common health problems encountered among older adults with dementia.Patients with dementia might not be able to express the pain and discomfort of constipation orally and may display aggressive behavior instead, mostly constipation will be untreated or the patient will be wrongly given an anti-psychotic drug.

We reviewed the literature to find studies on the prevalence of constipation in elderly patients with dementia presenting with behavioral and psychological symptoms.However, no studies were found indicating constipation as an important cause thereby stirring our curiosity to explore this easily reversible precipitating factor.

Aim: To evaluate the prevalence of constipation in persons with dementia and presenting with BPSD.

Method: Any patient with dementia presenting to the memory clinic with behavioral and psychological symptoms was referred to the elderly urgent care unit for detailed clinical assessment

Results: From July to September 2021,50 patients were referred from the memory clinic to the Elderly Urgent Care Unit. Out of these 36 patients were diagnosed to have constipation.

Conclusion: There has to be a paradigm shift neededto think of constipation as one of the main causes for behavioral changes in this cohort of patients upon initial assessment.



578

Caregiver Characteristics, Burden and Their Response on Online Educational Programme

Mrs Anja Kokalj Palandacic, Dr Polona Rus Prelog

University psychiatric clinic Ljubljana, Ljubljana, Slovenia

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Objectives: Millions of people over the world live with dementia.National Institute for Public Health of Slovenia estimates the number of people with dementia in Slovenia was 33.000 in 2018. This represents 1.60% of the total Slovenian population (2.067.284 people in 2018). Caregivers of people with dementia provide hours of complex care, that frequently cause stress which can result in immense burden.
For reducing caregiver burden we are offering an online educational programme. Doctors, clinical pharmacologist, occupational therapist and nursing staff give information on dementia, its symptoms, the correct use of medications, communication with a pearson with dementia and how to take care for sleep, daily activities, etc..

Methods/Design: With this study we aim to determine caregiver and recipient characteristics pre- and post- educational programme. We will assess caregiver knowledge on dementia, caregiver burden and their engagement in learning and skill implementation and determine the characteristics and disease severity of a person with dementia that is taken care of, and compare it to caregiver characteristics. We aim to determine a difference in characteristics of informal and formal caregivers.

Discussion: No study has yet compared caregiver characteristics and response to online education in less versus more severe care recipients and between formal and informal caregivers. We hope that this study will give answers how to adapt educational programmes according to severity of the disease and caregiver characteristics.

579

Pathways to improve the lives of people living with dementia: experiences from Brazil within the STRiDE programme

Dr Ana Carolina Arruda Franzon[1], Dr Elaine Fernandes Mateus[1], Dr Déborah Oliveira[2], Dr Fabiana Araújo Figueiredo da Mata[2], Ms Carolina Godoy[2], Dr Cleusa Pinheiro Ferri[2]

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

The Federation of Brazilian Alzheimer's Associations - Febraz is dedicated to transforming social and institutional healthcare practices and policies to ultimately support people living with dementia and their carers to live well. Our mission is to provide education, to advocate for and with families and individuals who live with dementia, and to strengthen the services and support offered by the affiliated Alzheimer's associations throughout Brazil. We are one of the seven non-profit organizations partnered with the STRiDE team – Strengthening responses to dementia in developing countries. The aim of this presentation is to share our experience of being part of this global strategy to improve the quality of life of those living with dementia and their family carers. We will present how evidence-based practice helped us inform the Brazilian National Dementia Plan, and how results from our local research framed a series of short documentaries narrating the experience of people living with dementia as a way of challenging stigma. We discuss how this groundbreaking joint work between researchers, policy managers and the civil society is relevant for advancing the public debate and awareness of dementia as a public health priority.



580

Role of community health workers in transdisciplinary models for decreasing the impact of dementia on care partners for persons suffering from dementia- a scoping review

Dr Subhadra K T
Kerala University of Health Sciences, Ernakulam, India

Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

Introduction: The care partners of people with dementia are often known as invisible second patient. They suffer from high rates of psychological morbidity, social isolation and physical ill health coupled with financial burden. They play an important role in the life of people with dementia and in providing a quality life for the person with dementia. Data suggest that impact of disease on care partner can cause higher frequencies of behavioral problems and agitation in patients with dementia when compared to those living with less distressed care partners. Studies have shown that collaborative care models with trans-disciplinary cadre of clinicians with nurses and community health workers (CHW) help in providing improved health and medical care to patients and families.

Aim: To conduct a scoping review to explore systematically the roles of CHWs in dementia-related services in terms of improvements in care partner's psychosocial parameters

Methodology: The review is conducted by searching PubMed, CINAHL, Scopus, CABI Global Health, Web of Science, PsycINFO, and Cochrane Library for the past 10 years using search terms caregiver burden and Alzheimer's disease or dementia

Conclusion: This scoping review sheds light on the potential roles of CHWs in addressing dementia and itsimpact on psychosocial parameters of care partners in a more cost effective and society friendly manner.Incorporating community health workers (CHWs) in this transdisciplinary approach can be a more cost-effective approach in dementia care strategies thus helping in decreasing the impact of dementia on care partners.

581

LANGaware: Utilizing multimodal, explainable Machine Learning for the early detection of neurodegenerative diseases

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Although Alzheimer's disease (AD) is associated with changes in spoken language, these have not been exhaustively subjected to large scale systematic analysis. We evaluated the effectiveness of LANGaware's language agnostic approach to detect language indicators coupled with Mild Cognitive Impairment (MCI) and early AD, assisting with their diagnosis. We evaluated LANGaware using speech recordings obtained from AD patients and matched healthy controls (NC) derived from various elicitation tasks across languages.

We obtain patient audio recordings from different verbal assessment tasks designed to highlight manifestations of cognitive decline through speech and language. We apply a multimodal approach, analyzing both audio and text transcript data via multiple sophisticated grammatical, syntactic, conceptual and linguistic features. The most discriminant features are extracted via rigorous feature selection stages, producing salient digital biomarkers capable of efficient classification of healthy and pathological cohorts, as well as robust differential diagnosis.

Evaluation results indicate that LANGaware achieves high performance across multiple metrics, for classifiers tuned for both different languages and multilingual configurations. Findings indicate that the discovered biomarkers contribute to the efficient prediction of AD / MCI versus NC cases. Additionally, they can be utilized to communicate valuable feedback to medical experts, enhance medical decision making, accelerate diagnosis and enable timely action.

We conclude that LANGaware provides a time and costeffective language agnostic platform for cognitive screening, pertaining to the detection of the early stages of neurodegenerative diseases, in a range of clinical settings. Future work includes extending our pool of biomarkers and supporting additional modalities and languages.



582

Telemedicine based intervention in a residential dementia care facility - feasibility and cost effectiveness

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aim: To study the feasibility and cost effectiveness of telemedicine based intervention in a residential dementia care facility in semi urban India.

Methods: Nightingales Centre for Ageing & Alzheimer's (NCAA) located in urban Bangalore provided telemedicine based interventions to 44 dementia patients residing at the Ellen Thombern Cowen Memorial – Nightingales Dementia Care Centre (ETCM-NDCC) located in semi-urban Kolar, India using specially designed dementia management software . The patients were initially diagnosed face to face and care plans were formulated by a geriatric psychiatrist and psychologists at NCAA. At ETCM-NDCC, the patients were then followed up once a week by the psychiatrist and thrice a week by psychologists to address general wellbeing and behavioral complaints through tele-consultation. The cost of dementia care at NCAA and ETCM-NDCC were compared and the quality of care at ETCM-NDCC was assessed based on NICE guidelines3.

Results: Feedback from the participants indicated a high degree of acceptance among the psychiatrist, psychologists, nurses and caregivers. The quality of dementia care through telemedicine was also as per NICE guidelines; however, it was noted that the training and expertise of the nurses and caregivers involved play a significant role in the effectiveness of this platform. Telemedicine based intervention also reduced the cost by 33 % in ETCM-NDCC as compared to NCAA.

Conclusions: Telemedicine-based intervention was effective in delivering dementia care to patients in residential care in remote areas. This model also reduces costs and increases accessibility to dementia care services in rural India.

583

Effective language-based strategies for communication with persons living with dementia: A scoping review of the caregiving literature

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Aims: Persons living with dementia (PLwD) have communication needs that can be challenging for their formal and informal caregivers. The caregiving literature offers effective language-based communication strategies designed to enhance coherence, clarity, reciprocity, and continuity when interacting with PLwD. However, little is known about the breadth of effective language-based strategies and the purposes for which their use is recommended. Therefore, this scoping review aimed to identify effective language-based strategies recommended for communication with PLwD.

Method: CINAHL, PsycInfo, PubMed, and Scopus databases were searched in January 2021 for peer-reviewed articles describing and/or assessing recommended language-based strategies. Empirical and nonempirical articles in English and French over all years were eligible for inclusion.

Results: After duplicates and ineligible records were removed from 5389 search results, thirty-three articles met the inclusion criteria. More than thirty language-based communication strategies were recommended, with the use of simple sentences, verbatim repetitions, and choice questions being the most frequently recommended. Strategies were most frequently recommended if they improve PLwD's language comprehension, expression abilities, or social collaboration. Strategies were recommended for use in various settings (e.g., long-term care, home care, hospitals).

Conclusion: A variety of effective language-based strategies are recommended in the literature to help caregivers resolve specific communication challenges and to enhance PLwD's comprehension, expression, and collaboration. What remains unknown is whether these recommended language-based strategies are all person-centered and the specific contexts in which they are person-centered. Future studies on these questions will help caregivers tailor their communication to the individualized needs of PLwD.



584

Assessing awareness in severe AD: a feasibility and pilot study.

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

AIMS: There is an urgent need to understand the nature of awareness in severe AD to ensure effective person-centred care. Transcranial Magnetic Stimulation (TMS) combined with Electroencephalography (EEG), Event Related Potentials (ERPs) and functional Magnetic Resonance Imaging (fMRI) are robust techniques for assessing awareness in clinical populations who are unable to communicate. We present novel feasibility and preliminary data on using these methods to assess capacity for consciousness and contents of awareness in severe AD.

Methods: a)TMS-EEG was performed in 6 healthy older controls and 3 people with severe AD. The perturbational complexity index (PCI^{ST}) was calculated as a measure of capacity for conscious awareness. b)ERPs were recorded during a masked visual perception paradigm and analysed for the presence of visual awareness negativity and P400 components, previously identified as associated with conscious visual perception. c) An fMRI movie-viewing task, validated in previous studies to demonstrate activation in a fronto-parietal network during conscious engagement with the film was also conducted.

Results: a) Participants with severe AD demonstrated a PCI^{ST} around or below the previously identified threshold for consciousness, suggesting reduced capacity for consciousness. b) In response to viewing faces, two patients with severe AD provisionally demonstrated similar visual awareness negativity to healthy controls. c) Healthy controls and one person with severe AD revealed spatially, but not temporally similar activation in a fronto-parietal network, suggesting differences in conscious engagement with the movie.

Conclusions: These biomarkers provide experimental approaches to assess awareness and improve understanding and care for people with severe AD.

585

Sex and gender differences along the 'Patient Journey' - a first step towards optimising care for persons living with Alzheimer's Disease.

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Topic

D**ementia research and innovation:** Sex and gender - impact, research, policy

Abstract

Past literature showed sex and gender differences in AD from clinicopathological phenotypes, risk factors, biomarkers to clinical trial recruitment. These highlight several sex- and gender-based factors that are not captured in a standard *'Patient Journey (PJ)'*. A PJ takes a patient-centric approach to paint a comprehensive individual's journey illustration from symptom onset to treatment completion. It is a crucial resource for persons living with AD, physicians, and industry, and when considering sex and gender differences, there are likely deviations between a male and female PJ.

We aim to map a comprehensive PJ that captures these differences. The goal of a personalised pathway would be to ultimately enhance the quality of care across the continuum by improving risk-adjusted outcomes for persons living with AD and meeting individual needs.

To derive stratified PJs, the project will assess characteristics and their impact on key milestones in the journey (Fig. 1) and cover 4 phases.

1. Screening and material development.
2. Data Collection: interview persons diagnosed with AD and caregivers on the proposed topics and characteristics (Fig. 1).
3. Compilation and analysis: interview responses and an in-depth qualitative data analysis of the surveys.
4. Finalisation of Pathways and Report: multi-country final report.

Figure 1.Proposed characteristics and topics that will be qualitatively assessed using the survey

A sex- and gender-stratified AD PJ can identify gaps along the journey and inform future developments in diagnostics, therapeutics, and all-around care. This is a stepping stone towards precision neurology, which aims to optimise the diagnosis and care.

LINKED IMAGES MISSING



586

Management of COVID-19 in Long Term Care Facility for people with dementia: Perspective from an Indian setting.

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

COVID-19 pandemic has majorly affected long-term care facilities (LTC) internationally. The negative impact of the pandemic and increased risk of infection on people with dementia (PwD) in LTC due to the prevalence of cognitive impairment and behavioral symptoms have been reported worldwide.

In India, there were no specific government-issued guidelines for long-term care during the pandemic. Nightingales Centre for Ageing and Alzheimer's (NCAA) in Bangalore, is a LTC for PwD with 100 beds. Although there were guidelines on preventing the spread of COVID infection, there were varying degrees of challenges in implementing these guidelines at NCAA due to shared accommodation, close contact physical care, and cognitive and behavioural issues in PwD. A major challenge was the psychosocial impact of the pandemic and lockdown on the staff providing care at NCAA.

We provide a commentary on challenges faced in response to COVID-19 and lockdown measures at NCAA. The absence of guidance from the government, the psychosocial impact of the pandemic, and lockdown on the staff, the effect of visitor restrictions on the residents, and the low staff to resident ratio hindered the delivery of quality care. We further discuss the experiences and learnings of managing around 100 PwD in the first and second waves of the pandemic. We believe the experiences will provide strategic directions and set standards for protecting and caring for older people with dementia amid the COIVD-19 outbreak in LTC facilities.

587

Human umbilical cord-derived mesenchymal stem cells improve brain function in Alzheimer's disease animal studies

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

Context: Alzheimer's disease is one of the progressive neurodegenerative diseases that affect people word wide, and there is still no definite cure for it. Human Mesenchymal stem cells derived from umbilical cord(hUC-MSCs) show promising result in studies and animal examinations and can be considered as a probable solution for this condition.

Aim: This review aims to analyze these stem cells' features, their mechanism of action, results of studies and the challenges ahead of this therapeutic technique.

Method: Review and original articles (since 2020) were gathered from PubMed, Science direct, Google Scholar and Web of Science with search titles related to "human umbilical cord mesenchymal stem cell therapy AND Alzheimer's disease".

Result: Animal studies indicate that hUC-MSCs can improve spatial learning and prevent memory loss by reducing the amount of Aβ plaques in cortex and hippocampus. Neuroinflammation is restrained by secretion of inti-inflammatory cytokine, reduction of pro-inflammatory factors and suppression of MAPK, ERK and JNK signaling pathways in hippocampus. Degradation of hyperphosphorylated tau alleviate production of neurofibrillary tangles. Synaptic plasticity is promoted, which can reverse cognitive impairment. hUC-MSCs can also inhibit neural apoptosis and promote neurogenesis.

Conclusion: Umbilical cord is an invasive source of stem cells which have shown superior differentiation properties than other types of stem cells and many promising abilities in treating Alzheimer's disease. But, low rate of migration and survival in brain, the risk of immunorejection and existing controversial results makes further studies and clinical trials necessary to evaluate the effectiveness of this therapeutic method in human.



588

COGNISANCE: Qualitative Findings on the Dementia Experience in Canada

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Aims: Dementia is characterized by a decline in memory and day-to-day functioning, resulting in life-changing physical, emotional, and psychological stress on people with dementia and their family. The projected impact of new dementia cases poses challenges for health and social care providers around diagnosing and supporting patients and their families affected by this condition. Phase 1 of this 5-Phase project aims to a) understand the current experiences of the diagnostic process and post-diagnostic support for people with dementia, their care partners, as well as health and social care providers in three Canadian provinces; and to b) describe barriers and facilitators to providing a diagnosis and post-diagnostic support from the perspectives of different stakeholders and examine differences across settings.

Method: Interviews and focus groups were conducted with persons with dementia, care partners, and health and social care providers. Qualitative thematic analysis was used to analyze the interviews.

Results: The data revealed barriers to diagnostic and post-diagnostic care, including stigma, lack of access, and wait times. Facilitators included education, relationships, and using a team approach. All participant groups felt that honesty and open communication were integral to the diagnostic process, and individualized support was identified as an essential feature of post-diagnostic care.

Conclusion: The findings improve our understanding of the experiences of dementia care from the lens of various stakeholder groups. Results informed the co-creation of campaigns and tools to improve the experience of post-diagnostic support for people with dementia, care partners, and health and social care providers.

589

Curated evidence-basedassistive products for dementia care and self-care

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

CogniHealth started an initiative,Project Purple, with the aim to curate evidence-basedassistive products that can be used for dementia care and self-care. Weresearched and tested products in the market that can help people with dementia stay independent and safe for as long as possible and help carers look after their own health and wellbeing.

Firstly, we conducted market research to identify products that could address several symptoms of dementia such as disturbedsleep,sundowning, poor eating & drinking, falls and wandering as well as address carer stress and anxiety. We have curated about 50 different products, ranging from technology innovations like intelligent hydration reminders, GPS watches, Dodow sleep device, light sensors to weighted blankets and aromatherapy devices.

Families were recruited and interviewed to understand their key care challenges, based on which products were supplied, tested, and reviewed.We worked with over 30 families across the UK - from ones at the start of their journey with dementia to those who have become former carers.

Thereafter, we collated feedback through Zoom interviews with the participants. Their feedback, experience of using the products, and their tips will be published on the CogniCare app and website that we have built for family carers looking after someone with dementia.

The families have shared how beneficial this experience has been for them right from being heard to the impact the process and products have had on them. They lookforward to accessing verified products all in one place.

This work was funded and supported by Life Changes Trust and Tide.



590

Dementia primary care in Canada: challenges and opportunities. Results of a national survey to identify dementia care needs of family physicians, people with dementia and care partners.

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

There is consensus that timely detection, diagnosis and ongoing care of people with dementia is primarily the responsibility of family physicians in Canada. Yet evidence indicates low to moderate diagnosis rates and significant challenges in management of dementia. This first-of-its-kind nationwide needs assessment survey was conducted to identify the barriers and experiences of physicians in providing dementia care, which included the vital experience of people with dementia and their care partners.

Close-ended survey questions were summarized through descriptive statistics. Qualitative data were coded into prevalent themes and subthemes using inductive and deductive approaches by two raters.

The surveys received 288 physician, 78 people with dementia and 485 care partner responses. Preliminary analysis indicates consensus between physicians, people with dementia, and care partners on 15 of 22 barriers to diagnosis and care. Barriers highlighted included gaps in education and support, community resources, and access to specialists, as well as the need for improved communication around care and diagnosis. A further 4 themes were highlighted by physicians and 3 themes by people with dementia that did not overlap, indicating divergent needs. 24.7% of physicians reported using practice tools for dementia care, 10% of whom use only 1 tool for all aspects.

Optimal primary care is a cornerstone of a comprehensive approach to supporting people with dementia and their care partners. Identifying gaps in knowledge and tools to support practice and developing new educational programs that are aligned with the needs of people with dementia are vital to improve primary dementia care.

593

Living really well with dementia in residential care

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

'Living well with Dementia', 'addressing ageism' and 'supporting older people with mental health conditions' are increasingly critical policy areas with our ageing populations.

As such, should the time arise that living in one's home becomes intolerable, historical factors, cultural pressures and system deficiencies conspire to deter people from choosing residential options, resisting suitable options and cast a shadow that can adversely impact quality of life and wellbeing.

Language that is commonly used, often without realising, can carry negative and limiting connotations which severely impact wellbeing and quality of life of our elder relatives, whom we individually respect, cherish and want the very best for.

We cannot easily change nor quickly reverse the limiting impact of historical factors, elements of our societal culture nor 'fix' the shortcomings of our Heath and Social Care system.

However, there are 'modern' models of care, leadership and partnership working, not necessarily new, but literally 'defy' the above limiting factors and remove them from the persons forward journey with substantial beneficial impact.

Models of care, with feelings based communication, founded in relationship and focussed on growth and possibility may not be prevalent in discourse concerning residential care, but are increasingly practised with massive positive impact.

Whilst the Health and Social care system is under considerable demand, perhaps stress and be difficult to navigate, this does not need to impact the positive experience, the growth and richness that is possible and increasingly practised in innovative residential environments, often to the surprise, appreciation and relief of loved ones.



594

COVID-19 infections and cognitive function in long-term care home residents in Southern Switzerland – empirical evidence of 'cognitive COVID'.

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aim: SARS-CoV-2, the virus that causes COVID-19, is neurotropic and may have a direct impact on cognition. We aimed to explore the association of SARS-CoV-2 seropositivity with cognitive function in a sample of older adults living in long-term care (LTC) homes.

Methods: We conducted a structured cognitive assessment in the context of a longitudinal study on COVID-19 seroprevalence among LCT residents in Southern Switzerland. Measurement of SARS-Cov-2 RBD IgG, IgM and IgA antibodies was performed with enzyme-linked immunosorbent assays (ELISAs) developed by Humabs Biomed. Trained interviewers assessed cognitive function using the validated REDcap electronic version of the 10/66 short schedule, which includes the CSI "D", the CERAD animal verbal fluency and ten-word list learning tasks.

Results: The sample included 162 participants aged 66 to 102 years (mean age=87.6 years; SD=6.4; 82.7% female). 47.5% of the sample resulted positive to a serological test performed between mid-November 2020 and mid-January 2021 (COVID-19 wave 2). In age- and education-adjusted linear regression models, global cognitive function scores were lower in residents with a positive serological test compared to those who tested negative (β=-0.17; $p<0.05$). We found similar results for the memory subdomain (β=-0.18; $p<0.05$), but not for language, verbal fluency, and orientation (all p values >0.05).

Conclusion: COVID-19 seropositivity was cross-sectionally associated with lower cognitive performance in older adults living in LCT homes relative to those who tested negative. Further investigations are warranted to study the potential long-term impact of COVID-19 on cognitive function and decline.

595

Implementation and feasibility of tele-consultation services for dementia during COVID

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aim: The study describes the operation of tele-memory clinic to improve the access to diagnosis and management of dementia during the pandemic. We report the demographic characteristics of individuals who availed the memory clinic services during the lockdown, reasons for assessment and strategies utilized for management of people with dementia at home.

Methodology:A total of 340 assessments were done during the pandemic using the telemedicine interface. Detailed demographic information, clinical history, activities of daily living and reasons for assessment were collected. Advice on management was provided and subsequent follow up were done. Outcome of the assessment were documented.

Results: This study explored the feasibility of introducing a telemedicine enabled memory clinic for management of people with dementia. The evaluation of 340 clinic sessions found high levels of satisfaction with the effectiveness of the model among the psychiatrist, psychologists and caregivers. Tele-memory clinic provided timely access to specialist care, enhanced follow-up and allowed better management of behavioural issues at home during the lockdown.

Conclusions: Telemedicine can improve the management of behavioral issues of people with dementia. It can mitigate the risk of infection associated with face to face consultation and yet provide the same quality of clinical assessment. The high satisfaction among the users allows for continued usage of tele-memory clinic platform the assessment and management of people with dementia in the community.



596

Help in Covid Times: A Trauma Informed Approach to Dementia Helpline Practice

Dr Margaret Brown[1], **Miss Jennifer Hall**[2]

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

In March 2020 Scotland went into lockdown, a traumatic and uncertain time for 95,000 people living with dementia in Scotland and their carers.

This presentation will describe how we identified and co-created a response to some of the distress we encountered through our Helpline.

Alzheimer Scotland's 24-hour Dementia Helpline has a dedicated team of highly skilled, homebased volunteers who remained ready to listen.

As the situation worsened, we began to hear extreme distress from our callers. We spoke to carers and people with dementia who would regularly express thoughts of suicide and utter despair. The overwhelming sense of guilt that carers described to the Helpline was upsetting and difficult.

Volunteers expressed feelings of helplessness, guilt, and frustration at not having the answers or the ability to improve the situation for callers. This led us to co-create a meaningful learning opportunity that introduces Trauma Informed Approaches into our Helpline practice. This aligned with experiences on the Helpline, built resilience and understanding of a trauma informed lens amongst the Helpline team.

The session *"Trauma Informed Responses to Helpline Practice",* is an introduction, raising awareness of trauma in people affected by dementia. It provides a safe space for Helpline Volunteers to:

- connect and explore a trauma informed approach
- examine early trauma and current trauma for the person affected by dementia
- explore a personal and organisational trauma informed approach

This session has had an instantaneous impact on Helpline practice. The early indicators of success have us striving to be a Trauma Informed Helpline.

598

Inclusive dementia care for an ethnically diverse population: a new conceptual lens

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Topic

Dementia awareness and friendliness: Diverse populations – inclusion, equality, cultural issues

Abstract

Together with Europe, Belgium knows an increasing share of older migrants with dementia. Various attempts are made to provide accessible and suitable care for them. Culturally sensitive and person-centered care are often put forward as approaches to achieve this goal. However, our studies involving older migrants with dementia, family and professional caregivers indicate that we need to rethink the dominant care approaches for this sub-population. These approaches do not meet the complex interaction of personal, cultural and religious aspects in defining care needs of older migrants and ethnic minorities with dementia, and fail to recognize the hidden structural and systemic exclusion mechanisms at the organizational and societal level shaping inequity in dementia care. With this paper we suggest a new conceptual lens for an inclusive dementia care provision for a diverse population. The conceptual lens centralizes the needs of the older migrant with dementia without being oblivious to needs of informal and professional caregivers that are present in the care relationship and which consequently influence the care provision. It points out that these individual needs are complex, dynamic, situational, and reflect challenges at the institutional and societal level. Accurately detecting, understanding and responding to the complexity of these needs is required in order to move toward inclusive dementia care. To conclude, this conceptual lens broadens the scope in the search for suitable and inclusive dementia care for an ethnically diverse population, suggesting that building blocks for this goal should be searched at the micro, meso and macro level.



599

Piloting an innovative knowledge translation and exchange approach on educational resources for care partners of people living with dementia

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Alzheimer Society of Canada, Toronto, Canada

Topic

Support for dementia carers: Education and training for informal carers

Abstract

Knowing that people have diverse learning styles and preferences for accessing information, the Alzheimer Society of Canada (ASC) piloted an expansion of a range of educational resources that we currently provide through a traditional medium (i.e., printed information sheets) to a multimedia range of knowledge transfer and exchange (KTE) tools.

The pilot project explored the practical application of KTE to a key education resource. A resource for the pilot project – an information sheet on communication for caregivers of people living with dementia – was chosen based on a data driven approach to assess need and impact (i.e., number of website views, downloads, printed resource orders and feedback from stakeholders). Using ASC's KTE framework and the results of an environmental scan that identified approaches used by other organizations, the team operationalized the KTE framework with a focus on: 1) audiences, 2) information channels, 3) feasibility and 4) accessibility. Through consultation with focus groups, staff and care partners, we developed a series of infographics and videos that provide practical communication tips for conversations with people living in the middle to late stages of dementia.

ASC also developed an operational process with the involvement of diverse stakeholders, ensuring those who turn to ASC for information can find up-to-date and evidence-based content through a variety of tools that are engaging, easy to understand and accessible. We will share how multimedia tools can be an effective educational and supportive approach for care partners who want to stay connected to people living with dementia.

600

Triple Jeopardy: Outcomes of a learning project in a high secure mental health setting, to enhance care for people with mental disorder and dementia

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

This is the first reported learning project about dementia care for nursing staff in a high secure mental health setting. This was a partnership project and programme of learning about people who are legally detained in hospital, have a mental disorder and dementia. This setting is difficult, and perhaps inappropriate, for people with dementia and staff may not be well prepared for care. This project addressed the risk of lack of staff knowledge when support and providing care for people with dementia in these secure settings. This project also addressed a lack of clarity about effective learning about dementia and how to understand the impact of learning on care.

We co-developed this learning programme as academics and nursing staff and teaching was a blend of online and face to face support. Staff were very expert in their own field of mental health nursing but had very little knowledge about dementia.

We report on the impact on staff members' knowledge and attitudes to dementia care using questionnaires from the learning sessions. These showed staff had increasing knowledge and recognition of personhood as specific outcomes.

The impact on practice was explored with groups of staff for up to two months after the learning sessions. These showed how staff were able to embed their learning, especially in improved communication. In particular, they showed enhanced expertise and compassion in providing good personal care. This resulted in an improved person centred, care experience for people with dementia and increased confidence in providing care for staff.



601

The development and co-creation of a digital empowerment intervention for people with dementia and their supporters who are fearful of disclosing the diagnosis to others

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Topic

Dementia diagnosis, treatment, care and support: Post diagnostic support for people with dementia and carers

Abstract

Background: Receiving a diagnosis of dementia can affect individuals' sense of identity, leading some to withdraw due to stigma, embarrassment or fear of what might happen if others were to find out about the diagnosis. "Who to tell, how and when" is a group intervention for people affected by dementia who are fearful of disclosing the diagnosis to others. The aim of this study is to adapt the intervention for online delivery, in light of the ongoing COVID-19 pandemic.

Methods: Application of a co-created, user-centred design in three phases. Phase 1: PPI group discussions with people with dementia, family members and other relevant stakeholders to inform platform, features and adaptation of pre-existing material. Phase 2: development of digital prototype. Phase 3: feasibility and usability testing with end users to inform prototype v. 2.0.

Results: We will present results from phase 1 and 2, including findings from the discussions with stakeholders and options appraisals for the peer support elements of a digital intervention. We will discuss general principles of adaptation from paper manual to digital intervention.

Conclusion: Online access to this intervention may be especially valuable for people who wish to maintain anonymity and privacy, for example people from cultural or ethnic groups where the stigma of dementia is high. Online versions of face-to-face interventions improve overall accessibility by providing choice.

602

Productive Ageing Approach to Supporting Digital Inclusion for People Living with Dementia and Their Carers

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Background: The COVID-19 pandemic has stimulated migration of community-based services to remote/virtual ones using information and communication technology (ICT). Although feasible in principle, difficulties accessing ICT due to cognitive impairment and low IT literacy can introduce inequality for disadvantaged groups. Technical support provided by cognitively intact older volunteers could promote digital inclusion.

Methods: This is an ongoing pilot research on the feasibility of training older volunteers to coach people living with dementia and their carers in using ICT for remote/virtual services using a mixed-methods approach.

Results: Among the 68 volunteers currently recruited (82% women, mean age 60.8 ± 5.1 years, 53% degree holder), their self-rated confidence of safely using videoconferencing software was 3.7 ± 0.7 (max. 5). Among the 78 dyads of people living with dementia and carers they support, majority were spouse/partners (51%). Qualitative data from carers suggested that people living with dementia adapted well to the online environment, despite being new to tablet computers and videoconferencing. There appear to be spill-over effects of learning to use other online platforms/tablet functions (e.g., App games). Carers considered remote delivery more convenient to arrange and save travel time, while traditional in-person sessions are more facilitative of larger-group interactions.

Conclusions: These initial observations align with previous reports that, even with memory impairment, people living with dementia can still be included in online services, and they see themselves as capable learners and would actively engage in novel learning using ICT, with appropriate support provided by peers.



603

Developing a plan to implement an eHealth intervention for people with dementia in care homes: a co-design study

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Topic

Dementia diagnosis, treatment, care and support: Telemedicine

Abstract

Aims: Early involvement of end-users in the design of an implementation plan is a key strategy for promoting translation of findings into practice. Despite positive findings around the use of eHealth in dementia care, how to ensure its uptake effectively remains unclear. The aim of this study was to co-design a theory of implementation to use an eHealth intervention for people with dementia in care homes.

Methods: An iterative qualitative co-design method was applied through a series of six workshops which focused on co-developing implementation strategies in response to factors identified to influence implementation. Participants included family carers of people with dementia, practitioners with experience of working in a care home and digital health experts. A deductive thematic analytic approach was taken, guided by the constructs of the Normalisation Process Theory (NPT).

Results: Implementation strategies identified included informing influential individuals about the intervention and developing educational materials to promote its value to promote 'coherence'. 'Cognitive participation' was targeted through strategies which aimed to maximise engagement with the intervention, including engaging care home management and identifying 'champions' to drive the intervention forward. To promote 'collective action', strategies included providing training, reminders for clinicians and equipment. Strategies around ongoing adjustment and evaluation of the plan targeted 'Reflexive monitoring'.

Conclusions: Co-design necessitates a shift in the traditional power balance between researchers and end-users to ensure collective ownership, equal participation and shared decision making. The theoretically informed strategies target mechanisms previously demonstrated to shape implementation process and outcomes, ready for user-testing in care homes.

604

Some Dance to Remember: Exploring the Psychosocial Effects of the Introduction of an Adaptive Irish Céilí Dance Group Activity with People Living with Dementia and their Carers

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Topic

Dementia research and innovation: Non-pharmacological interventions

Abstract

This research aimed to explore, in the context of the psychosocial effects of dance and movement, the experiences of facilitators and participants in a newly developed adaptive Irish Céilí dance programme for people living with dementia and their care staff. Research which explores the use of this dance genre as an arts-based activity for those living with dementia or their care staff is limited. The focus of this research is on the participants' lived experience. A qualitative approach, utilising semi-structured interviews, researcher observations, and a reflexive journal, was deemed the most appropriate for this research. The dance activity took place over a nine-week period. Interviews were staged prior to the first dance activity, at the mid-point stage, and after the final dance activity. Participant consent was sought on an ongoing basis. In advance of any data collection, ethical approval to conduct the research was sought from, and approved by, the Limerick Institute of Technology. The data was analysed using thematic analysis.

In the context of this research, Irish Céilí dance as an arts-based activity for those living with dementia and their care staff resulted in beneficial psychosocial outcomes including an enhanced ability for people living with dementia to reminisce. Their stories and memories of attending Céilí events in their past was evoked by participation in the dance classes and interview process. In turn, enhanced reminiscence was observed to have a positive influence on the mood and psychosocial well-being of both the participants living with dementia and the care staff participants.



605

Developing a Culturally Adapted Cognitive Assessment Tool for Qatar

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Background: Getting the right diagnosis is the most crucial step in the care of Dementia journey. Having a structured objective cognitive assessment is the central step in the diagnostic process.

existing widely used Cognitive assessment Tool like Montreal Cognitive Assessment (MOCA ,Nasreddine et al) has its limitations. Larner (2013) highlighted MoCA was normed in highly educated population and norms in lesser-educated, community-based, multicultural samples were not available, and its validity has never been thoroughly tested (Hummelova-Fanfrdlova et al 2006)

Here in Qatar in our routine clinical practice, we found MOCA scores were not rightly reflective of the cognitive ability of our Qatari elders as educational limitations played a factor in the ability of our elders to comfortably complete the assessment.

Addenbrookes Cognitive Examination -ACE 111 is a widely used tool to identify Cognitive impairment in conditions such as Dementia

We carried out the Cultural and Language adaptation of ACE 111,as a tool that our elders would find more at ease to attempt and complete.

Aim/Objectives: To Develop a Culturally adapted Cognitive Assessment Tool for Qatar

Methodology: Series of Multidisciplinary Multispecialty Led Workshops Including Addenbrookes Team from Addenbrookes Memory Clinic,UK with Qatar University and Hamad Medical Corporation Qatar -Multiple Specialties including Geriatrics, Geriatric Psychiatry, Neurosciences was held over 2020

Conclusion: Addenbrookes Cognitive Examination -Qatar Version is developed, Its now in the process to go through a validation study .

606

The stigmatization and the knowledge of dementia among future medical and social care staff

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

There is still little data on stigmatization and knowledge of dementia in Poland. Looking at these issues from the perspective of current students of medical and social faculties may be important for capacity building in dementia care in Poland.

The aim of this study is to assess the level of stigmatization and the knowledge of dementia among students in Poland. The study groups include university students of medical, humanities and social faculties: medicine, psychology, physiotherapy, occupational therapy. The study is conducted before the introduction of the dementia awareness campaign being a part of the *Cognisance*project.

Quantitative method was applied to examine the level of stigmatization and the knowledge of dementia among students. On-line questionnaire consisted of a sociodemographic section, the Alzheimer's Disease Knowledge Scale, the vignette of a person with moderate dementia, modified version of *the Family Stigma in Alzheimer's Disease Scale*and the question about the contact with any dementia campaign.

Analysis enables to determine the level of stigmatization towards people with dementia and its determinants among students in relation to the sociodemographic variables, including the educational background. Comparisons between groups of students of different faculties allow to additionally identify differences in the level of the outcome measures related to the social or medical field of study.

The results indicate the level of stigmatization and awareness of dementia among future medical and social care staff in dementia care in Poland and signal what elements in the curricula should be strengthened in order to optimize future dementia care services.

607

Association of Dietary Nitrate Intake with Cognitive Performance among Malaysian Older Adults with Elevated Blood Pressure

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Topic

Dementia research and innovation: Mild Cognitive Impairment (MCI)

Abstract

Several trials have suggested that inorganic nitrate intake may have benefits in reducing blood pressure and increasing cerebral blood flow. However, associations between inorganic nitrate intake and cognition in low-and middle-income countries have not been investigated. Therefore, this preliminary analysis embedded within DePEC nutritional intervention, aimed to determine the association between dietary nitrate intake (mg/day) and cognitive measures in Malaysian older adults with elevated blood pressure. A total of 71 older adults aged 50-75 years with elevated blood pressure measurements (systolic blood pressure: 120-159mmHg systolic; diastolic blood pressure: 80-99 mmHg) were recruited. Dietary nitrate intake was assessed using a validated Food Frequency Questionnaire (FFQ). Cognitive function was assessed using the Mini-Mental State Examination (MMSE) and The Montreal Cognitive Assessment (MoCA). Total nitrate intake was entered both as a continuous and categorical variable (tertials; <169.7mg/day; 169.7mg/day to <374.5mg/day; 374.5mg/day). Multivariate linear regression was used to explore the association between nitrate intake, cognitive function and blood pressure. Mean ± standard deviation (SD) of total nitrate intake was 340.70±270.20 mg/day, while for MMSE and MoCA scores were 25.3±0.3 and 20.8 ± 4.1, respectively. We found no associations between dietary nitrate intake (mg/day) with MMSE (p=0.834) and MoCA scores (p=0.450). Across increasing quartiles of dietary nitrate intake, there were no significant differences in systolic (p=0.548) and diastolic BP (p=0.101). Our findings suggest that dietary nitrate intake was not associated with cognitive function among older adults with elevated blood pressure. Further analysis in longitudinal studies with large sample size are urgently needed.

608

Emergency department visits for people with dementia towards the end of life: A systematic review of individual, clinical, and environmental factors.

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Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Aims: People with dementia can experience repeated crises and subsequent emergency department (ED) visits towards the end of life. However, attending the ED can risk distress, disorientation and further complications. The aim of this systematic review was to examine the factors associated with ED visits among people with dementia towards the end of life.

Method: Six databases (MEDLINE, EMBASE, ASSIA, CINAHL, PsycINFO and Web of Science) were systematically searched and supplemented with a review of grey literature. Data were extracted and synthesised using a pre-established strength of evidence algorithm. Results were categorised using a theoretical framework of individual, clinical, and environmental factors.

Results: Over 18,204 titles and abstracts were screened, 367 full-text papers reviewed, and 23 studies included for synthesis. There was moderate-to-high strength evidence that being of an ethnic minority background, having greater number of physical conditions, neuropsychiatric symptoms, and living in more rural areas were associated with increased ED visits. By contrast, being a woman, unmarried, of a higher socioeconomic position, living in a care home and receiving palliative care input were factors associated with reduced ED attendance.

Conclusions: This review identified specific characteristics of people with dementia who may be more at risk of attending the ED towards the end of life. It also highlighted potentially modifiable service-related factors. Further research is needed to explore the mechanisms behind these associations; however, these findings have potential to inform efforts for more targeted support for people with dementia near the end of life.



609

Older dementia caregivers can learn the technology to participate in group telemedicine with real-time tech support

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Background: COVID-19 has forced many to explore videoconferencing to meet with loved ones and engage in telemedicine. Older adults are less likely to have experience and confidence using videoconferencing technology. Many informal caregivers for people with dementia (PWD) are spouses, and thus older adults themselves. Challenges engaging in telemedicine prevent them from accessing the support they need to reduce caregiving-related distress and burden. We report here the technology-related issues that were encountered during a skills training program.

Methods: Family caregivers of PWD participated in a seven-session skills training program conducted via telemedicine. Details of technology assistance required before and during visits was recorded for each participant and their feedback regarding technology use was collected through survey and interviews at each group's conclusion.

Results: Approximately 70% of participants had some difficulty using videoconferencing technology. The difficulties ranged from reminders for enabling camera/microphone to personalized support including instruction on basic use of their device. Those who required significant initial support required continued tech support, but all were able to participate successfully without support by the final session. Participants who had technology challenges initially described feeling a sense of accomplishment and increased tech comfort by the end of the sessions.

Conclusions: While some older adults had difficulty using telemedicine technology, they were eager to learn and educable with personalized help. As technology and innovation to support PWD and their informal caregiver advances, we need to build in personalized tech support mechanisms to ensure that all interested users can participate/benefit.

610

Neurovascular dynamics is altered in Alzheimer's disease

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Aims: The vascular hypothesis of Alzheimer's disease (AD) argues that vascular factors, such as impairment to the blood-brain-barrier, are responsible for pathways leading to neuronal damage. Our aim was, by using novel non-linear methods of analysis, to investigate the phase interactions between cardiovascular oscillations and brain waves, and to establish how they change with AD.

Method: We recorded resting-state cerebral blood oxygenation (fNIRS) and brain electrical activity (EEG) simultaneously for 25 min in people with AD (N=17, age = 71.2±7.2yrs) and closely age-matched control participants (N=20, age = 68.7±6.6yrs). To characterise cardiorespiratory oscillations, heart rate (ECG) and respiration rate (using respiration effort transducer) were recorded. Methods for finite-time dynamics were applied to extract instantaneous phases, and to obtain the level of phase coherence between them.

Results: The wavelet power of fNIRS recorded over the frontal lobe is significantly reduced in AD, especially for oscillations with periods of 7-50 seconds (0.021-0.145Hz, corresponding to what are known as neurogenic and myogenic oscillations). The coherence between oscillations in the parietal and frontal areas is significantly reduced in AD for most of the oscillations, and in particular for those related to the endothelial, neurogenic and myogenic vascular activities. The fNIRS-EEG coherence is significantly reduced, particularly for oscillations with periods of 7-50 seconds. A positive phase shift between the heart rate and fNIRS signals was detected in AD, and a negative phase shift was detected for control participants.

Conclusion: Our results confirm that AD is associated with altered cardiovascular and neurovascular dynamics.



611

Evaluation of the effectiveness of the Virtual Workshop for Training Community Health Worker (CHW) in Santos/Brazil

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Topic

Dementia as a public health priority: Dementia policy and plans

Abstract

Objective: To evaluate the effectiveness of the CHW continuing education action to help detect possible signs of dementia.

Method: This pilot study was approved by the Human Research Ethics Committee of the Federal University of São Paulo. Participants received the link to access the online questionnaire that contained sociodemographic information, professional performance and knowledge about dementia. Inclusion criteria were: being a CHW in the city of Santos, being available for the 10 meetings, having access to the internet and electronic devices. The workshop involved 10 weekly meetings, lasting 1 hour and a half, at night, held on the Google Meet platform. In the pre- and post-workshop, the Alzheimer's Disease Knowledge Scale (ADKS 1 and 2) was made available in digital format to assess the workshop's effectiveness. During the workshop, topics related to the seven premises of the World Health Organization (2012) were addressed. All online assessment instruments were cataloged in an Excel spreadsheet for statistical analysis.

Results: 33 CHW participated. There was an increase in the mean from the initial assessment of ADKS 1 (16.3; sd = 3.46) to the final assessment of ADKS 2 (21.24; sd = 3.29), which demonstrates statistical evidence of this change ($p < 0.001$), with a mean increase after the intervention of 4.94 points.

Conclusion: It is urgent to invest in continuing education for the CHW so that there is greater awareness for the timely detection of dementia cases even in primary care, in addition to awareness of potentially modifiable factors.

612

Connecting generations in Belgium: influencing children's perspectives positively on ageing and dementia

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Topic

Support for dementia carers: Young carers

Abstract

Aims: Positive qualities of children can be used to lighten the burden of dementia for society. Every child has on average one grandparent with dementia. The primary objective of this study is to connect generations and increase quality of life by translating the 'hidden victims of the disease' into 'hidden resources'.

Method: We developed a mobile application ('MemoryHome') based on the ancient mnemonic 'the method of loci' (MoL). The digital tool allows children (n=31) to construct personalized memory walks throughout the known environment of grandparents and dementia patients. Previous research mainly focused on the MoL as a solitary activity for Alzheimer patients to delay memory problems. Our novelty is to use the MoL as a dyadic intervention to increase well-being by introducing the concept of a 'co-walker'. The visual-audio-guide encourages conversation between the elder person and the child.

Results: Deliverables will generate both scientific and social impact. By this intergenerational project we retrieve insight in children's experiences using the MoL to communicate and connect with the elderly and understanding of the feasibility of the intervention including the procedure and outcomes. This project results in co-created educational programs and artistic expositions of children's drawings of ageing and dementia for the general public.

Conclusion: Positive interventions could reshape children's attitudes towards ageing. Positive qualities of children can be used to lighten the burden of dementia for society.



613

Development of WHO's Package of Interventions for rehabilitation: A systematic review of quality dementia guidelines for rehabilitation and future directions

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Topic

Dementia diagnosis, treatment, care and support: Rehabilitation

Abstract

Aim: As a vital step for the development of the World Health Organization's (WHO) Package of Interventions for Rehabilitation, we conducted a systematic review of clinical practice guidelines (CPGs) for dementia to identify recommended rehabilitation interventions for dementia.

Methods: Following WHO Rehabilitation Programme and Cochrane Rehabilitation's methodology, quality clinical practice guidelines published between 2011 and 2020 were identified using four sources including academic databases (PubMed, Embase, CINAHL, PEDro), Google Scholar, guideline databases, and professional society websites. Guideline quality was assessed using the Appraisal of Guidelines for Research and Evaluation (AGREE-II).

Results: Three-hundred-thirty rehabilitation related recommendations, mostly concentrated in the areas of cognition, emotion and carer support, were identified from six quality dementia CPGs. Key insights include a notably small proportion of recommendations relevant to dementia rehabilitation, with a marked absence of recommendations designated for assessment or service, and lack of high-quality evidence in almost all areas of rehabilitation across most of the guidelines. Major limitations were found both in the quality of evidence and scope, in terms of the range of functional domains for which people living with dementia would require assistance.

Conclusion: Further rigorous research is needed to build quality evidence in dementia rehabilitation in general, and especially in neglected areas for rehabilitation such as education and vocation, community and social life, and lifestyle modifications. The need for a greater understanding and acceptance of the concept of rehabilitation in dementia is paramount as it plays a crucial role in delivering and accessing rehabilitation services.

614

Influencing factors and strategies to support communication between older adults with dementia and caregivers throughout the care trajectory

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Aims: Communication between older adults with dementia and their carers is often extremely challenging. Although communication is an essential aspect of life and caregiving, the conversational process is often complicated in the context of dementia. Therefore, we aimed to distinguish prominent factors that impact communication and we examined strategies to enhance communication throughout the care trajectory.

Methods: Influencing factors were determined by using a scoping review and we included a thematic analysis of the literature. These defined factors were validated using a large variety of video observations and additional qualitative interviews (n=15). To determine effective conversational strategies, we performed think-a-loud sessions with experts and we explored literature reviews of different fields of expertise (f.e. nudging, social influence, compliance-without-pressure and consumer behavior).

Results: The thematic analysis resulted in the 'COmmunication Nursing sTAff and Clients with Dementia'-model (Contac-d-model). The model visualized several factors in three main areas: the older adult, the caregiver and the context of the caregiving environment. Conversational strategies as 'The-foot-in-the-door', verbal mimicry and 'The illusion of choice' could support communication throughout the care trajectory and provide novel and useful insights.

Conclusion: This study gained important awareness into influencing factors on communication between older adults with dementia and their caregivers. The Contac-d-model should be interpreted as a frame of reference, informing about potential targets to change or improve the communication process in a given situation.



615

COVID-19 and cognitive performance: a nested case-control study in older adults from Ticino, southern Switzerland - preliminary results.

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aim: We aimed to study the association of serologically confirmed SARS-CoV-2 infection with cognitive performance in older adults without dementia.

Methods: We used a case-control design nested into a cross-sectional study. Caseness was defined using serologically confirmed COVID-19 infections based on anti-SARS-CoV-2 antibodies. We selected matched seronegative controls, and conducted in-person neuropsychological assessments, using validated, age-standardized, domain-specific tests of memory, reasoning, language, orientation, and attention.

Results: 38 older adults participated in the study (mean age was 83.13, 86.8% women). 17 were community-dwelling individuals and 21 lived in long-term care homes. 14 were cases (36.8%) and 24 controls (63.2%).

In linear regression models, compared to controls, cases obtained significantly lower scores in attention (β=0.388, p= 0.036), executive functions (β= 0.326, p= 0.046) and memory tasks (β=0.367, p= 0.023) and similar scores in tests of language and spatial-temporal orientation (p values > 0.05).

Conclusions: Covid-19 infection was associated with cognitive impairment, in particular in the memory, attention, and executive functions domains. Our results provide preliminary yet clear empirical support for the "cognitive covid" construct, and suggest that COVID-19 might have mid- to long-term effects on cognitive functions.

Cognitive domains covered and related used instruments are listed in the table.

Cognitive domain	Test
Memory	10 words list learning test (CERAD)
Attention	Trail Making Test part A and B
Executive Functions	Trail Making Test part B Stroop's test
Language	Semantic and phonemic verbal fluency tests
Orientation	Clock drawing test. Date, month, year, day of the week, place, city

616

Modifiable Risk Factors for Cognitive Decline and Dementia: Evidence from China Health and Retirement Longitudinal Study

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Existing evidence on the association between modifiable risk factors and dementia is mainly generated from western countries and/or based on meta-analyses of aggregated statistics. This study systematically examined the relative contribution of a wide range of modifiable risk factors in cognitive decline and risk of dementia in a Chinese representative sample.

Methods: Participants aged 60 years or older at baseline in the China Health and Retirement Longitudinal Study (CHARLS) were included. Individual-level data from four waves between 2011 and 2018 were employed. City/county-level air pollutant (NO2and PM2.5) concentration and GDP per capita were extracted from satellite instruments and statistics yearbooks. Three-level multilevel models and Cox proportional hazards models were fitted to assess the association between eleven modifiable factors and cognitive decline and dementia risk, respectively.

Results: A total of 6,758 participants were included. Higher levels of education (primary school: β = 4.51, 95% CI: 4.21-4.80; middle school and over: 6.28, 5.94-6.63) were associated with higher cognitive performance at baseline, while hearing problem (-0.74, -1.05--0.43), depressive symptoms (-0.11, -0.12--0.09), social isolation (-0.93, -1.15--0.71) and polluting cooking fuel usage (-0.65,-0.90--0.40) were associated with lower cognitive performance. The smoking history (-0.11, -0.19--0.03) was associated with the fastest cognitive decline. No significant association was found between air pollution and cognition. Most significant risk factors of dementia were stroke (HR=1.73, 95% CI: 1.14-2.63) and dyslipidemia (1.73; 1.28-2.34).

Conclusions: The relative contributions of the individual- and area-level factors of cognitive decline differed from prior studies, highlighting the need for context-specific dementia prevention strategies.



617

Knowledge about Dementia in a regional public health crisis: Using the DKAS-S assessment scale in a Venezuelan cohort.

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Topic

Dementia as a public health priority: Dementia, human rights and equitable society

Abstract

Introduction. Dementia knowledge and prevention can vary amongst populations, and face multiple challenges in different healthcare systems. The Dementia Knowledge Assessment Scale (DKAS) is a valid, reliable and feasible tool recently translated to Spanish for assessing knowledge about dementia; however, there is a limited information about its implementation at large scale in countries such as Venezuela,with a severe public health crisis, considered as a regional humanitarian emergency.

Objective: To assess the knowledge about dementia in a Venezuelan population using the DKAS-S scale.

Methods: In a clinical, descriptive, and cross-sectional study, we applied the DKAS-S scale to 90 participants between 40 and 75 years old, who attended the adult triage atthe emergency department in the Central Hospital of Maracay. The data was statistically analyzed using Epi Info 3.4.5.2.

Results: The average overall scale score obtained was 21.91 ± 6.27 points. A total of 35.6% of the population scored less than 20 points and 64.4% scored between 20 and 40 points. Amongthe four DKAS-S subscales, Subscale D, which is about risk factors and health promotion, 78. 2% scored lower than 6 points. Conclusions.Comparing with other countries, this study shows that the knowledge about Dementia is lower in this Venezuelan cohort, and the majority of participants are unaware of its risk factors, health promotion, and preventive measures, than similar cohorts reported in other countries. Based on these important findings, we suggest creating hospital and outpatient information campaigns aimed to prevention of risk factors, as well as carrying out more researches on the subject in developing countries.

618

Impact of COVID-19 on the life quality and loneliness of people with dementia and their carers: Findings from the DETERMIND and DETERMIND-C19 studies.

Dr Ben Hicks
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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aim: This presentation discusses the DETERMIND and DETERMIND-C19 studies (determind.org.uk). These examine inequalities in the post-diagnostic care pathway and understand their impact on life quality and well-being for newly diagnosed people with dementia and their carers.

Method: Using face-to-face interviews, this cohort study collected numerous assessments on cognition, life quality, service use and well-being from 261 people with dementia and 206 carers in England prior to the COVID-19 pandemic. Between July-October 2020, these participants were re-interviewed by telephone. Latent Growth Curve modelling examined change in life quality, loneliness and associations with participant characteristics.

Results: Compared with pre-pandemic data, carers had statistically significant decline in quality of life although life quality did not change for people with dementia. In multivariable analyses, higher levels of cognitive impairment, area deprivation, study site, and lower number of memory clinic contacts were associated with greater decline in carer quality of life. In carers, higher levels of loneliness were directly associated with carer type (co-resident), increase of anxiety in carer and higher cognitive impairment in people with dementia. In people with dementia, carer type (non-co-resident), well-being and cognitive impairment contributed to levels of loneliness.

Conclusions: Maintaining life quality and reducing loneliness in people with dementia during the pandemic appears to have come at the expense of that of their carers. This inequity has fallen hardest on those caring for people with more severe dementia, in deprived areas, and with least support from memory services. These negative effects may be prevented or reversed by continued post-diagnostic care.



619

The power of messaging: A global examination of a rights-based approach to dementia

Ms Brenda A Fagan
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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aim: What messages are dementia associations conveying to persons living with dementia (PLWD), care partners and the public about dementia? Per social constructionism, societal values are communicated through messaging that reflects people's attitudes and beliefs. Messaging has the power to shape attitudes about dementia and people living with the condition. This study used mixed methods to examine and compare dementia messaging for alignment with a rights-based approach.

Method: Using a purposive sampling method, I conducted an ethnographic content analysis of website homepages of Alzheimer's Disease International (ADI) member associations (*N* = 36) that represent countries that signed the global action plan on the public health response to dementia (GAPD). Open coding helped identify themes and sub-themes to generate categories corresponding to the pre-structured variables of *focus*, *attitude* and *intended receiver* of messages. I then compared proportions of the categories across all countries in the study.

Results: Most messages in the sample were person-focused, intended for families of PLWD, and delivered with neither a tragic nor hopeful attitude. PLWD were the intended receiver of 6.5% of all messages. Messages varied by country for focus, attitude and intended receiver. Sixty-one percent of the sample countries contained at least one individual rights-based message.

Conclusion: This study draws attention to variations in dementia messaging by national associations and the components needed to support a rights-based approach. Dementia associations are a referral source for information and should include messages of hope and empowerment for PLWD. Future research should include the perspective of PLWD.

620

COVID-19 and dementia: The association of cognitive performance with adherence to hygiene measures and concerns

Ms Gwendolyn Graf[1], Ms Deborah Pacifico[2], Dr Marco Kaufmann[1], Prof Emiliano Albanese[2], Dr Anja Frei[1], Prof Milo Puhan[1]

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aim: Older adults with cognitive impairment may be at higher risk of COVID-19 infection compared to cognitively healthy counterparts because of poorer adherence to preventive measures and risk perception. We aimed to explore the association of function with adherence to hygiene measures, and concerns regarding the COVID-19 pandemic.

Methods: In this cross-sectional study, we included a population based random sample of people, aged 65 or older, living in the Canton of Zurich (Switzerland) who participated in the Corona Immunitas study, a national serosurvey. We assessed cognitive function with the 10/66 short schedule and enquired about adherence to preventive hygiene measures, and level of concern regarding the pandemic.

Results: We included 663 participants, aged 64 to 101 years (mean age=73.0 y; SD=6.1), 52.5% male. In linear regression models, higher scores of overall cognitive function (B=.065, 95%CI 0.01 to 0.13, p=.036), spatial orientation (B=.28, 95%CI 0.01 to 0.55, p=.04), language comprehension (B=.809, 95%CI 0.39 to 1.23, p<.001) and language competency (B=.613, 95%CI 0.25 to 0.98, p<.001) were all positively associated with better adherence to hygiene preventive measures. Higher overall cognitive scores (B=-.071, 95%CI -0.13 to -0.01, p=.016) and language expression scores (B=-1.025, 95%CI -1.89 to -1.15, p=.021) were inversely associated with concerns regarding the pandemic.

Conclusion: Our results suggest that cognitive function can modulate the risk of COVID-19 infection through poorer adherence to preventive measures, and weaker risk perception. This may imply that also people with dementia likely need tailored interventions to avert their risk of contracting COVID-19.



621

Care Plans for People with Dementia and Guidelines for Community Connection

Ms Minji Kang[1], Ms Miyoung Kwak[2,1], Ms Okjin Rhee[1], Dr Jeewon Suh[1,3], Dr Imseok Koh[1,3]

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Korea has set up Local Dementia Centers at the local government levels to provide better access for people with dementia and their families. However, there are criticisms that it is inadequate to provide patient-centred care. Care for PWD needs to shift from provider-centred to patient-oriented. Applying care plans for PWD and community-connection guidelines starting in 2022 will be a representative case. In 2021, the Korean government collaborated with researchers from the National Institute of Dementia to develop community-connection guidelines for care plans for PWD.

The top three areas that the survey of workers at the LDC believes improving are as follows: the development of standardized guidelines (72.6%); information sharing (63.7%); and promotion of the LDC and guidelines to affiliated organizations (45.3%). The result also emphasized the necessity of staff training programs and creating an integrated management system. The care plans currently under development will ultimately include evaluation items for medication, psycho-behavioural symptoms, abuse/negligence, long-term care, companionship in case of emergency, financial burden, and other issues. For each item, the standardized guidelines will be created as a reference to be organically linked with other local community-based organizations.

Care plans and guidelines will be carried out by multidisciplinary teams (doctors, nurses, social workers, physical/work therapists, etc.). It is like local community integrated care, where medical care, long-term care, welfare, and public health services are included.

Korea contributes to globally shared solutions of better service by providing continuous and customized services, according to the care plan community-connection guidelines.

622

Build Big data by Linking Korean Dementia Registry and Management System with Other Related Systems

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Topic

Information systems for dementia: Registries

Abstract

Korea has provided standardized services for people with dementia and caregivers through Local Dementia Centers. By a dementia registration statistics system, visits to an LDC have been systematically managed. Data such as demographics, benefits receipt and counselling are registered.

However, there exists a lack of foundation in the system that would link all the stakeholders, such as LDC, local community organizations, public institutions (the National Health Insurance Service, etc.), and private institutions (Local Welfare Centers, etc.). This link will enhance sharing information, refer each other, and find the low access (blind spots) and duplicate payments.

The Ministry of Health and Welfare and the National Institute of Dementia began linking data between theLDCsystem and the NHI Service from 2021. For those aged 66 and over, the NHI Service's cognitive screening results have been shared withLDCs. It is expected to improve the efficiency of post-management and programs detecting dementia at theLDC.After 2022, it will be expanded further by establishing a linkage with the local government system(Next-Generation Social Service Information System).

It will allow the government at different levels to provide essential services to PWD by combining service information and pre-medical history. In the future, it will be possible to provide an infrastructure for various organizations to support comprehensive welfare needs for PWD. The big data collected via widely linked systems will be practically used for the public interest, such as policymaking or research on vulnerable populations.



623

Association between older adult and family member reports of wellbeing and caregiver preparedness, depression and anxiety and its relationship to early detection of dementia

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Objectives: Identifying Alzheimer's disease and related dementias (ADRD) early may be equally or more impactful on family members given the role that caregivers have in assisting patients navigate ADRD. This project describes the baseline characteristics of patient and family member dyads who are enrolled in the Caregiver Outcomes of Alzheimer's Disease Trial and measures the association between patient reported measures and family member reported measures relevant to early detection of ADRD.

Methods: The primary family member reported outcome is global mental health measured by the SF-36 mental health component sub-scale and secondary measures include depression, measured by the PHQ-9, anxiety, measured by the GAD-7, caregiver preparedness, and caregiving self-efficacy. Regression analyses to test the association between patient and family member measures.

Results: 1808 dyads.Family members average age was 64.2 years; 67.7% female; 13.4% African American and 84.6% White. 64.8% are the patients' spouse or partner and 27.8% are the adult child. After controlling for patient and family characteristics, higher levels of patient depression are significantly associated with poorer mental health for family members. Higher caregiver self-efficacy is significantly associated with lower rates of family member depression and anxiety and better mental health. Higher levels of caregiver preparedness is associated with better measures of family member mental health.

Discussion: In a large sample of dyads of older adults and family members who are participating in an ADRD screening trial we found that important constructs that measure the impact of early identification of ADRD on patients and family members are associated.

624

Meta-analytic comparison of risk factors for mild cognitive impairment and Alzheimer's disease between Hispanic and non-Hispanic white subjects

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Topic

Dementia research and innovation: Epidemiology

Abstract

Some of the recognized risk factors for mild cognitive impairment (MCI) and Alzheimer's disease (AD) are Hispanic ethnicity, having one or two copies of the APOEe4 risk allele, and a history of hypertension, stroke, or depression. The aim of our meta-analysis study is to compare the differences of the risk factors contributing to MCI or AD between Hispanic and non-Hispanic white (NHW) subjects by combining studies for a large cohort. Starting with data discovery in the Global Alzheimer's Association Interactive Network (GAAIN), we chose the Alzheimer's Disease Neuroimaging Initiative (ADNI) and the National Alzheimer's Coordinating Center (NACC) data sets for APOE and longitudinal analyses. We also included the Health and Aging Brain Study: Health Disparities (HABS-HD) data set to analyze health risk factors. Interestingly, Hispanic subjects with one or two copies of APOEe4 were less likely than NHW subjects to develop MCI or AD over time. In addition, Hispanic subjects with APOEe2 were less likely than NHW subjects to be protected against developing MCI or AD. We also found that Hispanic subjects had higher risks of developing hypertension and stroke, which are risk factors for developing MCI or AD, and that Hispanic subjects with a history of depression had a higher risk of being diagnosed with MCI or AD compared to NHW subjects. This study contributes to deciphering the differences in MCI and AD risk factors between Hispanic and NHW subjects, helping to inform future cohort studies to address health disparities.



625

Trends in electronic searches for dementia in Mexico: 2004-2021

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

Identifying search trends in relation to dementia-related keywords can be an important tool to determine the population's interest in these terms and whether there have been variations over time. Therefore, the aim of this paper is to describe the interest in searching for information related to dementia and dementia care in Mexico. For this purpose, an analysis of searches was carried out using Google trends during the period 2004-2021. The following keywords were used: dementia, senile dementia, Alzheimer's, Alzheimer's disease, and memory problems. In general, we observed the maximum interest was between 2004-2006, however, there are some important variations. The terms dementia and senile dementia show an increase in the last 5 years. While the terms Alzheimer's and Alzheimer's disease have remained constant with a medium level of interest, the term memory problems had a peak, but in general, has maintained low levels of interest. In conclusion, we observed that between 2004-2006 there was a marked interest in searches related to dementia that has not been observed again, which identifies a need to implement massive dissemination campaigns on dementia and Alzheimer's disease in Mexico this initiative could be led by dementia and Alzheimer's associations in collaboration with different governmental sectors and the media in Mexico.

LINKED IMAGES MISSING



626

Changes in services provided by Alzheimer and dementia association during the COVID-19 pandemic in Mexico

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Topic

Dementia awareness and friendliness: Development, growth and the role of Alzheimer and dementia associations

Abstract

In Mexico there is no long-term care system and unpaid family carers and civil society associations provide care. In particular, associations provide services, support groups, day centers, and training for caregivers. In 2019, 21 associations belonging to the Mexican Alzheimer's Federation (FEDMA) were registered in operation in 15 states of the country. However, in the context of COVID-19 pandemic, many of these associations had to modify the services they provided. The aim of this paper is therefore to present these adjustments and give an overview of the challenges they faced. Given a situational diagnosis carried out in October 2021, 16 associations that remained active were identified. Among the adaptations they made, we identified the migration of their psychoeducational groups and talks to virtual platforms, in some others, they were suspended or new forms of follow-up were adopted, such as telephone follow-up, and in one association, home visits were carried out. However, since the second half of the year, four associations have restarted face-to-face groups. To complement this diagnosis, a questionary is being completed by the associations in order to investigate the changes that occurred during the COVID19 pandemic in terms of services, work team, population attended, sources of funding, and monitoring of health protocols. The results will help to identify positive experiences or good practices that can be shared with the rest of the associations at the national level.



627

The Dementia Journey Survey. Designing culturally-based dementia support resources through community centered approaches

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Topic

Dementia awareness and friendliness: Diverse populations – inclusion, equality, cultural issues

Abstract

Approximately 560,000 people live with dementia in Canada, yet research on the experiences of ethnoculturally diverse people with dementia is largely unknown. As a result, healthcare programs and services do not reflect the dementia related needs of these communities. Additionally, 60% of primary care physicians indicated feeling uncomfortable supporting people with dementia, despite being the first point of access for people with dementia healthcare needs. A multi-phased initiative was designed in collaboration with the Alzheimer Society of Canada (ASC) and the College of Family Physicians of Canada (CFPC) to understand and address these research gaps, and the diverse experiences of people living with dementia with their healthcare providers.

Phase 1 resulted in the successful dissemination of the national "Dementia Journey Survey" that, in addition to receiving a 23% response rate from members of various culturally diverse communities, resulted in new supportive community partnerships with underserved and underrepresented culturally diverse communities.

Phase 2 will continue closing the knowledge gap of dementia-related experiences of these communities through further engagement and partnerships to co-design culturally and community-centered dementia support resources.

Using principles of community-based participatory research, a multi-step iterative consultation process will be designed with self-identified communities who participated in the survey, to develop culturally competent and culturally specific dementia resource supports that align with community needs.

These resources will serve as basis to support health literacy around healthy living, promoting dementia awareness and de-stigmatization and reducing risk factors for dementia.



628

Advancing Dementia Strategy in Lithuania

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Topic

Dementia as a public health priority: Successful healthcare policy interventions

Abstract

Lithuania is one of few countries in the European Union without a national dementia strategy, even though the WHO has encouraged member states to develop one by 2025. A dementia strategy is a way to plan a public health response to dementia with the goal of dementia prevention, as well as care and support for people with dementia and their carers to ensure that they fulfil their potential and live well, with dignity, respect, autonomy and equality.

The project"Towards a Dementia Strategy: Situation Analysis and Public Awareness", implemented from2021-2023 and supported by the EEA Grants 2014-2021 through the Active Citizens Fund.aims to advance the development of a national dementia strategy by implementing the objectives outlined in the "Towards a Dementia Plan: a WHO Guide":

- To undertake a situation analysis.
- To create recommendations for the development of a dementia strategy.
- To raise awareness about dementia in Lithuania.

The results of the project are contributing to the well-being of people living with dementia, their carers and family members, supporting dementia strategy development in Lithuania, and empowering civil society organizations to be actively involved in dementia awareness and friendliness development across sectors.

Toensure the sustainability of the project results in the long term,in the beginning of 2021, the partners of the project has founded association "Dementia Lithuania". The association is taking the lead as nationally and representing the people living with dementia and their carers in Lithuania in the internationally.



629

Global burden of Alzheimer's disease in Mexico: national and state-level comparisons

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Topic

Information systems for dementia: Registries

Abstract

Aims: To present the national and state-level distribution of the rate of burden of disease of Alzheimer's disease in people over 70 years of age in Mexico, using data derived from the Global Burden of Disease Study 2019.

Method: Analysis of data taken from the 2019 Global Burden of Disease Collaborative Network, reporting rates of years lived with disability due to Alzheimer's disease, disaggregated by state level and sex, of people over 70 years of age. State rates per 100,000 population are presented, as well as a map of state-level distribution to identify geographic differences.

Results: The states with the highest rates of years lived with disability are Michoacan, Durango, Zacatecas, Oaxaca, and Nayarit (rates >1069), women having the highest rates. On the other hand, the states with the lowest rates are Mexico state, Quintana Roo, Morelos, and Baja California (rates <873).

Conclusion: Conducting a state-level health diagnosis can help to identify priorities for care that can serve as a basis for the design or implementation of care programs for people living with dementia and their caregivers and family members.

LINKED IMAGES MISSING

630

An intergenerational volunteer program for persons living with dementia and their caregivers

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Background: People living with dementia are at increased risk of social isolation, loneliness, and lower quality of life. Furthermore, dementia-related stigma is a pervasive concern worldwide which impacts not only individuals living with dementia but also family members and caregivers. One promising solution is to increase the accessibility of intergenerational volunteer programs that foster relationships between people living with dementia and students.

Aims: The objective of this project was to implement and evaluate a person-centred volunteer program within the community and in long-term care homes where individuals living with dementia engage in one-on-one interactions with university students.

Methods: Thirty-three Individuals living with dementia in the community and in long-term care, 35 caregivers, and 58 university students are currently enrolled in the volunteer program. Persons living with dementia are matched with two student volunteers based on interests, preferences, language, and culture. Student volunteers spend four hours per week volunteering with the person living with dementia (two hours twice a week). Therefore, each person living with dementia receives an additional eight hours a week of one-on-one support over four days, over an extended period of eight to twelve months.

Results: Results about the implementation, adoption, effectiveness, and sustainability of the intergenerational program and the outcomes for students, caregivers, and persons living with dementia will be discussed.

Conclusions: This volunteer program also has the potential to expand to many communities and to promote dementia-friendly communities and culture change in long-term care homes.



631

Dementia inclusive design of affecTive basEd iNtegrateD carE for betteR Quality of Life tool

Dr Špela Glišović Krivec[1], Mr David Krivec[1], Dr Nicholas Vretos[2], Dr Vassilis Solachidis[2]

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

For improving the well-being of a person with dementia, we need to facilitate quality life of the person and care partner. TeNDER (affecTive basEd iNtegrateD carE for betteR Quality of Life) is a HORIZON2020 project that includes 13 partners from 7 EU countries, working together to help people with dementia, cardiovascular or Parkinson` s disease, their families and others in the care pathway by addressing challenges experienced in daily living, care management and arrangements. TeNDER services intended to automate, support and extend the care supply chain, by covering physical related, behavioral, social events and clerical pathway integrated in TeNDER's ecosystem. These events are identified by sensors that are able to track the patients' movements, identify abnormal events and send the data to TeNDER server for the reports and for informing the carer and the care professionals. Services will also create opportunities to facilitate communication among users. Our strength is that the TeNDER ecosystem is co-designed with patients and other relevant stakeholders. The modular tool that can be used for daily management, recognizing sleep habits, environmental and safety parameters, emotional detection and receiving recommendations is framed with users` needs and wishes. We involved people already in pre-piloting phase and we continue with the inclusive design all along the way. Each participant can provide his / her opinion, experience, suggestions continuously to the research team. By this, patients, carers and professionals bring their unique perspective and actively and meaningfully contribute towards several aspects of the development.

633

Hello to BrainGuide by UsAgainstAlzheimer's

Ms Brooks Kenny
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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

Background: Over 5.8 million Americans live with Alzheimer's disease, and over 60% of dementia cases aren't detected. UsAgainstAlzheimer's recognized that people are unaware of available resources and developed a brain health platform to increase awareness.

Innovation: BrainGuide™ by UsAgainstAlzheimer's is a novel, free platform available in English and Spanish that empowers people to take the best next steps in managing their own or a loved one's brain health. BrainGuide includes confidential memory questionnaires – taken by phone or online – followed by tailored education and resources based on the answers provided. BrainGuide isn't intended to diagnose or make treatment recommendations regarding Alzheimer's or any other disease.BrainGuide was built as a collaboration with nonprofit, advocacy and industry leaders, and medical and technology experts. It runs on Amazon Web Services technologies making the platform available to anyone with telephone or Internet access.

Results: 1. Over 275,000 visits to the BrainGuide site and over 150,000 completed memory questionnaires, with 79% of visitors being women; 2. Over 50,000 people pointed to a doctor to discuss their brain health; 3. 80 plus resources to address topics including risk-reduction approaches, checking memory concerns, supporting a family member, or taking action after a diagnosis of mild cognitive impairment (MCI) or Alzheimer's disease.

Conclusion: BrainGuide provides confidential brain health information, tailored resources andfollows key scientific advances in risk reduction, importance of brain health and growing public awareness of Alzheimer's to empower everyone to take steps to maintain their brain health.



634

Dementia diagnosis and patient monitoring in the era of COVID-19: the case of Thessaly, Greece

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aims: The study aimed to evaluate the impact of COVID-19 on dementia diagnosis and patient monitoring, and investigate solutions to increase accessibility to health services in the Prefecture of Thessaly, Greece.

Method: Comparative estimates of visits, new diagnoses, and impact on persons living with dementia for the period of March 2020 until June 2021 were retrieved during scheduled interviews with verified public and private health services available to the Prefecture of Thessaly, Greece (N=125).

Results: Response from local practitioners ranged from 63.15-74.46% depending on the prefecture. All individual Greek professionals offering telemedicine services offered feedback. During lockdown periods, visits were diminished to 62.57±36.57%, as compared to the previous year, 4 doctors reported no live sessions at all, and 2 a significant increase. Office visits reached 93.51±21.19% by June 2021, while previous rates were not resolved in 13 cases. Non-anticipated deterioration of cognitive performance and/or behavioural/psychiatric manifestations were reported in mild cognitive impairment (45.10%), moderate (41.18%) or severe dementia (31.37%). A surge for new diagnoses was reported by 42.86% of practitioners, and 19.05% described a decrease, pending diagnoses or no demand. Telemedicine was helpful for carers, but employed as a diagnostic or monitoring tool just 3 times.

Conclusion(s): COVID-19 may had substantial impact on health services provision to selected persons living with dementia. Although telemedicine has been made available, few people requested such solutions. Further studies are needed to understand the barriers in health care and the efficient integration of evaluation tools in telemedicine.

635

Co-creating dementia friendly communities with organizations in local communities

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Topic

Dementia awareness and friendliness: Dementia friendliness

Abstract

As a response to detected real needs of persons with dementia living at home, in 2016 Spominčica - Alzheimer Slovenija started developing an education programme for employees in organizations providing services accessible to the public. This gave birth to the Dementia Friendly Points (DFP) initiative. The first DFP was opened in July 2017 at the Human Rights Ombudsman office after the employees' training. The opening was covered by national media. EWGPWD member presented his life with dementia and stressed the importance of building dementia inclusive society. The DFP network is a national awareness-raising and education programme involving a wide spectrum of organizations in local communities. It helps create dementia-friendly communities by providing information, ensuring social inclusion, acceptance and safety of persons with dementia and their families. Member organizations provide friendly and accessible use of their services for persons with dementia, share the information and knowledge about dementia and promote the dementia-friendly principles in the community. Until 2021 more than 250 organizations, from Ministries, pharmacies, libraries, Centres for social work to shops and hairdressers have joined the DFP network. During COVID-19, the DFP network proved to be of great support to families living with dementia in local communities. DFP's know the need of people living in the community and can provide valuable information and support also in times when the accessibility to other services was severely reduced. Spominčica is performing continuous evaluations and on this basis developing and implementing dementia-friendly services in local communities with the aid of DFP.



636

Knowledge, attitudes, and practices (KAPs) about neurocognitive disorders in health students in Low- and Middle-Income Countries (LMICs): preliminary results from two sub-Saharan African countries

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Topic

Dementia as a public health priority: Healthcare system readiness

Abstract

The increasing number of people living with neurocognitive disorders, epilepsy or mental health disorders is a worldwide challenge, especially in Low- and Middle-Income Countries (LMICs). This KAPS project aims to study knowledge, attitudes and practices of future doctors, pharmacists and nurses about these chronic disorders in 12 LMICs. We present the KAPs results on neurocognitive disorders of the first two sessions conducted in Gabon and Benin.

KAPs questionnaire collects information about socio-demographic characteristics, knowledge, attitudes (including stigmatization), practices, and a specific content according to each profession. The STROBE initiative for observational studies in epidemiology was the basis for developing and standardizing study methodology. Sessions took place in Gabon (February 2020) and Benin (August 2021) on University campuses using the French version of the questionnaire, in collaboration with local teaching professors. Investigators collected answers through a self-administered questionnaire linked to a database management system.

Respectively 75 students (45 doctors, 28 nurses and 2 pharmacists) and 109 students (75 doctors, 22 nurses and 12 pharmacists) in Benin and Gabon participated. Knowledge score was lower than the attitudes and practices scores ($p<0.001$). The questions with low percentage of correct answers dealt with definition and diagnosis of neurocognitive disorders.

The KAPs project is an ongoing international cross-sectional study of knowledge, attitudes and practices of health students in chronic disorders. After collecting information from 12 LMICs, a Delphi consensus with international experts will be the key step to elaborate guidelines for training health professionals in LMICs.

637

Innovative approaches to support persons with dementia and carers

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Spominčica - Alzheimer Slovenija, Ljubljana, Slovenia

Topic

Dementia diagnosis, treatment, care and support: Psychosocial interventions

Abstract

Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity according to WHO. In collaboration with several EU partners in Erasmus+ (KA) projects we have been using several non-pharmacological interventions in Slovenia. We found positive outcomes of the engagement of people with dementia and their carers. We use Creative Arts Therapies (AD-ARTS project) like art, dance, drama, or music to accomplish individualized clinical goals and to complement other therapies focused on minimizing cognitive and behavioral challenges. We are increasing people's competencies and by using recreational activities, providing both a personal sense of control and social support, positively affect emotional health. We use innovative teaching approaches to help people learn foreign language step by step in a natural and pleasant way (E.L.So.M.C.I and SuperLingo project). In this approach, we use songs to reduce stress and through the lyrics convey positive emotions, but at the same time enhance cognitive abilities and slow down the progression of dementia. In SINCALA project, we are holding narrative-based workshops with carers and developing a support program based on experiences carried by Alzheimer Hellas. The goal of this intervention is to support different family members of a person with dementia – spouses, adult children and grandchildren that are providing care and support and to help reduce frustrations, express their inner thoughts and feelings in a safe non-judgmental space; thus making families resilient in how they cope with the challenges that caring brings.



638

Experiences of English-speaking, dementia care partners during COVID-19: a qualitative analysis

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Topic

Dementia as a public health priority: COVID-19 and dementia

Abstract

Aims: Public health restrictions due to the COVID-19 pandemic have affected care partners of people living with dementia. This study explores care partners' ability to offer care, and changes and interruptions to care provision during the period of the COVID-19 pandemic.

Method: As part of an international cross-sectional online survey, qualitative data were collected from 852 English-speaking care partners of people living with dementia. Responses to an open-ended question about ability to care were coded and analysed thematically. The analysis was undertaken by three independent interdisciplinary coding dyads.

Results: A number of main themes and subthemes were generated through the analysis. Reduced in-person contact with the person living with dementia and restrictions in health and social care services created practical, psychological and emotional impacts for care partners. The lack of adequate information from health/social care services, deterioration in the condition of the person living with dementia, and additional care hours/duties were identified. Care partners also mentioned the fear of virus transmission and increased awareness of public health measures as factors that changed or interrupted their ability to provide care.

Conclusions: The ability of care partners to provide care was changed or interrupted, and disruption to routines and services available impacted on their well-being. These findings reflect the complexity of the care partner role and highlight the importance of supporting care partners, in particular during periods of service restrictions such as those experienced as a result of the pandemic. Findings will be of interest to policymakers and service providers.

639

STRiDE PAR: Mapping Long-term Care in Jamaica: Addressing an Ageing Population

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Topic

Dementia diagnosis, treatment, care and support: Support for people with dementia

Abstract

Background: In the context of Jamaica's ageing population, low fertility rates, high levels of migration and approximately 71% of older Jamaicans having at least one NCD, it is expected that the prevalence of persons living with dementia (PLwD) will significantly increase, requiring dementia-friendly health and social care services embedded in a sustainable long-term care (LTC) system. However, little is known about Jamaica's LTC system and its capacity to meet the needs of PLwD.

Aim: This presentation will map the current LTC system in Jamaica and describe its capacity to meet this public health issue.Method:A review of empirical and grey literature on LTC was supplemented with interviews, consultations and group discussions with stakeholders at knowledge exchange, impact and engagement events as part of the STRiDE Dementia project on dementia care improvement.

Results: Key findings include: (1) Jamaica's LTC system depends substantially on informal care (both unpaid and paid); (2) there is a need for strategic coordination for LTC across the state, cross-ministerial, private, and volunteer sectors; (3) compulsory insurance and social protection schemes appear to exacerbate rather than narrow socioeconomic inequalities in LTC; and (4) there is a lack of systematic LTC data gathering and related information systems—for both institutional and community-based care.

Conclusion: For Jamaica's LTC system to address its ageing population, there must be aspirational and concrete actions for a national, coordinated investment into community-based care. We discuss recommendations to develop a sustainable LTC system for Jamaica and similar LMICs.



640

Idiographic memory deficit, but not nomothetic memory deficit, predicts memory complain in a representative sample of the Brazilian Longitudinal Study of Aging (ELSI-Brazil)

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: Memory complaint is a frequent issue for older adults, even though they do not effectively underperform in memory tests on a nomothetic approach. We aimed to verify an idiographic approach of memory deficit and its relation to memory complaint.

Methods: Secondary data analysis from a representative sample of the Brazilian Longitudinal Study of Aging (ELSI-Brazil), that performed the memory test and self-rated their current memory. We extracted a regression corrected memory test score based on age, education, and sex and transformed it into a z-score. We defined nomothetic memory deficit (NMD) if the corrected memory z-score was below -1.5. We defined idiographic memory deficit (IMD) if the standardized difference between the predicted memory score and the obtained score were higher than 1.0. We conducted a logistic regression with age, sex, education, IMD and NMD as predictors of memory complain.

Results: We used data from 9,013 participants. 743 (49.6%), out of 1,498, have IMD with concomitant memory complaints, and 241 (48.6%), out of 496 participants with NMD, have memory complaints. Being younger, having lower education, being female and having IMD are associated with memory complain, but not having NMD (table 1).

Conclusions: We identified IMD as a significant predictor of memory complaint, but not NMD. An idiographic approach might be more sensitive to subtle memory change, increasing early diagnosis accuracy. It might also help discriminate between older adults with incipient mild cognitive impairment from subjective cognitive complaint once their performance is intraindividual below the expected and there is memory complaint.

641

Health promotion initiative: A dementia-friendly local community in Sweden

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Dementia is a great public health concern worldwide. Despite this, little is known from a health- promoting perspective about dementia in general as a public health issue, in dialog with people living with dementia, applicable at individual, group, and societal levels with regard to policies and practice. This study therefore aims to explore the experiences related to living with dementia in the local community by advancing a health-promoting perspective. Semi-structured individual and group interviews were conducted with participants (n = 22) with lived, professional, and personal ex- periences of dementia living in a medium-sized municipality in Sweden. Transcripts were analyzedby thematic analysis. Four themes emerged: health promotion through knowledge and public awareness, health promotion through opportunities to be active, health promotion through meaningful meeting places, and health promotion through improvements in the welfare system. We found that more knowledge and public awareness about dementia are needed to advance a health- promoting perspective and increase the prominence of dementia as a public health issue. Further research and policy need to focus more on how professionals in dementia care practice could be involved in promoting health and well-being for people with dementia.



642

Assumptions about Dementia: Perspectives from Environmental Planners and People Living with Dementia

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Topic

Dementia diagnosis, treatment, care and support: Environment and architecture for dementia

Abstract

Background: Research about what constitutes dementia-sensitive environments receives ongoing attention: Current efforts aim at built environments that enable people living with dementia to remain active and independent in their familiar environment, for as long as possible. Environmental planners rely on case studies, literature, and design guidelines, to develop assumptions about how people living with dementia might interact with built space.

Research question: What are environmental planners' assumptions about dementia?

Methods: In this ongoing study, which includes people living with dementia as co-researchers, we are conducting qualitative expert interviews that focus on environmental planners' conceptualizations about dementia, and dementia-sensitive, indoor and urban built space. We are discussing the results with people living with dementia, to better understand how the assumptions of experts by profession (the environmental planners) correspond with, or differ from the perspective of experts by experience (the co-researchers).

Preliminary Results: Environmental planners' assumptions about dementia correspond with the perspective of the co-researchers, but mostly relating to design principles for people who live with more advanced stages of dementia; e.g., safety, protection, and comfort. However, our co-researchers consider a more nuanced image of dementia, e.g., the needs of young people who live with early stages of dementia.

Conclusions: Involving people living with dementia in research opens up important insights that can contribute to a more nuanced anticipation of the abilities and the needs that diverse people living with dementia have in the built environment.

643

Dementia, mild cognitive impairment and tooth loss among attendees at the outpatient clinic of a Geriatric Centre in Nigeria.

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Aims: To determine the association between dementia, mild cognitive impairment, and tooth loss among attendees in an outpatient clinic of a geriatric centre in Nigeria.

Method: A cross-sectional study was carried out at the Tony Anenih Geriatric Centre, University College Hospital, Ibadan, Nigeria. Three hundred attendees were recruited, and the diagnosis of mild cognitive impairment was made using Petersen's criteria while diagnosis of dementia was made using ICD 10 diagnostic criteria. The number of teeth was counted in each quadrant of the mouth.

The cognitive status was assessed using Mini Mental State Examination, Word List Learning, Word List Learning Delayed Recall and Animal Fluency. Functioning of patients was assessed using Instrumental Activities of Daily Living. Dementia severity was assessed using Blessed Dementia Rating Scale.

Result: There were three groups: Persons diagnosed with mild cognitive impairment, persons diagnosed with dementia, and those without cognitive impairment. The prevalence of mild cognitive impairment was 8.0%,dementia 4.0%.

The mean numbers of tooth loss among persons without cognitive impairment, mild cognitive impairment and dementia were 2.40(4.66), 2.69(4.55) and 4.42(6.99) respectively.There was no significant difference in the groups with p=0.72 and p=0.13 for mild cognitive impairment and dementia respectively.

However, Blessed Dementia Rating Scale showed a significant association between tooth loss in dementia compared with toothloss in persons without cognitive impairment (p=0.001).

Conclusion: Persons with dementia showed a higher number of tooth loss compared to persons without cognitive impairment in the activities of daily living as measured by Blessed Dementia Rating Scale.



644

Sharing Alzheimer's disease research data within the Global Alzheimer's Association Interactive Network

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Topic

Dementia research and innovation: International collaborations, challenges and opportunities

Abstract

Open data sharing efforts advance research by allowing access to existing data to analyze new trends and foster collaborations across institutes and countries. As a part of the worldwide endeavor to decipher Alzheimer's disease, the Global Alzheimer's Association Interactive Network (GAAIN) connects researchers to data collected by Alzheimer's disease and dementia studies from around the world. To date, GAAIN links together 57 studies from 17 different countries, over 500,000 subjects, and over 30,000 data attributes into one navigable network. Studies that participate in GAAIN benefit from increased publicity, exposure, and opportunities for collaboration while data ownership and subject privacy are protected. Researchers who use GAAIN can discover new data sets, visualize results from preliminary analyses, and are directed on how to apply for data access from data owners. The architecture underlying GAAIN is uniquely designed to address the different needs of both data owners and researchers. The GAAIN platform accommodates longitudinal studies, cross-sectional studies, and clinical trials and is fully leveraged when researchers aggregate multiple studies across different institutes and countries into meta-analyses. In our web-based tool, the GAAIN Interrogator, researchers can define variables, create custom cohorts, and perform preliminary analyses. Analysis results include odds ratios from logistic regressions, correlations from linear regressions, survival fractions from Cox regressions, and in the case of pooled datasets, weighted odds ratios from Mantel-Haenszel meta-analyses. Using GAAIN, researchers can remotely preview and explore data sets, helping to contribute to the global effort to solve Alzheimer's disease and dementia-related pathologies.

645

Adaptive Interaction: Equipping caregivers to communicate non-verbally with people who can no longer speak

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Topic

Dementia diagnosis, treatment, care and support: Education and training for professionals and formal carers

Abstract

Introduction: Caregivers find it difficult to interact with people with dementia who can no longer speak. Adaptive Interaction is an approach that uses the nonverbal fundamentals of communication to connect with people without speech. Equipping caregivers with non-verbal communication skills could improve relationships and quality of care for people living with dementia who can no longer speak.

Method: We recruited six formal caregivers to work with six residents in a long-term care home who were no longer verbal. Adaptive Interaction training was delivered over three days using hands-on practice and reflective learning to equip staff with the knowledge and confidence to interact non-verbally.

Results: After receiving training in Adaptive Interaction, caregivers identified more communicative behaviours in the residents with dementia who could no longer speak. The caregivers also engaged in more frequent positive social behaviours and meaningful actions during interactions.

Discussion: Adaptive Interaction training equipped caregivers with skills to identify nonverbal communication behaviour and build interactions with residents with dementia who can no longer speak. Improved connections with people with dementia who cannot speak, can enhance their care and impact staff feelings of competence.



646

Impact of Covid-19 in the diagnosis and treatment of dementia in Cameroon

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

Dementia remains a public health problem in Cameroon. Due to human and diagnostic resources limitations, many cases of dementia are not diagnosed and thus, patients do not received adequate treatment and support. During this ongoing Covid-19 pandemics, health professionals are facing many challenges either for the diagnosis and the management of patients with dementia.

All the region of Cameroon are affected by Covid-19 pandemics. This urge government to take certain measures in order to reduce the spreading of Sars-Cov2 including: frequent hand washing/sanitizers, compulsory face mask in crowding places, vaccines, social distancing. Health centers were at the first line of this prevention. And this has profoundly affected the structure and functioning of our fragile health care system. Dementia diagnosis and management have also been impacted.

Most of our patients with dementia are at high risk of severe Covid-19 with high mortality and morbidity. Patient and their careers hesitate before coming to hospital or did not come at all. This delays the diagnosis and exposes the patient to develop severe presentation. Patients who are already on treatment, has been followed up either in the hospital, or most frequently with distance consultation using new communication tools like social media, instant message, etc.... Some of them living in rural area were most likely to stop the treatment with dramatic consequences frequently.

There is a urge need to develop strategy at the local and national level in order to set up strong guidelines for diagnosis and management of patients with dementia.

647

Preferred communication Methods: how a response to the Covid pandemic has changed and enriched the ways we can communicate with people with dementia and their caregivers

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

The aim of the presentation is to share the change in practice adopted by The Dementia & Delirium Team at University Hospital Southampton (UHS) in response to the Covid crisis and how this has been sustained to deliver a service which includes people with dementia and their caregivers as true partners in care.

Prior to the Covid pandemic our communication approaches were either face to face or via telephone calls. When UHS took the decision to enforce a 'no visiting' policy as part of the Covid Management Plan, our face-to-face access to patients and their caregivers was eliminated.

The team therefore implemented a more proactive and creative approach which has subsequently generated new ways of communicating with people with dementia and their caregivers and enriched the quality of relationship between them and the Team. For example, the Team now uses text messaging in recognition of the fact that many people with dementia and their caregivers use this as their preferred communication method. Caregivers have expressed gratitude for this approach as they tell us that it gives them time and space to gather their thoughts before responding and empowers them to contact the Team at a time and pace which suits them.

The changes in practice have been embedded in the Teams Standard Operating Procedure in recognition of the impact and value of using existing and new technology, underpinned by person centred approaches, to provide a sense of connectedness between people with dementia who are in Hospital and their caregivers.



648

Horses and Humans: Therapeutic Interventions for People Living with Early-Stage Dementia and their Care Partners

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Topic

Support for dementia carers: Informal carers support – pre, during and post

Abstract

The Connected Horse program is a non-pharmacological approach to dementia support. A dyad model and equine assisted activities to engage in self-activating practices, nonverbal communication skills, self-awareness and regulation for both care partners (CP) and the person living with dementia (PWD).

The study was designed as comparative booster session 6 months after 3-week session. The design was originally created by Stanford School of Medicine, Leadership Program, Connected Horse (N=26). The entire research study used a single group, pre/post-test design with standardized measures of stress, burden, mood, sleep, and social support for CP /PWD.

The research conducted over three years through the U C, Davis School of Medicine, ADCenter/ School of Veterinary Medicine, dyads (N= 42) The booster followed 17 individuals, 14 booster assessments compared post intervention scores.

The data validated previous findings with improvement in reduced feelings of depression for CP and improvement in sleep for both CP / PWD: improved mood, greater self-awareness, activation of future planning, increased confidence, appreciation of one another in dyad, positive trends for improved perceived social support for CP, reduced anxiety CP / PWD. Although not significant, CP results indicated increased awareness of burden and behavior impairment.

The booster session results indicate initial care partners benefit of reduced feelings of depression remained stable between workshops/6 months later. Though not conclusive, the data raises questions about the benefit of equine therapeutic interventions. More information is needed for conclusions of initial interventions provide long activated

Results: The study is encouraging to explore opportunities for CP alternative approaches.

649

I Am A Person With Dementia: Advocating for Understanding and Dignity with First Responders and Emergency Personnel

Mrs Angie Frantz[1], Mr David Troxel[1,2]

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Topic

Dementia diagnosis, treatment, care and support: Dementia and dignity

Abstract

As a company that provides for the needs and care of our residents in our Expressions Memory Care communities, we are also charged with being advocates for them. We have found that many times this can be a challenge with those who engage with them outside of our communities, most noticeably in the healthcare sector. When our residents need to visit a physician, be transported to a hospital or higher level of care, those who are now involved in their care at times have not been trained to understand the best way to communicate with someone who has Dementia. During the global pandemic we have seen in a new way the importance of advocacy for our residents, who are going to hospitals alone and frightened of what is gong on around them. One of our tools/products that we utilize to get to know and understand our residents is "Expressions of My Life Story" that provides a glimpse of who this person with dementia is and their life history. We wanted to incorporate a brief glimpse of this information along with the changes that happen to someone with dementia into a flyer that can travel with the resident to other care settings, that can help to meet their needs and help with communication. It also speaks to other types of dementia that may be going on with a resident. Our goal is for others to treat our residents with dignity and honor who they are a a person today.

LINKED IMAGES MISSING



650

Neuropsychological care and intervention for Spanish-speaking older adults at risk

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Topic

Dementia research and innovation: Innovation, entrepreneurship and technology

Abstract

The Institute of Behavioral Neurosciences of the UAGRM has been developing since 2014, intervention initiatives in older adult populations in Bolivia. In 2020, as a result of the global pandemic, these actions are organized from virtual Neuropsychological Laboratory "Rene Calderón Soria" NEUROLAP, which takes relevance as a project to reach patients and families suffering from dementia. On NEUROLAP, the Differential Assessment of Memory (EDM) is proposed as a neuropsychological detection protocol for cognitive impairment for people over 65 years of age. Our laboratory ventures not only with EDM, but also develops in March 2020 a platform for the care of people with dementia, called RECUÉRDAME; which allows the identification of the cognitive impairment phase, resorting to a cognitive screening protocol developed for its administration by telephone, thus rescuing the need for primary care of this population in respect of social distancing. Once the screening has been carried out, the evaluated person and familyare directed to one of the programs currently in force in virtual mode according to their characteristics and needs, these programs are: 1) Intergenerational school: prevention of cognitive impairment, 2) TATAMONITORES: Program of training of healthy older adults to work with affected older adults in geriatric institutions, 3) MERI: Neuropsychological intervention program for people with a diagnosis of dementia, 4) Me sigues te sigo: Joint neuropsychological intervention program and 5) Atypical vascular dementia: Virtual Neuropsychological Intervention Program for people with AVD. Finally, we offer a psychoeducation program (accompaniment and counseling) for relatives of people with neurocognitive disorders.

651

Is One Hemisphere Better than Two? tDCS targeted to the left hemisphere is more effective than tDCS targeted to both hemispheres for improving executive function in AD

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Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

People with dementia typically have worse atrophy in the left hemisphere, although brain damage is expected in both hemispheres. When applying tDCS, should we strengthen the more damaged left hemisphere, or stimulate both hemispheres considering both hemispheres are likely damaged due to atrophy. To investigate this question, a mixed group of people living with dementia (AD and FTD) practiced the n-back (an executive function task) in three separate nine-session rounds, two months apart, with a different form of tDCS in each round: (1) 4mA unilateral stimulation, with one anode electrode over the left dorsolateral prefrontal cortex area and a cathode electrode over the occipital lobe area; (2) 4mA bilateral stimulation, using the same configuration, but with an extra active anode electrode over the right dorsolateral prefrontal cortex, and (3) SHAM stimulation. Evaluations were done prior to stimulation (i.e., baseline), at the final stimulation session, and two weeks' post-stimulation. Participants' performance on the N-Back practiced in the stimulation sessions was measured, but also their performance on an equivalent version that was never trained to check for generalized improvement. For the practiced N-Back, participants improved similarly in all conditions. However, for the untrained N-Back, participants only improved in the real tDCS conditions, and this improvement remained two weeks post-stimulation only when they received unilateral tDCS. This result suggests unilateral tDCS was superior and is consistent with the interhemispheric competition treatment hypothesis which argues the weaker hemisphere should be stimulated or the stronger hemisphere inhibited to improve the balance between the two hemispheres.



652

Views of aging: Intersections of multiple stigmas influencing help-seeking and up-take of interventions for sensory and cognitive health

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Topic

Dementia awareness and friendliness: Attitudes, awareness and stigma

Abstract

Aims: Views aging can affect health and longevity. Many older adults experience multiple health conditions that warrant an integrated person-centered approach to care. Age-related hearing and/or vision impairments are highly prevalent and increase risk for dementia. Ageism and other stigmas may delay help-seeking and be barriers to rehabilitation. Despite the importance of ageism and disability-specific stigmas as threats to aging well, little is known about their intersection or interventions to modify these risk factors for dementia. First, we aimed to investigate links between performance on sensory and cognitive tests, self-perceptions of those abilities, and views of aging. Our second aim was to develop and evaluate a group intervention to boost positive views of aging, increase control beliefs, and guide goal-setting and planning to promote sensory-cognitive health.

Method: Structural equation modelling (SEM) was used to analyze behavioral and questionnaire data from over 300 participants. A pilot intervention was conducted to determine if views of aging and attitudes to sensory and cognitive health could be modified. Guided by the pilot intervention, a randomized control trial was implemented to determine the clinical feasibility.

Results: SEM confirmed significant links among views of aging, self-perceptions and performance across sensory and cognitive domains. The pilot intervention demonstrated significant reductions in domain-specific negative attitudes for cognition, hearing and vision domains. Preliminary RCT results will be shared.

Conclusions: Intervention to boost positive views of aging can modify attitudes about sensory and cognitive health that, in turn, could reduce delays in seeking and increase benefits from sensory-cognitive intervention.

653

A pilot digital school to fight digital illiteracy and hostility in people living with dementia

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Topic

Dementia diagnosis, treatment, care and support: Well being and quality of life

Abstract

Aims: COVID-19 pandemic and repeated lockdowns revealed the lack of accessibility of vulnerable groups to health care services and a high prevalence of digital illiteracy. The aim of this intervention is the attainment of basic knowledge and digital skills in order to have access to services in case of emergency, promote social bonding and strengthen cognitive abilities.

Methods: A pilot 3-month intervention will be implemented to allow digital skills learning using a tablet. The trial will be available to 20 pairs of people living with mild to moderate dementia and their care partners, and 40 people of matching age. Participants will meet twice a week to follow 90 min sessions.

Results: The intervention is expected to allow guided learning of digital skills, adapted to user needs and preferences, and increase user independence. Interactive digital applications will be also used to enhance user concentration, perception, cognitive performance and executive function. Independent application of these skills at home and their impact in people living with dementia and their care partners will be evaluated.

Conclusions: The implementation trial will be helpful to people living with dementia in order feel less stressed when using digital tools. In addition, it will be possible to use these tools for social networking, daily planning and management. Understanding the benefit of these applications will further promote a sense of security and facilitate seeking and adopting supporting and telemedicine solutions.



654

Female reproductive period, parity, hormonal replacement therapy and cognition – preliminary findings from ELSI Brazil

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Topic

Dementia risk reduction: Risk factors

Abstract

Aims: Current research suggests that Alzheimer's dementia may be more prevalent in women and that female sex specific risk factors could be involved. The aim of this study is to estimate the association between female reproductive period, parity, hormonal replacement therapy (HRT) and later life cognition.

Methods: Using baseline data from the Brazilian Longitudinal Study of Aging (ELSI-Brazil), collected in 2015/16, a cross sectional study was conducted with a sample of 5314 women aged 50 or older. Global cognition was measured by performance in orientation, verbal fluency, and memory tests. Information on age at menarche and at menopause, parity and HRT was obtained from interviews. Age, education, income, alcohol use, smoking, self-reported multimorbidity, depressive symptoms (measured by CES-D) and BMI were used as covariates. Linear regression was performed to verify correlation between female specific risk factors and cognition.

Results: The mean age (+-standard deviation) of the sample was 64 (+-10) years, consisting of 4987 (94%) menopausal women, with mean age at menarche 13 (+-2) and at menopause 47 (+-6). The mean reproductive period was of 34 years (+-7) and the mean parity was 5 (+-4). In this sample, 1383 women (26,1%) had received HRT. Cognition was negatively associated with parity (coefficient=-0,018; standard error (SE)=0,003; p-value=0,00) and not associated with HRT (p-value=0,52). For reproductive period, the coefficient=0,003; (SE=0,001; p-value=0,07).

Conclusion: preliminary results showed negative correlation of global cognition with parity and a trend towards a positive association with longer reproductive periods. HRT did not show correlation with cognition.

655

EMPOWER TO ENRICH THE ELDERLY PROGRAM FOR VULNERABLE OLDER ADULTS IN NIGERIA

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Topic

Dementia risk reduction: Public health campaigning

Abstract

The process of ageing involves a combination of biological, psychological, and social factors. The rising proportion of older adults and increase in life expectancy, has increased interest in maintaining and promoting cognitive health in later life. Older people want to contribute to society and to feel needed for the skills and knowledge they have gained over a lifetime of experience.

Participation in cognitively stimulating activities has been considered to maintain or strengthen cognitive skills, thereby reducing age-related cognitive decline. An important aspect of healthy ageing is the promotion of good mental health and well-being in later life, staying active and having a sense of purpose are just as important for the mental health and well-being of older people as they are for younger people.

Thus, the aim of empowering older adults in our community, to improve their self -efficacy, self-esteem and cognitive skills by engaging them in meaningful activities such as trading, vocational activities which has a beneficial impact on their health & total well- being.

Twenty older adults in the community were empowered in their different vocation of choice. These older adults have evidences of been financially independent, a decent standard of living, a degree of comfort and having a sense of belonging in the community.

In conclusion, empowerment-based programs should be provided for older people in the society for them to take advantage of the opportunities to feel safe, supported and optimistic about life and its possibilities.



656

Association of Multidimensional Poverty with Dementia Among Aging Adults in South Africa

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Topic

Dementia risk reduction: Risk factors

Abstract

Multidimensional poverty is associated with chronic health conditions, yet little is known about the association between multidimensional poverty and dementia in low-and middle-income countries (LMICs). We interviewed 227 older adults in Soweto in 2019 and 2020 with the Assessing Dementia 8 (AD8) and the Rowland Universal Dementia Assessment Scale (RUDAS) to measure dementia. We compared level and depth of poverty between adults without dementia and those with dementia and look at association between poverty and dementia controlling for gender, age group and marital status.

More men (32.1%) had no dementia compared to women (24.7%); and 20% of adults with dementia compared to 9.7% of those without dementia were found to be poor on four dimensions or more. The difference in multidimensional poverty index for k=3 was 77.1% and 67.3% between adults with and without dementia. Education, health and employment were the main contributors of poverty. Multidimensional poverty was strongly associated with dementia as measured by AD8/RUDAS (adjusted OR 2.31, 95% CI 1.08-4.95), with higher odds for older female (OR 2.03, 95% CI 1.00-4.12) or those living in large households (OR 1.27, 95% CI 1.05-1.53).

This study found that the prevalence and depth of poverty is higher among older adults with dementia. A lack of education, poor health and unemployment are major dimensions of poverty which was associated with higher risk of dementia. These findings suggest that early improvement in social determinants of health through targeted structural policies may prevent dementia later in life.

657

Developing a cultural framing for dementia caregivers' training in Nigeria: An ethnographic assessment of the training needs in Ibadan, Oyo State

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Topic

Support for dementia carers: Education and training for informal carers

Abstract

Nigeria does not currently have a substantive framework for dementia care and the adaptation of non-indigenous approaches hardly fit into the local realities of the condition. Hence, informal caregivers do not have sufficient culture-based knowledge about how to manage the five domains (managing behaviors, psychological outcomes, interpersonal relations, social, and institutional processes) of dementia care. Therefore, the study aims to establish the need for culture-sensitive caregiver training and develop a cultural framing for caregiver training in the domains.

The study adopted an exploratory cross-sectional design and implemented an ethnographic analysis of the existing practices of dementia care in Ibadan, Nigeria. The study incorporated in-depth interviews (29 participants) and participant observation (6 participants) to explore the ecological validity of acceptable cultural practices among caregivers. Ethics approval was obtained from the University of Ibadan/ University College Hospital Ethics Committee.

Preliminary evidence shows that caregivers need culture-sensitive training. Caregivers require training to manage behavioural and psychological outcomes by focusing on the culture of respect, filial piety, shared cultural memories including music, arts, and family history. To handle the challenges of interpersonal relations, caregivers require training to adopt the culturally-appropriate language of presenting the condition to concerned persons. Also, to provide care for addressing social and institutional processes, caregivers should require training to provide and enhance supervised social participation. This goal is achievable through training on identifying culturally-acceptable family arrangements, including visitation, and communitarianism without subverting the autonomy of the person living with dementia.

Caregivers require training on the cultural elements of each domain.



658

Associations between Social determinants of health and cognitive and functional level in Latin American countries.

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Topic

Dementia research and innovation: New and future approaches and treatments

Abstract

Global brain health initiatives called for further research on factors related to the cognitive and functional level in the aging population, especially in low and middle-income countries (LMICs), to mitigate the global impact of dementia. Further knowledge of the predictors of aging brain health in LMICs is crucial.

In the current study, we focus on Colombia a country considered highly unequal, and with experiences of high levels of social adversities including violence exposure and forced displacement due to the civil war suffered for almost 60 years. Further, Colombia exhibits a high burden of chronic non-communicable diseases in comparison with HICs. Here we aim to analyze the association of demographic (SDG), social determinants of health (SDH), and physical and mental health factors (PMHC) with cognitive and functionality levels in the aging population of Colombia. We analyzed the Colombian Survey on Health, Well-Being, and Aging developed in 2015 with a representative and a randomized sample of 23,694 individuals collected in urban and rural across 244 municipalities. We combined hypothesis-driven (structural equation modeling) and data-driven (machine learning) approaches to accurately identify the most accurate determinants of cognition and the functionality.

Our results revealed complex interactions between SDG, SDH and PMHC factors in predicting cognitive and functional level in aging. Compared to more physical-medical factors, the social factors were the most relevant predictors of the cognitive level. Instead, the physical-medical factors impacted more in functionality. We also observed a convergent robustness and concurrence of selected predictors of cognitive and functionality levels in our sample.



659

Conversational Rhetoric Features of elder with dementia risk in Chinese Context -- A Multimodal Corpus Approach

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Topic

Dementia diagnosis, treatment, care and support: Behavioural and psychological symptoms of dementia

Abstract

The incubation period of dementia patients is different. The onset time also varies, resulting in great difficulties and differences in the screening and diagnosis of dementia. By applying the multimodal corpus research method, through the combination of quantitative and qualitative research methods, we find and describe the conversational rhetoric characteristics of patients with dementia and dementia risk in natural conversation and explore the potential operating mechanism behind it. We hope that through the summary and induction of the description of conversational rhetoric characteristics, we are able to provide more scientific judgment indicators for clinical screening and diagnosis. Also, we wish to improve the existing diagnosis system, and make linguistic contributions to the early screening and diagnosis based on artificial intelligence in the future.



660

CSF biomarkers for Alzheimer's disease in a Costa Rican sample

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

CSF biomarkers can to improve significantly the early and accurate diagnosis of AD, which is why they are currently widely used worldwide.

Aim: To characterize the results of biomarkers in CSF to support early diagnosis of Alzheimer's disease.

Methods: Retrospective study of 51 patients evaluated at the HSJD Memory Clinic. CSF was collected by lumbar puncture. A complete cognitive and neurological evaluation was performed. The variables considered were: age, clinical diagnosis and biomarkers results.

Results: The sample was distributed in 24 men (47.06%) and 27 women (52.94%) with an average age of 66.14 years. MCI diagnosis was the most common (49%), followed by AD (35%). Beta-amyloid values were obtained with a mean of 1396.88 pg / mL [95% CI 1241.90-1551.87]. A statistically significant association was found between the diagnosis and the levels of this protein (ANOVA p = 0.030). A significant association between MCI and AD was identified (p =0.014). The t-tau levels presented a mean of 404.18 pg / mL [95% CI 276.62 - 531.74]. No statistically significant association was demonstrated between the diagnosis and the levels of this protein (Kruskall-Wallis, p = 0.8973). Cognitive functioning through the MMSE showed a correlation in both proteins.

Discussion: Due to the ease and low cost, CSF biomarkers for AD are more feasible to be incorporated as part of clinical diagnosis and research low-income countries. In our country, it is important to improve laboratory techniques through the advice international experienced, as well as to carry out studies in larger samples.

662

Leading the way to excellence in palliative and dementia care: Dementia Australia's Nightingale Program

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Dementia Australia, Adelaide, Australia

Topic

Dementia diagnosis, treatment, care and support: End of life and palliative care

Abstract

Background: Dementia is the second leading cause of death for Australians and the leading cause of death amongst Australian females. Despite this, engaging palliative care services for people living with dementia is often overlooked. People living with advanced dementia are at risk of multiple complications and the majority will also have multiple co-morbidities. This results in a very individual experience and varied course of decline which does not fit the traditional palliative time-lined model of care.

Aim of the Program: The Nightingale Program is a unique and innovative nurse-led, specialist palliative care service, providing support over an extended period of time; not just in the last months of life. The approach to care is flexible, dynamic and directed by the person living with dementia and their families, empowering them anticipate needs and make end-of-life choices. A care plan is developed that is collaborative with other service providers, incorporating clinical strategies and dementia education. The nurses will also model care, giving care partners confidence to support the person with dementia at home.

Outcome: This case study shows how a responsive care plan that incorporates all aspects of care; physical, psychosocial and spiritual, can support families and enable people to die peacefully and with dignity in the care setting of their choice.



664

Comparison of cognitive impairment and short-term and long-term memory function of the elderly with monolingual and bilingual Alzheimer's disease

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Topic

Dementia diagnosis, treatment, care and support: Diagnosis, diagnostic tools and cognitive assessment

Abstract

This study was a causal-comparative study and its statistical population consisted of all elderly people with bilingual and monolingual Alzheimer's disease in Tehran in 2014. A sample of 60 people (30 bilinguals and 30 monolingual) they were selected by available sampling method. The instruments used were the Brief Mental State Examination Test (MMSE) and the third edition of the Reporter Behavioural Memory Test, and univariate analysis of variance was used to analyse the data. The results showed that bilingual elderly with Alzheimer's showed less cognitive deficits than monolingual elderly. Also, bilingual seniors with Alzheimer's had better short-term and long-term memory performance than monolingual seniors with the disorder. However, more research is needed in this area to increase the ability to generalize the results to the general public.

666

CAMP: Cognitive Assessment & Memory Program. CAMP is a digital therapeutic, app-based platform that provides first in class assessment and treatment for mild to moderate dementia and Alzheimer's. CAMP is physician ordered, home health driven, clinician administered, and practitioner monitored. CAMP technology is transforming medicine.

Mrs Joey Robinson[1], Mr Nick Nunn[2]

1CAMP: Cognitive Assessment & Memory Program, Carson City, USA. 2Camp: Cognitive Assessment & Memory Program, Carson City, USA

Topic

Dementia diagnosis, treatment, care and support: Treatment and dementia

Abstract

CAMP is a digital therapeutic app-based platform that provides first in class assessment and treatment for mild to moderate dementia and Alzheimer's. CAMP is physician ordered, home health driven, clinician administered, and practitioner monitored. CAMP technology is transforming medicine. CAMP seeks to evolve the process of early detection and treatment. Physicians write an order for home health for patients they feel may have a cognitive impairment. From there, home health clinicians perform a MMSE or MoCA. If the patient scores between 11- 26 (indicating a mild to moderate deficit), the patient is given an in-depth initial assessment to identify where the deficits lie. Based on the results of the initial assessment, custom-tailored cognitive exercises are administered via the CAMP app in the comfort of the patient's home with a trained clinician twice a week. The program also screens for depression, anxiety, and sleep issues, all of which can affect cognitive performance. In addition, patients are given a biometric armband to track sleep, activity, heart rate, and blood pressure. CAMP takes an overall approach to patient health to ensure the patients remain living independently longer. CAMP provides primary care physicians with a login so that they can track and monitor the patient's cognitive performance and biometrics remotely. The program includes a built-in cognitive care plan to simplify the process for the physicians and ensure optimal patient care.



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