

31st Alzheimer Europe Conference

Resilience in dementia: Moving beyond the COVID-19 pandemic

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Abstract Book



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Keynotes and Plenary presentations

K1. (Keynote presentation) Resilience in dementia – adapting to the COVID-19 pandemic as a dementia advocate

Kevin Quaid

European Working Group of People with Dementia, Ireland

Kevin Quaid is the Vice Chair of the European Working Group of People with Dementia. Kevin will speak about navigating Covid-19 while living with Lewy Body Dementia. He will share how his experience with a dementia diagnosis made him more resilient and able to cope with the pandemic.

K2. (Keynote presentation) Inclusive dementia care: the needs of the LGBTQ community

Patrick Ettenes

LGBT Foundation / Bring Dementia Out

To address the lack of visibility of and awareness of LGBTQ+ people living with dementia in care and housing services, this talk will highlight some of the real lived experiences of LGBTQ+ people living with dementia coming from the personal experiences of someone with early onset dementia who is involved in supporting dementia, care and housing organisations to understand and address the challenges LGBTQ+ people living with dementia face.

These challenges include, but are not limited to, organisations often being heteronormative and cis-orientated. There are often issues around next of kin (even for married same-sex couples) being excluded from care decisions, and a return to being secretive about sexual and gender identity for fear of discrimination.

Trans people living with dementia in particular may not remember they have transitioned. or are wrongly gendered by care or housing providers.

Using personal experiences from the past eight years and professional experiences over the last five years, this talk will provide a valuable insight into the real life experiences of many LGBTQ+ people living with dementia and provide information to enable those working to support those working in dementia, care and housing services to ensure they feel enabled to better support LGBTQ+ people who are currently not having their needs met.

PL2: (Plenary) Lessons from the COVID-19 pandemic

PL2-01. Responding to the COVID-19 Pandemic: Some lessons from Scotland

James Pearson

Alzheimer Scotland

The COVID-19 pandemic has given rise to a crisis unprecedented in recent history. The virus and the measures put in place to prevent its spread have impacted on all aspects of society. For people living with dementia, and the families and friends who care for people with dementia this direct and indirect harms of this pandemic have been devastating.

Everything they relied on to maintain their wellbeing and live as independently as possible in their own communities, their daily routines; social interactions; community-based groups and activities; and formal health and social care support, have been disrupted as a direct consequence of the pandemic and the public health restrictions.

Like many organisations Alzheimer Scotland had to transform everything we did from how we supported people with dementia, their families, and carers to comply with public health restrictions, to how we adapted our campaigning to respond to the rapidly emerging and overwhelming levels of crisis they were facing, and which exposed, in the cruelest ways the fragility of an already over stretched health and social care system in Scotland.

This presentation sets out how Alzheimer Scotland adapted to this crisis and the lessons we have learned which have informed our approach to practice and campaigning.

PL2-02. Protecting people with dementia in residential care-what we did right and what we got wrong!

Pat McLoughlin

The Alzheimer Society of Ireland

Data from the Health Protection Surveillance Centre in Ireland indicated that, as of midnight on 14th of July 2020, 79% of all notified deaths from Covid-19 occurred in the over 75 age groups and that deaths in nursing homes represented 56% of total deaths in Ireland.

The presentation will report on the outcome of examinations by an expert panel established by Government on the management of Covid-19 in nursing homes and the findings of a Special Committee of Parliament on Covid -19 Response, which included nursing homes. The presentation will outline the key recommendations from both reports. The presentation will also include the views of the Alzheimer Society of Ireland as submitted to both reviews. A critique of the investment made in dementia care, during the pandemic will also be included.

PL2-03. Multidomain prevention studies and lifestyle changes during the COVID-19 pandemic

Miia Kivipelto

Karolinska Institutet

Older adults have higher risk of dementia, and they are the group most severely affected by the COVID-19 pandemic, in terms of higher morbidity and mortality. The pandemic has had significant effects on many modifiable risk factors for dementia and Alzheimer's disease (AD), and on ongoing randomized clinical trials for dementia risk reduction and prevention.

Negative effects of the pandemic include direct consequences of the COVID-19 disease, and indirect effects due to disruption of regular healthcare services, social and physical distancing or mobility restrictions imposed by several countries to curb the spread of the infection.

Multinational initiatives on dementia prevention include the World-Wide FINGERS global network of multidomain dementia prevention trials (40+ countries), and the linked EU-FINGERS, which includes observational and intervention studies for dementia/AD prevention across six European countries.

For multidomain dementia prevention trials, the pandemic has imposed adjustments in study protocols to accommodate suspension of in-person data collection, alterations in approaches to recruitment and intervention delivery. There has been a rapid increase in the testing and implementing of e-health tools. Current findings suggest that social components of multidomain interventions are important, and there are ongoing efforts to create hybrid models including face-to-face plus digital components, to facilitate personalised, effective, and feasible interventions and implementation. End-users' involvement in planning and testing these tools is central.

To monitor the pandemic's effect on factors relevant for brain health, the WW-FINGERS-SARS-CoV-2 survey was launched within the WHO Global-forum on Neurology and COVID-19. Approx. 30 countries are participating, and data is currently available from 18 countries (~18,000 persons) on changes in lifestyle, psychosocial factors and chronic disease management.

The WW-FINGERS-COVID-19 survey, together with other global initiatives, will provide knowledge for adaptations needed to ensure successful recruitment and adherence in forthcoming multidomain trials and to plan scalable dementia preventive interventions in a pandemic/post-pandemic landscape.

PL3: (Plenary) Innovations in dementia diagnosis and care through new technologies

PL3-01. The importance of flexible care settings and home care management in clinical trials within a rapidly changing COVID-19 environment

Martin Traber, Elena Pons Salvador

Roche

The COVID-19 pandemic had posed unique challenges to people living with Alzheimer's Disease and their families.

People with Alzheimer's Disease are disproportionately more affected by the pandemic than other parts of the population, as lockdowns and social distancing measures have made their social support and medical systems more difficult.

The situation has only exacerbated existing inequalities and engendered new ones, highlighting the barriers that prevent people from seeking and obtaining a timely diagnosis, and having access to treatment. Continuing Alzheimer's research progress in this context is essential.

During this plenary, Dr. Martin Traber, Global Medical Lead Alzheimer's disease at Roche, will bring perspectives on how to ensure the validity and integrity of clinical trials globally while finding new ways to adapt to the new challenges raised by the pandemic. Specifically, the importance of flexible care settings and home care management will be highlighted.

We will hear that critical efforts to develop potential new diagnostic solutions and medicines continue and how working together with all partners in the healthcare ecosystem will drive real change for people living with Alzheimer's and their families.

PL3-02. Improving continence care of nursing home residents thanks to new technologies

Adrian Wagg

University of Alberta

Maintaining the quality of life of vulnerable nursing home residents, many of whom are at the end of life, is key to quality of care. Providing dignified continence care with minimal disruption to daily life is thus important. Urinary incontinence affects between 75 - 98% of nursing home residents, depending upon sample and report. For many, the management of continence consists of toileting regimens and the use of containment products. Ensuring that disruption from frequent check and change routines is kept at a minimum is important to providing efficient high-quality care. Technological advances in containment products mean that options are available to construct a meaningful voiding diary upon which management may be based. Such solutions can provide time and cost saving care with less disruption to resident's lives, potentially improve the quality of life for residents and the quality of working life for those who provide care, allowing time to be devoted to other aspects of caring.

PL3-03. From virtual brain simulation to personalised prevention and treatment of dementia

Petra Ritter

Charité University Medicine Berlin

Constructing individual models of the brain and simulating them helps us to understand mechanisms of brain function and dysfunction. Knowing mechanisms is essential for developing measures for prevention and therapies. Computational brain models capture more closely the actual neuronal processes and thus augment the classification and prediction of brain diseases such as Alzheimer's. Computational brain models are also used for in silico testing of therapies such as pharmacological interventions, brain stimulation or surgery. Personalized brain models contain sensitive health information. The Virtual Brain Cloud - a project of the European Open Science Cloud (EOSC) and a Partnering Project of the Human Brain Project and EBRAINS - provides a digital platform that enables collaborative research on sensitive health data in an audited environment that is compliant to the General Data Protection Regulations of the EU and thus protects the rights and the freedom of the data subjects and patients. The platform provides the computational resources and infrastructure that is required for complex simulations - including high-performance computing. It enables innovative dementia research through integration of various data types into complex multi-scale dynamical models of the brain.

PL4. (Plenary) Dementia as a public health challenge

PL4-01. Czech National Action Plan for Alzheimer's Disease and Related Illnesses 2020 – 2030: First Implementation Steps and Lessons Learned during the Pandemic

Hana Marie Broulikova

Vrije Universiteit

The Czech National Action Plan for Alzheimer's Disease and Related Illnesses (Plan), which will be implemented during the period 2020–2030, was developed in 2019. The Plan consists of three main parts: a vision, a situational analysis, and proposed recommendations. Due to the pandemic, the Plan was approved by the government only in 2021. To ensure a smooth transition to the implementation phase, some first steps were made and projects of the first implementation wave were initiated prior the approval. First, in 2020, an official position of the national dementia coordinator was created within the Ministry of Health. The coordinator oversees and facilitates the implementation. Second, in collaboration with the WHO, a tool supporting informal caregivers (iSupport) and guidelines on risk reduction of cognitive decline and dementia were adapted to the Czech context. Third, a grant call was opened for the development of the national interdisciplinary guidelines identifying standard diagnostic and care pathways of a person with dementia, and proposals are currently being evaluated. These guidelines are crucial to strengthen the network of services.

Unfortunately, one step that could not been implemented before the governmental approval of the Plan was an appointment of a ministerial advisory group of stakeholders. This group will work closely with the coordinator and supervise the implementation of the Plan. The COVID-19 pandemic clearly showed the importance of such a body firmly anchored within the Ministry of Health. Without an established and trustworthy advisory group, communication of reliable advice and support towards people with dementia and their caregivers is unnecessarily hindered and fragmented. Consequently, the aim is to create a body and processes flexible enough to react to urgent situations swiftly and effectively.

PL4-02. Are we getting better at taking sex and gender differences in Alzheimer's care into account?

Maria Teresa Ferretti

Women's Brain Project

In recent years, cumulating evidence has indicated that high variability exists among people living with Alzheimer's disease. Far from being one entity, we are starting to identify disease subtypes, which might require tailored approaches for diagnosis, prognosis and treatment. Precision medicine, as applied in oncology, might provide substantial progress in the field, from molecular diagnosis to tailored therapeutics.

In this regard, sex and gender differences are emerging as leading features driving patient heterogeneity in Alzheimer. These differences offer therefore a useful starting point to discuss potential applications of precision medicine in neurology.

In this talk I will present the latest evidence on clinically relevant sex (i.e. biological) and gender (i.e. socioeconomic) differences and their implications for clinical research and practice. As risk factors, symptoms and response to treatment varies between men and women, tailored prevention, diagnosis and treatment should take sex and gender into account. I will also describe recent evidence, generated by the Women's Brain Project, indicating lower than expected recruitment of women in clinical trials for Alzheimer's disease. The implications for clinical trial design and development of digital health technologies for AD will be presented. Finally, I will review the evidence on sex and gender differences in caregiving, calling for ad hoc measures to support men and women caregivers.

A proper understanding of sex- and gender differences will be key towards a precision medicine paradigm in Alzheimer's, which takes into consideration the specific needs of each patient and their caregiver.

PL4-03. Preventable causes of dementia and their public health implications

Gill Livingston¹, Naaheed Mukadam², Andrew Sommerlad¹, Jon Untley¹, Sergi Costafreda¹

The number of older people continues to rise, especially in low- and middle-income countries, as people live longer. However, while there are certainly more people living with dementia, the age specific incidence of dementia has fallen in many countries, while it has risen in others, suggesting that the risk of dementia can be modified. The fall in age specific incidence has been in high income countries, and within those countries, in those who are more educated and with higher socio-economic status.

Our research shows 40% of dementias worldwide may be preventable by addressing 12 risk factors: less education, hearing loss, head injury, high blood pressure, excessive alcohol, obesity, smoking, depression, social isolation, physical inactivity, air pollution and diabetes. I will provide an updated overview of the evidence about these factors for dementia including from the 2017 and 2020 Lancet commission on dementia prevention, intervention and care. I will also discuss new, some of which is currently unpublished, evidence.

Dementia risks cluster in individuals, particularly those with less socioeconomic resources. I will discuss the effect of disadvantage on dementia risk within and between countries and what this means for public health. I will conclude that prevention is about policy and individuals. Contributions to the risk and mitigation of dementia begin early and continue throughout life. The potential for prevention is high and this is particularly so in low and middle-income countries (LMIC) where more dementias currently occur. People who are most deprived need these changes the most and will derive the highest benefit.

PL5. (Plenary) Round table discussion: Beyond the pandemic: Reinventing dementia care and treatment

PL5-01. From Dementia Prevention to Brain Health

Craig Ritchie

University of Edinburgh

With the findings from programmes of research like the European Prevention of Alzheimer's Dementia (EPAD) and PREVENT Dementia clearly pointing to the genesis of neurodegenerative disease occurring decades before symptoms emerge, a window of opportunity is opened for prevention. This requires high risk populations to be targeted (using the Lancet Commission Report on Dementia Prevention as a framework) for early detection. Risk factor modification and specific pharmacological interventions will follow under 'personalised prevention plans'.

While this recognises the need for secondary prevention of dementia, primary prevention can also be achieved by developing, maintaining or recovering brain health at a population level across the life course from birth onwards.

The work leading to the development of a national programme in Scotland to ease research into practice will be presented.

PL5-03. Improving the support and care of people at the dementia stage

Marjolein De Vugt

Maastricht University

Over the last years, there has been considerable progress in the development and rigorous evaluation of psychosocial interventions in dementia. This has led to valuable benefits for people with dementia and their caregivers in daily life.

But still urgent problems exist. First, dementia in the context of everyday life is complex, with challenges and needs varying between persons over time. We need better understanding of the complexity of these daily challenges, experiences and patterns to improve tailoring of support. Currently, we lack knowledge which solutions are most viable for an individual in a specific context at a specific point in time. Second, effective psychosocial interventions are implemented sporadically at best, due to a low implementation readiness of proven effective interventions. Differences in culture, language and care systems between and within countries need to be taken into account to improve the transfer of interventions from one context to another.

Advancing personalized approaches and tackling the implementation gap are essential to significantly move the psychosocial research field forward and to boost benefits for people with dementia and caregivers.

Parallel presentations

P01. (Parallel Session) Adapting day and community care

P01-01. The impact of COVID-19 on community organisations supporting people with dementia; how did organisations and staff sustain their resilience during a time of crisis.

Grant Gibson, Catherine Pemble, Richard Ward, Karen Watchman

University of Stirling

The COVID-19 pandemic has raised challenges for health and social care systems supporting people with dementia across the globe. One related sector which has received comparably little attention has been the wide variety of community based, volunteer driven organisations providing community-based support and assistance to older people. The staff and volunteers working in these organisations provide essential contributions to the lives of people living with dementia, including supporting them to remain engaged with their local communities. Such organisations

however have faced huge challenges to the continuation of their activities during the onset of the pandemic and as the pandemic continues. Using a combination of online interviews and action learning sets with 40 staff and volunteers from a range of Scottish community organisations, this research explores how community organisations sustained the resilience of their staff and their volunteers, as they attempted to adapt their services to new and rapidly changing circumstances during the first phase of the pandemic between March and October 2020.

Our findings illustrate a sector struggling to continue with their services as the pandemic took hold and evolved, but who also demonstrated remarkable resilience in the face of the various challenges they faced. In order to sustain their own resilience and the resilience of their services staff adopted numerous strategies, including maintaining contact and partnerships with colleagues and ensuring they had clear personal support mechanisms in place. However deteriorating relationships with larger, national bodies and governmental responses to the pandemic created challenges as organisations had to 'fill the gaps' created by the sudden removal of many statutory support services. Our findings show remarkable resilience among community organisations, but also showed decay in the relationships binding such organisations to wider national organisations or health/social care services, which should be addressed in preparation for any future crises.

P01-02. Cocreation in Covid-19 times: Developing inclusive tools for community living people with dementia, family carers and care professionals: the POLAR study

Carolien Smits¹, Dinant Bekkenkamp², Freek Gillissen³, Rose Doolan⁴, Els Bakker⁵, Wiesje Van der Flier⁶, Jennifer van den Broeke⁷

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Aim: The POLAR study aims to provide insights and inclusive online tools to support the diversity of community living persons with dementia, family carers, volunteers and care professionals in Covid-19 times and beyond.

Method: Participatory development and piloting.

First, three cocreation teams (4 family carers, 6 volunteers of Alzheimer Nederland, and 5 community care professionals) met in online sessions to discuss their Covid-19 experiences. They subsequently elaborated on the requirements of online tools to support people with dementia and their caregivers.

The researchers developed prototype tools that were then discussed in the second team meetings.

Finally, the adapted tools are used and evaluated by family carers, volunteers and care professionals in a 12-month pilot study in Amsterdam. The tools are also disseminated via online national platforms.

Preliminary results: The cocreation sessions highlighted the negative impact of Covid-19 and the associated measures on the lives of people with dementia and their family and professional caregivers. Family carers asked for easily accessible multi lingual videoclips. The videos should acknowledge their expertise and help them keeping in contact with their informal and professional care network. The volunteers asked for guidelines for organizing online alternatives to live supportive meetings with family carers and people with dementia. The professionals wanted support in the shared decision-making process concerning the adaptations of their professional care practice, in particular finding alternatives to live meetings at the homes of clients. The prototype tools are currently disseminated online and tested in the Amsterdam pilot study.

Conclusion: The cocreation teams produced online supportive tools for the diversity of persons with dementia, family and professional caregivers: five multi lingual videoclips for family carers; guidelines (Google Translate) for Alzheimer volunteers for organizing online alternatives to live supportive meetings; care adaptation decision tools for care professionals. <https://www.coronatiejden.nl/polar/> (Google Translate)

P01-03. A Person-Centred Approach to Remodeling Day Care

Nikki Lorimer, Maureen Taggart, Geraldine Ditta, Fiona Kane, Lesley Miller, Gillian Council

Alzheimer Scotland, United Kingdom

As a consequence of the pandemic and subsequent restrictions, our Day Care services were closed, and Alzheimer Scotland worked to find remodeled ways of supporting people with dementia. Our teams moved physical groups online and provided extensive telephone support, to reduce such key issues as stress and distress and address other issues. The team also delivered critical home visits.

A flexible approach was required when reintroducing day care services, given the required measures including physical distancing, transport limitations and infection prevention.

To achieve therapeutic outcomes for people with dementia and their carers we developed a blended model of support which evolved from the positive learning of the remodeled day care and the success of our digital support.:

- Shorter sessions for smaller numbers of people over more days
- Telephone support led to stronger relationships and deeper trust, which enabled session planning in a truly person-centered way.
- A whole team approach using the collective knowledge of all colleagues
- Person-centred session planning
- Connecting individuals with dementia with others who shared their interests
- Activities planned based on individual interests

Individuals with dementia were connected with others with similar interests achieving therapeutic outcomes for the person with dementia and carer.

People told us they felt more connected because they could access digital groups the day care session making them feel part of a larger group and allowing the person facilitating the session to participate.

We have learnt that this model is successful because it is truly person-centred. The approach taken by our teams allowed us to meet the person with dementia's emotional, social and practical needs and made people with dementia, their carers and families comfortable and confident in our service and built mutual respect. This model is an outcomes focused model for the future providing more choice and flexibility.

P01-04. Developing the 4 Key principles of online community support for people affected by dementia

Matthew Harrison¹, Shirley Evans², Natasha Howard³

¹Imperial College London, ²Association for Dementia Studies, ³Alzheimer's Society

Prior to Covid19 restrictions, many people with dementia were dependent on coming together in community groups to stave off the huge negative impact of social isolation that dementia brings (Alzheimer's Society, 2020). Whilst digital solutions have been promoted in dementia for many years, the impetus for their adoption has intensified since Covid19. Community Makers is an active UK wide network that has grown rapidly since April 2020 in response to the negative impact of social distancing on people and families affected by dementia. Its express aim is to break down the perceived barriers to the adoption of digital solutions that could have a dramatic impact on social connectivity whilst maintaining physical distance. The network is led by the Alzheimer's Society, UK Dementia Research Institute Care Research and Technology Centre (UKDRI CRT) and The Association for Dementia Studies (ADS), at the University of Worcester.

Aside from the network a principle output has been the online toolkit (<https://communitymakers.co>) which is a resource of creative ideas to inspire groups with different approaches to digital involvement, including ideas on how to reach people without technology or technical skills. This resource is based on four key principles of online community support:- relationships, purpose, technology and community. The development of these principles has been informed by an iterative approach of engagement with people affected by dementia via online workshops and a rapid realist review in line with Pawson, 2006. We wanted to investigate what works for whom and why and in what circumstances as a basis for the development of the toolkit.

We will present our co-design approach and our realist review methodology and explain how we have arrived at the four key principles. We will illustrate the application of the principles by applying, analysing and evaluating them with three real world case studies.

P01-05. Adapting post-diagnostic dementia support in England and Wales during the COVID-19 pandemic

Marie Poole, Alison Wheatley, Louise Robinson

Newcastle University

Post-diagnostic support for people with dementia and their carers has been significantly impacted by the COVID-19 pandemic. Measures such as national and local lockdowns, limits on people meeting, COVID secure environments, personal protective equipment, and shielding for clinically vulnerable people, have resulted in limited services and people withdrawing from care and support.

We aimed to explore how post-diagnostic dementia services were impacted by the pandemic, how they responded, and implications for support going forward to meet the ongoing needs of people with dementia and their carers.

We conducted interviews with 21 professionals working in health, social care, and the voluntary sector previously recruited via an ongoing qualitative study on improving post-diagnostic dementia support (PRIDEM). Framework analysis was used to analyse the interviews.

Emergent findings indicate that services and staff found innovative ways to respond to COVID restrictions and worked creatively to adapt services. Challenges included: shifting guidance; changing roles and service provision; the impact of the pandemic on staff. Maintaining crucial support for people with dementia and their carers relied on finding new ways to organise and provide services such as: providing remote and/or socially distanced support; shorter but more regular contact; and re-organising caseloads. Professionals also identified some unintended positive outcomes which they could maintain and develop to support good post-diagnostic support in the future.

In conclusion, services had to be responsive, dynamic and adaptive to meet the challenges of delivering post-diagnostic dementia support during COVID-19. Some of these changes may be taken forward to evolve post-diagnostic support. Adopting some of these changes may be advantageous, but much has also been lost through reduced in-person contact. Blended approaches to patient-facing services incorporating virtual and face to face work may be useful to the delivery of post-diagnostic support, offering flexibility and options for services and service users.

P02. (Parallel Session) Arts and culture

P02-01. Memories are made of this: Developing evidence for the conceptual base for the use of personalised music in dementia care.

Danai Theodosopoulou¹, Anne Kille², Simon Horton²

Dementia syndrome disrupts the autobiographical memory system, including memories of specific episodes, personal experiences and facts about one's life, all of which contribute to a sense of self. Disruption can affect psychological well-being, potentially contributing to psychological and behavioural symptoms, while social communication can be compromised.

This presentation will draw on the findings of two studies to contribute to theoretical conceptualisation for personalised music intervention. It will synthesise the outcomes of a systematic review investigating the effect of personalised music on behavioural and psychological symptoms in people living with dementia with a qualitative analysis of Desert Island Discs broadcasts in which interviewees are invited to associate personalised music choices with their life narratives and an exploratory focus group study with practitioners who use music interventions with people living with dementia.

In the systematic review of 29 studies, we explored the effect of personalised music on behavioural and psychological symptoms in patients with dementia and found evidence for a positive, but not lasting effect on behavioural and psychological symptoms. The effect was greater in active personalised interventions compared to passive listening to personalised music. The sharing of personal autobiographical events was found to help maintain a coherent continuity of self. The use of personalised music was found to be effective in evoking autobiographical memories and emotions, which mediate access to identity and sense of self.

The qualitative thematic analysis of 18 Desert Island Discs broadcasts identified the emotional dimensions of autobiographical music memories, with 'nostalgia' being of particular salience. The focus group discussion explored the professionals' views on the implementation of music interventions.

The findings will present the implications for the design of personalised music interventions in dementia care and future research.

P02-02. Saturdays Doon The JM

Jeni Sinclair¹, Shonagh Murray², Lydia Davidson²

¹Alzheimer Scotland, ²Fearless Players

Introduction: "Saturdays Doon the JM" was created by Alzheimer Scotland in partnership with The Fearless Players Theatre and Dundee Rep Theatre,

The shared experiences of people from Dundee, now living with a diagnosis of dementia, were brought to life, in a series of online reminiscence sessions.

The project culminated in a theatrical performance recounting their history in an engaging, respectful, and empathetic manner. The JM was a popular ballroom and meeting place in Dundee, with people going 'doon' (down) there on a Saturday.

Aim: Its aim was to encourage participation, and gain a meaningful insight into the lives of people living with dementia.

Design: Seven people took part in a series of six online sessions

Each participant encouraged to "tell their story" exploring shared experiences and memories of life in Dundee over 50+ years.

Responses elicited through gentle prompting, questioning about various topics

Participants recollected their past lives, unique to them, and shared experiences by others in the group

The Fearless Players nurtured the participants, making those involved feel included in the creation of a piece of work

Workshops were fun but meaningful

Memories were woven into a theatrical performance

Key findings: Narrative provided insight into the lives of a community of Dundonians, from young adulthood, through middle age, from their courtships and partnerships to being people now living with dementia.

The sessions encouraged conversation, humour and facilitated real identity.

People felt part of something creative and important

"Doon the JM" was a truly collaborative performance

Allowed people living with dementia to contribute, share, clearly illustrating that people can continue to live well with the condition

This imaginative and creative project has universal applicability & great potential

It is theatre without borders, celebrating people and their capacity for joy

P02-03. Housing for Cognitive Health: A Pilot Study in Co-Design using Virtual Reality

Martin Quirke¹, Lesley Palmer¹, Judith Phillips²

¹Dementia Services Development Centre, University of Stirling, ²University of Stirling

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 design proposals, in combination other digitally enabled design communication methods, provides the opportunity for underrepresented groups, such as older people (50+) and those 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 United Kingdom, where this research took place, the majority of housing is

constructed by large commercial development companies. As a result, new housing focusses almost exclusively on provision for families and younger professionals, broadly ignoring the needs of a rapidly ageing society.

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 and other technologies 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 the session with some examples of the design recommendations resulting from the research, that could help address housing needs and preferences of older people living with dementia.

P02-04. WITHDRAWN

P02-05. 'Yes, But Do You Care?'

Judy Williams¹, Philip Connaughton²

¹The Alzheimer Society of Ireland, ²Dance artist/choreographer

The 'Yes, But Do You Care?' artwork creatively re-imagines the lived stories of family carers and their experiences of dementia care through the lens of the new Irish capacity legislation and explores understandings of autonomy and dependency.

Goals: To publicly explore potentially challenging aspects of care in Ireland today through sharing of re-imagined 'hidden stories'. This involves exploring the possible implications of the new capacity legislation for family carers, the Assisted Decision Making (Capacity) Act 2015.

To build new audiences and offer topical thinking and reflection space (plus offer panel discussions/Q&A for audiences to understand the process of the artwork and the motivation of family carers to be involved).

To encourage philosophical consideration of how human rights can be promoted and protected in Ireland, and share an understanding that rights and greater capacity may have unintended consequences that need to be explored.

The artists, Marie Brett and Philip Connaughton, worked closely with members of The Alzheimer Society of Ireland's Dementia Carers Campaign Network and with their Advocacy and Research function to ensure that consideration was given to the needs of the family carers who took part.

The Dementia Carers Campaign Network (DCCN), supported by The Alzheimer Society of Ireland, is an advocacy group for those who have experience caring for a loved one with dementia. They aim to be a voice of, and for, dementia carers in Ireland and to raise awareness of issues affecting families living with dementia. Since the group was set up in 2013, they have participated in research on dementia and the needs of family carers, spoken at conferences and events, met with political representatives to campaign for policy change, and taken part in awareness raising activities.

P03. (Parallel Session) Elevating the patient voice: public involvement in IMI ND projects

P03-01. Alzheimer Europe's work to promote Public Involvement in dementia research

Ana Diaz-Ponce, Dianne Gove

Alzheimer Europe

The presentation will provide an overview of AE's work on including people affected by dementia in research in the context of Public Involvement. It will refer to the way the organisation is conducting PI activities in several European projects and will specifically address some of its core principles such as person-centred approach to PI which includes active listening and continuous learning, reciprocity, respect, and the provision of appropriate support to people taking part in PI. It will also refer to some other more pragmatic requirements needed to conduct PI activities in a meaningful way.

P03-02. The European Prevention of Alzheimer's Dementia Research Participant Panel

Stina Saunders¹, Eileen Penman

¹University of Edinburgh, Centre for Dementia Prevention

Intro: The European Prevention of Alzheimer's Dementia (EPAD) study was a cross European longitudinal cohort study recruiting healthy individuals to detect early signs of Alzheimer's disease. While the study ended in October 2020, local research sites continue data collection through different funding other than IMI in order to build on previously collected data. It was crucial for the success of EPAD to involve research participants in the set-up, running and improvement of the study delivery.

Aim: To present the EPAD Participant panel model and to discuss representativeness of individuals taking part in longitudinal studies to prevent dementia.

Method: In our presentation, we discuss the framework for involving participants as collaborators in the EPAD study. The EPAD panels were set up at the beginning of the study and consisted of research participants, with administrative support from the study team. Local panels fed into a central panel which met annually. The panels provided critical input for reviewing study documents, giving feedback and offered suggestions for improving the study experience.

Results: The presentation is delivered by a research participant in the EPAD study together with a study team member. We introduce the aim and structure of the panel, highlight the importance of involving research participants as

collaborators in working towards a common goal with the research team and discuss ways to improve representativeness of individuals taking part in longitudinal studies to prevent dementia.

Discussion: Setting up participant panels is a method for systematically collecting the views of research participants. A deliberate governance structure within a study set-up to capture, analyse and enact feedback means participants are listened to and any changes within the scope of the study protocol can be implemented. It is vital longitudinal studies recruit individuals with a diverse background in order to achieve better validity and generalisability of study results.

P03-03. Patient Involvement and Engagement in IDEA-FAST

Johanna Graeber, Hanna Kaduszkiewicz

University Medical Center Schleswig-Holstein

Involving and engaging patients in clinical research has gained popularity in recent years. These activities have shown to be beneficial to enhance the quality of medical research. Patients have unique knowledge of their disease and therapy, which makes their input especially valuable for developing new medicines and health technologies.

IDEA-FAST is a multinational, multi-disease project with the aim to find objective measures of fatigue and sleep disturbances. These symptoms are common for patients with neurodegenerative disorders such as Parkinson's Disease, but are hard to measure in daily life. With the help of different technologies such as wearable devices and apps, we hope to find correlates of fatigue and sleep disturbances during the daily routines of patients. In a feasibility study and while planning a clinical observation study, patients and patient organisations have played a big role. Due to the complexity and size of the project, we have formed two groups. The Patient Specialist Advisory Board consists of patients from all target diseases. They take on specific tasks and advise in situations when their experiences as patients are valuable. The Patient Involvement and Engagement group consists of patient experts, representatives from patient organisations and researchers. They meet regularly to coordinate patient involvement, discuss patient issues and take part in the decision-making process. This approach allows patients who want to be involved in our research to choose their form of contribution and commitment. The activity and advice of patient experts and patient organisations have been an asset to our project. Patient experts have been involved in choosing suitable devices, advising on patient-facing materials or distribution of a questionnaire. Patients have an active part in decision-making processes and bring valuable input to IDEA-FAST.

P03-04. A roadmap of activity to develop patient and public involvement and engagement structures in Mobilise-D

Alison Keogh

University College Dublin, Insight Centre

The ability to move freely throughout our daily lives is a key indicator of health and independence. Monitoring and treating impaired mobility is a significant health challenge that relies in part on researchers and clinicians being able to accurately measure mobility in a real-life setting. Digital technology, including body-worn sensors have the potential to revolutionize mobility assessment. Mobilise-D is an IMI funded project involving over 300 researchers from 34 academic and industry partners across Europe (<https://www.mobilise-d.eu/>). As with any other public-private partnership, the Mobilise-D consortium represents the coming together of industry collaborators and researchers across the areas of healthcare, data science and engineering to solve the unmet need of accurately assessing mobility in a real-world scenario. Central to the project is the need to demonstrate that mobility is an important concept of interest and that digital mobility assessment and digital mobility outcomes are a key part of the concept. Therefore, it is important to work with patients to ensure that any solution is fit for purpose, can integrate into their lives in an acceptable manner, and is clinically meaningful to them and to support medicines labelling claim. This talk will outline the development of patient and public involvement and engagement (PPIE) structures within the Mobilise-D consortium. The structure that was created will be described and its outputs and future plans will be discussed, to demonstrate how patient, academic and industry partners are working together to develop and deliver an optimal solution.

P04. (Parallel Session) Leaving University after PhD? Opportunities and experiences across sectors

Rabih Chattat¹, Frans Verhey², Fania Dassen², Jesper Van Thor², Joeke van der Molen-van Santen², Saartje Burgmans², Joris Wiersinga²

¹Dipartimento di Psicologia, ²

This interactive seminar targeted at early stage researchers addresses the important topic of career development. Together we will explore opportunities to continue your career outside academia, and we will provide you with a taste of how it is to work in industry, health care or to even start your own business.

Our 1st speaker Jesper van Thor works at Statistics Netherlands (CBS) and specializes in careers of doctorate holders. He researched how PhD's look back at their PhD-track and will share some numbers with us about the sectors doctorate holders end up after their PhD.

Our other invited speakers Joeke van der Molen-van Santen, Dr Saartje Burgmans and Joris Wiersinga all have diverse, interesting careers across sectors and will share their personal career path and choices they have made along the road. They will also reflect on the transversal skills you obtain during your PhD and how these skills make you valuable for other sectors outside academia.

This seminar is aimed at early career dementia researchers attached to the INTERDEM Academy; interested attendants who are not part of this network are also welcomed. The INTERDEM Academy has been established in

2014, and it has been committed to stimulating the career development and capacity building of researchers in the area of psychosocial interventions and timely diagnosis in people with dementia, as well as supporting the pathway to senior academic posts in the INTERDEM network.

The network has grown to around 200 early stage researchers. For questions regarding this seminar or INTERDEM Academy, please contact Fania Dassen, training manager of INTERDEM Academy (interdem-masterclass@maastrichtuniversity.nl)

P05. (Parallel Session) Learning the lessons of COVID-19 in nursing and residential care

P05-01. Locked Out: Learning from the loved ones of care home residents in Scotland during the COVID-19 pandemic

Sarah Swift¹, George Palattiyil², Debbie Tolson³, Dina Sidhva³, Lynn Jamieson², Jo Hockley², Trish Hafford-Letchfield⁴, Neil Quinn⁴, Rikke Iversholt⁵, Kerry Musselbrook⁵, Sumeet Jain², Bruce Mason²

¹Sarah Swift, ²University of Edinburgh, ³University of the West of Scotland, ⁴University of Strathclyde, ⁵Iriss

In response to the COVID-19 pandemic, the Scottish Government mandated the cessation of care home visiting in March 2020. Our study, conducted between March and October 2020, explored the impact of the lockdown, social distancing, and other COVID-19 related measures upon visiting relatives of care home residents, staff members, and other key stakeholders. This presentation will share the findings emerging from semi-structured interviews with 36 visiting relatives of people living in care homes, and a survey completed by 444 relatives. Though our study was not dementia-specific, two-thirds of visiting relatives who participated in interviews shared that their loved one was living with dementia.

Our findings highlight the negative impact of COVID-19 measures upon the mental health of care home residents' loved ones, in addition to the sense of bereavement and living grief experienced by many. The loss of touch and intimacy due to social distancing measures significantly affected participants, and reinforced the limitations of short-term technology-led solutions such as video calling. The experiences shared by our participants emphasise the importance of the role of visiting relatives in care homes, supporting wider initiatives campaigning for the recognition of visiting loved ones as partners in care.

We will present a set of key recommendations informed by our findings, designed to reconnect families and restore relationships between visiting relatives and care homes. These recommendations are applicable beyond the Scottish context within which the research was conducted, and are intended to support care home residents and their loved ones in continuing meaningful communication and interaction during the post-COVID transition.

P05-02. Action On Rights - Alzheimer Scotland

Lorna Hart-Thomson

Alzheimer Scotland

Background: As a result of the Covid pandemic, Care Home residents were unable to see friends and family due to the restrictions placed upon them. The Public Health response was ultimately about keeping people safe, and care homes were closed to external visitors. However, families found this extremely unfair, and unacceptable.

In February 2021 new guidance emerged in the 'Open with Care' document, encouraging more meaningful contact. Funded by the Scottish government. Alzheimer Scotland established a team to empower families, and help them resolve such key issues as high levels of emotional distress; the deterioration of people living in care; grief; and the many inconsistencies in the interpretation of the guidance.

Aims of the team:

- To ensure meaningful contact between those living in care homes and their families and friends
- To be fully informed about care home visiting guidance, local public health restrictions, and the support available to people
- To make more informed decisions, and have better dialogue with care homes around visiting

Key Findings:

- Good communication was established between families and care homes
- Families were empowered to act for themselves
- The team advocated on families' behalf if required
- Partnership approaches with national and local organisations were crucial
- The skilled interventions of the team enhanced the quality of visits
- Non-confrontational approaches led to more positive outcomes
- Good practice was shared across the sector

Conclusions: The Action on Rights team identified a number of issues in the implementation of the 'Open with Care' guidance. Through information sharing, emotional support, and advice about achieving more meaningful contact, they have enabled families, and restored relationships. Given this success, Alzheimer Scotland has agreed to expand the remit of the team, so this structured approach can be employed in all complex cases*.

*Complex case could include – legislation, welfare rights, paying for care etc.

P05-03. Resilience of nursing home residents in times of COVID-19: a shared responsibility and the need for a tailored approach

Jasper De Witte¹, Tine Van Regenmortel, Floor Vinckers

¹HIVA KU Leuven

Background: Restrictive measures taken by nursing homes during the COVID-19 outbreak from March 2020 (e.g. quarantine, prohibiting physical visits and group activities) could form important stressors for which residents need sufficient resilience to safeguard their quality of life. Resilience refers to the capacity to positively adapt to difficult situations, and is related to individual, relational and structural factors. Based on the perspectives of nursing home residents, family members and volunteers, this qualitative study investigates which resilience processes nursing home residents applied to deal with the restrictive measures, and which elements were crucial to safeguard their quality of life.

Methods: We conducted 30 semi-structured interviews with nursing home residents and family members, a focus group with 10 volunteers, and three dialogue meetings with a mix of respondents. The data were collected in psychogeriatric and somatic wards in Flanders and two regions in the Netherlands. All data were transcribed verbatim and analyzed through an open, inductive method.

Results: The restrictive measures taken by nursing homes are important stressors for residents, as indicated by feelings of loneliness, sadness and fear. The residents use both primary and secondary control processes to deal with the impact of these measures, which varies among residents and depends on their resilience. The latter is determined by specific factors on the individual (e.g. health limitations, psychological hardiness), relational (e.g. possibilities for social interaction) and structural domain (e.g. nursing home policy, the number of COVID-19 infections, characteristics of the building).

Lessons learned: Since the impact of the restrictive measures depends on the resilience of nursing home residents, it is crucial to reinforce their strengths on the individual, relational and structural domain. This is a shared responsibility of all stakeholders, who require sufficient discretionary space that enables them to tailor specific measures around the unique needs and possibilities of individual residents.

P05-04. Culture Box: provision of creative activities and public health materials to people with dementia in care homes during the pandemic

Victoria Tischler¹, Mary O'Malley², Julian West³, Hannah Zeilig⁴

¹University of Exeter, ²University of West London, ³Royal Academy of Music, ⁴University of the Arts London

Background: People living with dementia in care homes have been severely negatively impacted during the pandemic with those from Black, Asian and Minority Ethnic (BAME) groups disproportionately affected. As well as high rates of mortality, social isolation, loneliness and responsive behaviours have increased as visits from family and loved ones were stopped due to social distancing measures. Visits from artists and creative practitioners also ceased. Culture Box aimed to respond to this by providing regular postal and digital deliveries of creative activities for use in dyads (a resident with dementia and a member of care staff) and public health guidance suitable for those with cognitive impairment.

Method: Participatory Action Research (PAR) is being used. PAR provides a dynamic and cyclical method that involves 1. Planning, 2. Action, 3. Evaluation and 4. Reflection phases, all informing one another. The Planning phase used modified (due to remote working) co-design with people living with dementia, care home staff and those from Black, Asian and Minority Ethnic (BAME) communities. Action includes production and delivery of Culture Boxes every week for 12 months. Survey data was collected at baseline on social isolation, responsive behaviours and personal preferences regarding creative activities. Dialogic interviews plus photos and videos are being collected at 3 time points to determine the impact of materials provided. The Reflection phase includes project team notes and discussions, and alteration of materials provided if warranted.

Findings: Eighty-nine people with dementia and 36 staff members across 33 care homes are participating in the study. Data collection and analysis is ongoing. The Culture Boxes have been received positively with materials eliciting interaction and enriching relationships between staff and residents through e.g., identification of shared interests. For staff, Culture Boxes have provided much needed ideas and materials at a time of unprecedented stress during the pandemic.

P05-05. Living and working in UK care homes during the COVID-19 pandemic: evidence from the front line

Andrea Capstick

University of Bradford

For some time after the onset of the coronavirus pandemic in the UK there was little media coverage of its impact on people with dementia living in care homes. We now know that around 40 percent of all UK deaths from coronavirus took place in care homes, and more than 70 per cent of those who died are likely to have had some degree of dementia. Many other care home residents with dementia experienced serious deterioration in their physical and mental health as a result of Covid-19 response measures, such as social isolation, removal of family visits, compulsory testing procedures and use of personal protection equipment. Care staff dealing with these unprecedented events have received relatively little attention or recognition by comparison with their hospital-based colleagues, and recovery is likely to be a long and difficult process.

Between July and November 2020, we collected a variety of qualitative data (interviews, focus groups, written testimony and photo-diaries) from 20 members of the dementia workforce whose employment was either directly within

UK care homes or who had an interface with long-term care environments during the first wave of the pandemic. This presentation shares the findings from this research, exploring four key themes to emerge:

Confusion, stress and anxiety resulting from the implementation of frequently-changing government guidance which often appeared not to have been designed with people with dementia in mind.

Feelings of guilt related to the illness or death of people living with dementia with whom the participants had formed long-standing relationships.

Distress related to witnessing the impact of Covid-19 response measures on people with dementia.

Creative responses: participants also told us how they had often found solutions to new problems by 'thinking outside the box'

Suggestions will be offered for supporting recovery in care homes.

P06. (Parallel Session) Gender and sexuality

P06-01. Sexuality and cognitive impairment in residential aged care: Staff perspectives

Linda McAuliffe¹, Deirdre Fetherstonhaugh, Maggie Syme

¹La Trobe University

Sexuality contributes to our well-being and extends into older age, despite cognitive or physical impairment. However, the ability to enjoy intimacy and express sexuality is often controlled and compromised when one moves into residential aged care. The purpose of this study was to identify what factors influence senior residential aged care staff when making decisions regarding intimate relationships and sexual expression among residents with cognitive impairment.

The study used vignette methodology to explore reactions to a fictionalized case study of a couple who develop a close, mutually satisfying relationship - Norm (who has mild cognitive impairment) and Carol. Staff were first asked whether they would intervene in the relationship. Using an innovative approach, several variations to the case study were then presented to explore whether staff views changed according to level of cognitive impairment; marital status; family involvement; exhibited distress; and degree of intimacy.

The study survey was sent to all 2931 Australian residential aged care facilities. Completed surveys were received from 543 facilities (representing a 19% response rate). When asked whether the intimate relationship between the couple should continue, over 90 % of respondents agreed, with only 10% indicating they would intervene. However, when the case study was varied, respondents indicated they were more likely to intervene - particularly if Norm was exhibiting distress in Carol's presence (89%), if Norm was married and his wife was living in the community (40%), or if Norm experienced moderate cognitive impairment (29%), and less commonly if Norm and Carol did not have family that visited (18%).

This study provides insight into how residential aged care staff make decisions regarding the intimacy of older people living with cognitive impairment in the residential aged care setting, and how informal policies guide practice in the absence of formal policies to promote and protect resident intimacy and sexuality.

P06-02. Exploring Dementia Service Access and Avoidance by LGBTQ+ Older Adults in Ireland: A mixed method study

Megan Oglesby, Louise Hopper

Dublin City University

Objectives: The researchers aimed to examine the experiences of LGBTQ+ people living with dementia (PLWD) and their caregivers in relation to how they make use of dementia services, and whether negative experiences in dementia or general health services cause service-avoidance. The researchers also examined whether service avoidance by LGBTQ+ participants was a contributor to caregiver stress.

Methods: Six interviews were conducted, three with professional dementia-service providers, and three with LGBTQ+ service users. Thematic analysis was used to analyse the transcripts. A survey was also released that addressed three hypotheses relating service use and caregiver stress.

Results: Five themes were identified from the interviews which outline recommendations for making dementia services more LGBTQ+ inclusive, and three convergent themes also emerged from the open-ended questions of the survey. The statistical analysis however, could not reject the null hypotheses proposed and a small sample size challenged the accuracy of the quantitative results. The study also outlined number of future research possibilities based on the findings.

Conclusions: The findings suggest that heteronormativity can cause service use avoidance by LGBTQ+ PLWD in services specifically aimed at socialising, however that the saliency of symptoms can overpower the want to avoid and encourage service use. Similarly, socioeconomic problems that are more salient than symptoms can discourage service use. Though interview participants indicated increased anxiety over possible discrimination of themselves or the person they are caring for in a healthcare context, caregiver stress was similar between carers of LGBTQ+ and non-LGBTQ+ PLWD and as service use was lower in caregivers of LGBTQ+ PLWD other predictors of caregiver stress may be more prominent than service avoidance. Finally, it was suggested that the creation of LGBTQ+ socialising service that involves both dementia and LGBTQ+ organisations would be beneficial to LGBTQ+ people living with dementia and their primary caregivers.

P06-03. WITHDRAWN

P06-04. Sexuality of people with dementia and their spousal caregivers

Maaret Meriläinen

Memory Association of Oulu Region

People with dementia (PwD) and their spouses face more sexual dysfunction than other peers, but still, they seek less help with their problems. Sexuality is perceived as a private and shameful affair that does not belong to others. Discussion about sexuality of PwD is very problem oriented. We might talk about hypersexuality and other problems but totally forget many welfare effects.

In Sexuality and dementia -survey (2019) I wanted to find out what kind of sexual activity couple with dementia have, how they feel about it and what kind of worries they might have. I got responses from 22 PwD and 52 spousal caregivers.

People with dementia perceive sexuality as a more important part of a relationship than spouses. On the other hand, intimacy can be a huge strength for both in the early stage of dementia. 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. Their responses also highlighted that caregiver may have intimate relationship with a new partner which causes both guilt and joy. More than 40% of the caregivers who responded to the survey considered the possibility of falling in love with another person.

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.

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. 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.

P07. (Parallel Session) Collaboration and best practice: common challenges & lessons learned from the IMI ND portfolio

Christophe Bintener¹, Carlos Díaz², Lennert Steukers³, Dalia Dawoud⁴, Angela Bradshaw⁵, Lewis Killin²

¹, ²SYNAPSE Research Managers, ³Janssen Pharmaceutica NV, ⁴NICE The National Institute for Health and Care Excellence, ⁵Alzheimer Europe

Neuronet is a three-year Coordination and Support Action that kicked off in 2019. The aim of Neuronet was to set up an efficient platform to boost collaboration across research projects focusing on neurodegenerative diseases, including but not limited to Alzheimer's disease. These projects have all been launched by the world's biggest public-private partnership in the life sciences, the Innovative Medicines Initiative (IMI).

In order to fulfill its aim, Neuronet partners set up thematic working groups with expert members from the different projects, addressing common challenges in four focus areas: data sharing, regulatory interactions, ethics & patient privacy, and sustainability. In this parallel session, the panelists will showcase the learnings from these groups with regard to collaboration and good practice.

The session will kick-off with short introductions to each focus area. First, Neuronet Coordinator Carlos Diaz will introduce the attendees to Neuronet's approach. Next, Neuronet Leader Lennert Steukers will provide a snapshot of the lessons learned concerning data sharing and re-use in IMI projects.

After that, Dalia Dawoud from the National Institute for Health and Care Excellence (NICE) speaks about lessons learned in approaching Health Technology Assessment & Regulatory bodies.

This is followed by Angela Bradshaw from Alzheimer Europe, who introduces the attendees to common challenges in ethics and patient privacy, and how projects aimed to overcome them.

Finally, Lewis Killin from SYNAPSE research management partners introduces an area that far too often doesn't receive the attention it should: sustainability, and how projects approached this critical milestone.

The presentations will be followed by a general discussion between panel members.

P07-05. Sustainability

Lewis Killin

Synapse Research Management Partners

Research projects share a common issue in securing viable, long-term sustainability for their outputs after their funding period has finished. To remedy this, and as one of its objectives, NEURONET has sought to identify and share a range of sustainability strategies and tools that are relevant and applicable to the IMI neurodegenerative (ND) portfolio. To this end, NEURONET has convened a series of sustainability working group (WG) meetings, where all projects in the supported IMI ND portfolio have been invited to share their approaches to and experiences with sustainability. This also introduced an opportunity to open discussion and feedback regarding common sustainability issues within the portfolio, such as intellectual property, legal, financial and technical issues.

In sharing best practices and learned lessons, WG members have underlined considerations for every stage of sustainability model development. Generally, projects have had to formulate sustainability models in terms of their marketable assets, potential stakeholders and research landscape. This entails further considerations about maintenance, promotion and brokering of said assets. This represents a change from a common model defined by a reliance on permanent customers who agree to sustain open-ended project activities, rather than specific project assets or outputs. Therefore, where confident sustainability planning represents a change in approach, investigators

and project teams may require support to help make decisions or clarify definitions that would facilitate the sustainability of their assets.

Overall, the sustainability challenges faced by projects in the IMI ND portfolio are well-recognised, and so tools and frameworks have been developed to aid investigators and project teams define sustainability as clearly and as early as possible. To aid projects further, NEURONET is also dedicated to producing a guidance document, containing a catalogue of sustainability models raised in the WGs, practical advice and tools for decision making. This will be prepared for August 2022.

P08. INTERDEM: Social health as a driving force in dementia prevention and living well with dementia

P08-01. COVID-19-related social support service closures and mental well-being in older adults and those affected by dementia: a UK longitudinal survey

Rabih Chattat¹, Clarissa Giebel, Daniel Pulford, Claudia Cooper, Kathryn Lord, Justine Shenton, Kym Ward, Sarah Butchard, Mark Gabbay

¹Dipartimento di Psicologia

Background: The COVID-19 pandemic has had a major impact on delivery of social support services. This might be expected to particularly affect older adults and people living with dementia (PLWD), and to reduce their well-being. The aim of our longitudinal study was to explore how social support service use by older adults, carers and PLWD, and their mental well-being changed over the first three months since the pandemic outbreak.

Methods: Unpaid dementia carers, PLWD and older adults took part in a longitudinal online or telephone survey collected between April and May 2020, and at two subsequent timepoints 6 and 12 weeks after baseline. Participants were asked about their social support service usage in a typical week prior to the pandemic (at baseline), and in the past week at each of the three timepoints. They also completed measures of levels of depression, anxiety and mental well-being.

Results: 377 participants had complete data at all three timepoints. Social support service usage dropped shortly after lockdown measures were imposed at timepoint 1 (T1), to then increase again by T3. The access to paid care was least affected by COVID-19. Cases of anxiety dropped significantly across the study period, while cases of depression rose. Well-being increased significantly for older adults and PLWD from T1 to T3.

Conclusions: Access to social support services has been significantly affected by the pandemic, which started to recover slowly. With mental well-being differently affected across groups, support needs to be put in place to maintain better well-being across those vulnerable groups during the ongoing pandemic, even in light of restrictions being removed in England from 19th of July.

P08-02. Measures of social health in the context of cognitive decline and dementia – Results of a systematic review

Rabih Chattat¹, Henrik Wiegelmann², Karin Wolf-Osterman, Joanna Rimaszewska, Marta Lenart, Dorota Szczesniak, Myrra Vernooij-Dassen

¹Dipartimento di Psicologia, ²University of Bremen

Background: Studies indicate that there is a positive influence of various social health markers like social support on the maintenance of cognitive functioning during aging. However, there is still a lack of consensus around how aspects of social health are measured, which contributes to the difficulty in collecting scientific evidence and making comparisons between results. The objective of this systematic review therefore is to identify and organize measuring instruments used so far to assess social health domains in the context of cognitive functioning and dementia. Moreover, it will point out research gaps indicating the lack of markers covering specific social health domains.

Methods: Three electronic databases were searched (PubMed/MEDLINE, PsycINFO, CINAHL) to identify articles published in English language between 2000-2020. Additionally, reference lists of the final literature sample were checked. Articles reporting on social health related instruments were included. Four reviewers split into two teams were independently screening titles and abstract with a double-check principle, then reviewed selected full texts. All disagreements were solved by a third expert opinion. The formal instruments identified will then be charted and systematized according to a predefined framework of social health. In addition, they will be assessed and prioritized based on key research aspects and characteristics of the instruments used.

Results: This presentation will address main findings of the literature review. We will provide a novel classification of formal instruments used to measure social health domains within the context of cognitive functioning and dementia. Furthermore, characteristics, contexts applied and psychometric properties of these instruments will be presented systematically. A synthesis on how consistently or inconsistently social health is measured will be given and domains that lack coverage with formal instruments will be highlighted. Finally, recommendations for the future development of social health measures will be discussed.

P08-03. Social health and prevention of dementia

Rabih Chattat¹, Myrra Vernooij-Dassen², Marieke Perry, Eline Verspoor, Isabelle Van Der Lepen, Karin Wolf-Ostermann, Wolf-Ostermann, Henrik Wiegelmann, Joanna Rymaszewska, Dorota Szczesniak, Marjolein De Vugt, Esme Moniz-Cook, Rabih Chattat

¹Dipartimento di Psicologia, ²Radboud University

Background: Dementia is a multifactorial syndrome. We do not fully understand its origins and have no cure until now. Our ultimate goal is to study the underexplored relationship between the social domain of health (WHO, 1946) and cognitive decline and the onset of dementia, guided by our hypothesis. To facilitate testing of the hypothesis we here aim to further underpin and refine the concept of social health.

Methods: This effort is part of the JPND funded 'Social Health and Reserve in the Dementia patient journey (SHARED)' including 20 epidemiological databases and Social Health in the Men and Mice (SHiMMY) study. We developed a conceptual framework.

Results: The relevance of the social health in relation to the onset of dementia is supported by neurobiological and social pathways and preliminary evidence on its association. Social health is a relational concept within which well-being is defined by how the individual relates to his or her social environment and vice versa. The individual level reflects the individual's social competencies (e.g. with social health marker social engagement). The social environmental level reflects the network availability (including social network composition) and relational activities (including social support).

The first testing of our hypothesis in the Rotterdam study indicated that better perceived social support at baseline was associated with better brain structure over time.

Conclusion: This conceptual framework for social health allows to identify the role of social health in cognitive decline and dementia. Preliminary evidence and the first results of hypothesis testing indicate that social health might have potential for preventive interventions.

P08-04. DISTINCT: Using social health principles to improve the applicability and effectiveness of technology in dementia care-

Rabih Chattat¹, Martin Orrell

¹Dipartimento di Psicologia

The DISTINCT programme (Dementia: Intersectoral Strategy for Training and Innovation Network for Current Technology) has developed a multi-disciplinary, intersectoral educational research framework for Europe to improve technology and care for people with dementia and carers, and to provide the evidence to show how technology can improve the social health of people living with dementia with 15 PhD students. This will provide a comprehensive training programme to acquire a deep understanding of the nature of dementia and needs in relation to social health and the use of technology and to equip them with the right skills needed for work in academia, industry or the health and social sector. This will enable us to determine the practical, cognitive and social factors needed to make technology more useable for dementia; to evaluate the effectiveness of specific contemporary technology to improve social health; and to identify conditions for successful implementation of technology (facilitators and barriers for reach, adoption, implementation and maintenance) in dementia care. The dissemination of the knowledge and evidence on how technology can be best applied and implemented in dementia care will hence improve the lives of people with dementia and carers.

P09. (Parallel session) Maintaining dementia as a public health priority

P09-01. Alzheimer's Society Report: Worst Hit

James White

Alzheimer's Society

In November 2021, Alzheimer's Society published the report, 'Worst Hit', investigating the effects of the Coronavirus pandemic on people affected by dementia, how those impacts could be mitigated and what support structures need to be put in place to ensure that people with dementia and their carers can recover from the pandemic's effects. Below is a summary of the report's recommendations:

Mitigating the effects of Covid-19: People with dementia were disproportionately impacted in terms of deaths and were particularly impacted by measures taken by local and national governments.

To ensure that they are sufficiently protected from any future waves of the pandemic, the report recommends that local government have access to an Infection Control Fund until at least April 2021.

Additionally, any future changes to guidelines which affect the lives of people with dementia should be communicated well and consider their specific needs.

Supporting people affected by dementia: People affected by dementia have experienced significant harm from restrictions to social contact and reductions in services over this period.

The report recommends that informal carers be recognised as playing an integral role in caring for people with dementia and they should be able to visit their loved ones in care homes.

Additionally, UK governments must set out a clear recovery strategy, including rehabilitation to counteract effects on cognitive or physical functioning, support for mental and physical health, and speech and language therapy.

Social care reform: Covid-19 has exposed many of the weaknesses in the care system. People desperately need the long-promised reform, addressing the following:

Universal and free care at the point of use, pooling the risk of dementia care costs across society.

A clear minimum set of national standards.

Carers to be properly recognised.

Care to be person-centred, include an element of choice, and be integrated with health.

P09-02. Supporting family carers of people with dementia past the pandemic: A discrete choice experiment of public preferences for enhanced services and supports

Áine Teahan¹, Sharon Walsh², Edel Doherty², Eamon O'Shea¹

¹Centre for Economic and Social Research on Dementia, ²School of Business and Economics, NUI Galway

Background: The Covid-19 pandemic onset resulted in near-complete cessation of community-based health and social care services, further highlighting the essential role played by family carers in long-term care systems for people with dementia. Even prior to Covid-19, community-based care was mainly provided by family carers, many of whom experience decreased mental, physical and financial well-being due to their caring role. As many countries endorse ageing-in-place policies, enhanced support for family carers will be needed to ensure people with dementia can remain living at home for as long as possible and practicable. Funding additional supports is a major policy issue in many countries. This research aimed to elicit public willingness-to-pay additional taxation to finance different packages of care and levels of support for family carers of people with dementia in Ireland.

Method: Informed by multi-stakeholder engagement, including family carers, we designed a discrete choice experiment (DCE) exploring willingness-to-pay additional taxation to fund different support packages for family carers. We conducted the DCE survey with 509 general public members in Ireland. Data was collected between January and February 2021, and analysed using mixed logit models in Stata.

Findings: Our findings highlight citizens are willing-to-pay additional taxation for day-care, long-break respite, carer's allowance, and carer peer support groups. We estimated the welfare impact of moving from current provision to enhanced support packages incorporating these four support attributes. Welfare gains accumulate to €1,035.80 for the most comprehensive levels of provision across these attributes.

Conclusion: The public are willing-to-pay additional taxation to fund supports that family carers themselves have also ranked as important. These findings provide evidence of need and potential for greater investment in family carers in Ireland and internationally. Enhanced support systems could facilitate family carers to better maintain their own mental, physical and economic well-being alongside that of the person with dementia.

P09-03. Amplifying dementia as a global public health problem: A cross-country comparison of the impact of COVID-19 pandemic

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Background: Emerging evidence describes impacts of the COVID-19 pandemic upon people living with dementia and their informal carers, however without evidence-based global comparisons to date. The aim of this international study was to explore and compare the impact of COVID-19 and associated public health restrictions on the lives of people living with dementia and informal carers and access to dementia care across five countries.

Methods: People with dementia and informal carers from the UK, Australia, Italy, India, and Poland participated in remote semi-structured interviews. Participants were asked about their experiences of the pandemic and how restrictions have impacted on their lives and care. Transcripts were analysed by researchers in each country using thematic analysis, then combined across sites.

Results: Fifteen people living with dementia and 111 informal carers participated across the five countries. Four themes emerged: (1) Limited access and support; (2) Technology and issues accessing remote support; (3) Emotional impact; and (4) Decline of cognitive and physical health reported by carers. Whilst variations were noted, the pandemic has indirectly affected people with dementia and carers across all five countries. The pandemic removed access to social support services and thus increased carer burden. Remote services were not always provided and were limited in benefit and usability for those with dementia. Carers frequently described noticeably deteriorating cognitive and physical health in people with dementia.

Conclusions: The pandemic has amplified dementia as a global public health problem, and both people affected by the condition and their carers need support to better access vital support services to live well. This is even more important with emerging new waves and new variants of the virus affecting different countries, in our globally connected world.

P09-04. European estimates on the number of persons across the Alzheimer's continuum

Anders Gustavsson¹, Nicholas Norton¹, Thomas Fast², Lutz Frölich², Jean Georges², Drew Holzapfel², Tunahan Kirabali², Pierre Krolak-Salmon², Paolo Maria Rossini², Lydia Lanman², Antonella Santucci², Chadha², Wiesje van der Flier²

¹Quantify Research, ²

Introduction: Dementia is one of the greatest challenges for Europe, but estimates on numbers of persons with early Alzheimer's disease (AD) are missing. They are needed to inform policy decisions on preventive measures and planning for future therapies targeting AD pathology, both directed towards early stages of AD.

Methods: We synthesized the published literature on prevalence across the Alzheimer's continuum and derived a simple model to estimate numbers of persons, stratified by geographic regions, 5-year age groups, sex and stage. Stages included AD dementia, mild cognitive impairment (MCI) due to AD (henceforth prodromal AD) and cognitively normal populations with Alzheimer pathology who are at risk of developing symptomatic AD (henceforth preclinical AD). Across all stages, a positive amyloid-beta biomarker (Aβ+) was considered necessary and sufficient for confirmation of being on the Alzheimer's continuum. Here we present European estimates.

Results: The number of persons with AD dementia, prodromal AD and preclinical AD in Europe were estimated at 6.9, 15 and 52 million, respectively. Together they constituted 75 million across the Alzheimer's continuum, or 25% of all Europeans aged 50 and above (2.3%, 5.1% and 18%, respectively). The prevalence increases steeply with age and is higher for women. Combined with the impact of higher life expectancy in women, this results in the majority being female (72%, 62% and 55% of all persons per disease stage). Evidence of differences across countries in predementia stages of AD is largely lacking.

Discussion: The majority of persons with AD do not have dementia but are in early stages of disease, providing a window of opportunity for prevention. A major challenge will be to accurately, efficiently and equitably identify and treat the right patients if and when new therapies targeting AD pathology become available in Europe.

P09-05. Almas house - Knowledge Service during the COVID-19 pandemic

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¹Centre for Development of Institutional and Home Care Services, ²

Background: In Oslo, 9 600 persons have dementia in 2021 and the number will double by 2040. Research and experience show that they and their carers need sufficient information and access to assistive aids and technology that could support them and make their situation better and safer. Alma's House in Oslo City is the knowledge centre with a demonstration flat that display dementia friendly design and assistive technology. The target groups are persons with dementia, their carers, and other members of the public, health personnel and decision makers. The centre have around 15 000 visitors per year.

Aim: The goal was keeping the knowledge center open as a public health service despite the Covid-19 pandemic.

Method: We analysed the activity program and identified factors that enabled change due to pandemic challenges. We considered the infection control restrictions as mask and distance. Facemasks were no challenge but keeping distance of 1 to 2 meters was a challenge in existing program. The area of the flat allowed three people per visit due to new restrictions while there are usually 17 visitors. We identified that the guided tour with the demonstration of aids and technology and dementia friendly interiors was suitable to digitize. In collaboration with the Oslo Metropolitan University, and the Occupational Therapy program, we made a 3D film.

Results: The 3D film and customization of the tour made it possible to keep Alma's House open to the target groups during the pandemic. Alma's House have had fewer, but still 4500 visitors in 2020 -2021.

The 3D film shows user needs and presents various solutions. The film gives Alma's House the opportunity to reach people outside Oslo. Because the film are subtitled in English, the knowledge service Alma's House is now available for people with dementia and their carers around the world.

P10. (Parallel session) Rehabilitation in dementia

P10-01. Co-design of digital solutions to rehabilitation and dementia – a partnership project between the Scottish Dementia Working Group and AHPs

Alison McKean¹, Scottish Dementia Working Group Members¹, Elaine Hunter¹, Gail Hogg², Claire Martin², Natalie Chung²

¹Alzheimer Scotland, ²

Aim: People living with dementia have a right to rehabilitation which is the ethos of Scotland's AHP Dementia policy (Alzheimer Scotland 2017) and a key priority area for the Scottish Dementia Working Group (SDWG). Occupational Therapy Home Based Memory Rehabilitation (OTHBMR) is an individualised post diagnostic intervention delivered in people's own homes. The covid-19 pandemic meant that we had to consider new ways of working to provide rehabilitation and this session will share how we co-designed digital solutions to support the delivery of OTHBMR and the impact of future delivery.

Methodology: A partnership between the SDWG and occupational therapists identified two digital platforms for development – film and animation. The focus was on sharing information and providing education for people living with dementia and the workforce. It had been noted that animation is a unique platform to deliver educational movies to alleviate a lot of stigma around dementia and Alzheimer's (Botek 2013)

Working Groups were established and met virtually to develop resources using a co-design process, which will be shared. The resources were based on the expertise of people living with dementia.

Outcomes/Next Steps: To date, two films have been developed and four animations, which are receiving further feedback from colleagues within the SDWG. A selection will be shared as part of the session.

A preview of the animation 'Danny's Story' has been shared on social media with a positive response including the value of this approach for people who experience literacy difficulties. All members of the group are committed to building on this.

The work will be incorporated into Scotland's national OTHBMR improvement project

Key messages:

- Film and animation have a role to play in supporting rehabilitation and dementia.
- Key to the co-design process was that all team members were learning together and having fun together, which produced positive outcomes.

P10-02. Differences in the assessment of the relevance of support services between family caregivers and professional dementia experts: digiDEM Bayern

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Background: Family caregivers (fc) of people with dementia (pwd) often experience a high caregiver burden. To provide targeted support services to fc, knowledge about their assessment of such services is essential. The aim of this study is to conduct a comparative analysis of the assessment of the importance of support services for fc versus professional dementia experts (pde).

Method: An online survey was conducted as part of the project "Digital Dementia Registry Bavaria – digiDEM Bayern", as basis for the development of a needs assessment tool (DEMAND). Data collection was anonymous. Participants were asked to provide information on gender, background, and years of experience in dementia care. Afterwards, experts were asked to rate 44 different support services for relevance to dementia care on a scale of one (not important) to ten (important).

Results: 30 fc and 29 pde participated in the survey. Mean experience with dementia was 13 years. 66% of the participants were female. Significant group differences could be found in the services "family support group/self-help group" (mean(fc)=5.97; mean(pde)=7.83; p=0.013, r=0.665), "outpatient care" (mean(fc)=7.7; mean(pde)=9.03; p=0.016, r=0.651), "services for support in everyday life (e.g. circle of helpers, neighbourhood assistance)" (mean(fc)=7.27; mean(pde)=8.69; p=0.022, r=0.614) and "provision of aids" (mean(fc)=9.0; mean(pde)=7.97; p=0.043, r=-0.534).

Conclusion: International literature shows that utilization rates of support services are often low. The analysis implies that low utilization rates may be caused by a mismatch between the services offered and those needed by people with dementia and their caregivers. Additionally, the results demonstrate that family caregivers rated most support services as less important than professional dementia experts. This could indicate that caregivers generally rate their own need for support as low.

Funding: This research is funded by the Bavarian State Ministry of Health and Care (StMGP) as part of the Bavarian Digital Registry – digiDEM Bayern (funding code: G42d-G8300-2017/1606-83).

P10-03. Education and training to support physiotherapists working in dementia care: a scoping review

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Introduction: The care of people with dementia is of global concern. Physiotherapists can play a key role in assessment, falls prevention, pain management and gait re-education. Dementia care forms a significant part of the workload of a physiotherapist. However, there is a paucity of evidence on what constitutes effective education and training for physiotherapists working in dementia care.

Aim: The aim of this scoping review was to explore and chart the evidence relating to education and training for physiotherapists working with people with dementia with a view to identifying gaps within the literature. It is hoped that these findings will inform the design and delivery of a dementia educational program for physiotherapists.

Methods: This scoping review followed the Joanna Briggs Institute (JBI) methodology for scoping reviews. Databases searched included Medline, CINAHL, SocINDEX and PsycINFO. Titles and abstracts were reviewed independently by two reviewers for assessment against inclusion criteria. A total of eleven papers were included in this scoping review. Data extraction focused on study characteristics such as author, year, educational interventions including design, delivery, costs, and mode of delivery. The Kirkpatrick Framework which is a hierarchy of evaluation of training was used to classify the data extracted.

Results: A chronological narrative synthesis of the data outlined how the results related to the aims and objectives of this scoping review. Most educational interventions only reached level 2 on the Kirkpatrick framework- which assesses the extent of learning and includes knowledge, skills, confidence and attitudes. The range of outcome measures used to assess participants knowledge and confidence in dementia was diverse. The most effective educational interventions were multi-modal.

Conclusion: A greater understanding of what constitutes effective dementia education and training for physiotherapists will lead to appropriately designed educational interventions, ultimately leading to enhanced patient care.

P10-04. Memory Technology Resource Rooms; Evaluation of the Role, Contribution and Value to People with Dementia in Ireland

Emma O' Brien¹, Emer Begley², Eibhlís Cahalane³, Simone McGoldrick⁴, Kevin Cullen⁵

¹Memory Technology Resource Rooms, HSE, ²National Dementia Office HSE, ³HSE, Service for Older People, ⁴HSE, Older Persons Mental Health Services, ⁵Work Research Centre

Background: The Memory Technology Resource Room (MTRR) Network was established in 2018. There are now 27 MTRRs across Ireland. This presentation will report on the findings of a recent independent service evaluation.

MTRRs offer a dedicated person-centred post-diagnostic support for people with dementia, their 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. The MTRRs provide compensatory and cognitive rehabilitation strategies to maximise and support independence.

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 from community services, 35.3% secondary/acute care, 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, 34% receiving additional non-AT advice, and 66% signposted/referred to relevant community services.

90% of visitors rated their visit as very useful and 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; majority 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. The informal and non-clinical setting was noted as a positive aspect by those attending. It also provides continuity of care; offering practical advice and solutions and is a resource for local health care staff. Based on the central role of the MTRR Network and expert staff employed, evaluation recommendations included enhancing the service to deliver post-diagnostic supports such as cognitive therapies and psycho-education.

P10-05. "Accessing specialist palliative care for people with dementia"

Lisa Cronin

N/A

Background: Dementia is a life-limiting condition and evidence suggests that people with dementia can benefit from specialist palliative care input as part of their post-diagnostic care. However, there is little published about the utilisation of specialist palliative care services by people with dementia, with evidence suggesting that they are less likely to gain access to these services than people with other life-limiting diseases such as cancer or heart failure.

Aim: The aim of this study was to explore how people with dementia access specialist palliative care services, from the perspectives of healthcare professionals involved in the referral process.

Methods: Convenience sampling was used to recruit participants involved in referring to, and accepting referrals for, a specialist palliative care inpatient (hospice) and community-based service, in the Mid-West of Ireland. Semi-structured interviews (n=10) were conducted with consultants, specialist registrars, clinical nurse managers and an assistant director of nursing. The data was analysed using a thematic approach.

Results: Four major themes emerged: (a) current capacity for providing dementia specific specialist palliative care (b) appropriateness of referrals and recognising need (c) inadequate and inequitable geographical distribution of services (d) service integration and inter-professional collaboration. A needs assessment rather than a particular diagnosis underpins the referral process to specialist palliative care. However, there is little consensus on the 'grey' areas within a need's assessment for a person with dementia, and many assessment tools do not consider the particular symptoms and needs of a person with dementia.

Conclusion: The particular symptoms and disease trajectory of dementia may require a changed model of specialist palliative care access and provision, and further staff training (of referrers and accepting services), to fully meet the palliative care needs of people living with dementia.

P11. (Parallel session) Physical Activity, Sport & Nutrition for Brain Health

Neil Fullerton¹, Emma Stevenson², Willie Stewart³, Stephanie Adams⁴, Craig Ritchie⁵

¹Alzheimer Scotland, ²Newcastle University, ³University of Glasgow, ⁴University of Edinburgh, ⁵Brain Health Scotland

Join us for this expert led discussion on the importance of maintaining brain health, the role of physical activity, sport and nutrition, and the latest on research and public health initiatives.

P12. Sponsored parallel: DZNE. Ethnic minorities

P12-01. Dementia & migration – EU-atlas & the situation in two selected countries

Tim Schmachtenberg, Jessica Monsees, Maria Isabel Cardona, Jochen René Thyrian

German Center for Neurodegenerative Diseases

People with a migration background (PwM) are a vulnerable population in terms of healthcare. They can display poor health outcomes with mental and dental health being particularly affected. Furthermore, they might face communication or financial barriers, discrimination, and display a low health literacy. These circumstances contribute to a low utilisation of healthcare services. PwM with dementia are a subpopulation of particular vulnerability. An analysis from 2019 estimates the number of PwM with dementia to be about 475,000. There is evidence that PwM might have a higher risk of developing dementia and face worse consequences. They are affected by inequalities, such as underdiagnosis or underprovision of healthcare. This demonstrates that this is a population that requires healthcare that is adapted to their needs.

The aforementioned issues and an expected rise in numbers of PwM with dementia are a challenge for healthcare systems worldwide. To provide care to those affected, targeted information is needed about this population and their situation.

As a first step, the 'EU-Atlas: Dementia & Migration' illustrates the prevalence of dementia in PwM broken down by region and migration background, compares national dementia plans and care guidelines regarding their focus on migration, and analyses the healthcare situation for all EU, EFTA, and UK countries.

After 2.5 years, the EU-Atlas on dementia and migration is completed, and in this session, the final results and the consequential implications for research and politics will be presented. Furthermore, there will be in-depth presentations from two countries to illustrate how dementia and migration can be approached and handled in specific contexts. At the end of the session, a discussion will be held on what conclusions can be drawn from the results of the EU-Atlas and the situation described in the two presentations regarding the care of PwM with dementia for research and care practice.

P12-02. Provision of care for migrants with cognitive disturbances: a nationwide survey on the preparedness of Italian dementia services

Marco Canevelli

Department of Human Neuroscience, "Sapienza" University

Introduction: It has been estimated that more than 500,000 people with a migration background live with dementia in Europe. There is the need to collect "real world" data on the preparedness of healthcare services to support the inclusion of migrants in the public health response to dementia. The aims of the present study were i) to estimate the number of migrants attending Italian memory clinics (CCDDs) and ii) to identify possible barriers and resources for the provision of diversity-sensitive care.

Methods: A survey of all Italian CCDDs was conducted between December 2020 and April 2021. An online questionnaire was developed to obtain information on the number of migrants attending Italian CCDDs in 2019, the challenges encountered in the diagnostic approach, possible facilitators in the provision of care.

Results: Overall, 343 out of the 570 contacted CCDDs completed the survey questionnaire (response rate: 60.2%). Nearly 4,527 migrants attended these services in 2019. Migrants accounted for a median 1.1% (IQR: 0.9%-2.8%) of overall CCDD accesses. More than one-third of respondents reported that the number of migrants attending their facilities had increased in the last 5 years. The overall quality of the migrants' cognitive assessment (in terms of accuracy and culture-sensitiveness) resulted as low or sufficient in most cases. A minority of CCDDs had translated information material on dementia (6.7%) and reported the possibility to contact cultural mediators (37.3%) and interpreters (10.5%). Profound geographic differences were observed across Italian regions concerning the number of migrants attending CCDDs and the availability of dedicated resources.

Discussion: A relevant number of migrants is attending Italian CCDDs that are still not adequately prepared to deliver diversity-sensitive care and support. Our data will inform tailored public health policies aimed at reducing health inequalities and promoting the wellbeing of all people with dementia living in Italy.

P12-03. The process of increasing awareness of the challenges of cognitive testing in ethnic minority groups and people with low educational levels in Norway

Peter Bekkhus-Wetterberg

Norway

I will describe the process of increasing awareness in Norway of the special challenges associated with cognitive testing in people with diverse cultural backgrounds and varying levels of education. Also how these topics have been included in official national dementia guidelines, and how basic cognitive tests developed for these populations have been promoted through national centres of research and information on dementia.

P13. (Parallel session) Mental health and dementia during the pandemic

P13-01. One Year of Caring & Coping with Dementia in COVID-19

Laura O'Philbin, Bernadette Rock

The Alzheimer Society of Ireland

In March 2020, the COVID-19 Pandemic forced The Alzheimer Society of Ireland to suspend most of its face-to-face dementia services. Following the publication of two reports about dementia and COVID-19 in 2020, The ASI published a third report in 2021 capturing the impact of COVID-19 on people with dementia and their families one year after Ireland was first locked down.

Online and telephone surveys were carried out with 17 people with dementia and 240 family carers across Ireland. Focus Groups with nine Dementia Advisors and six front-line service managers also took place.

Results paint a bleak picture, highlighting the ongoing struggle of people with dementia and their families as they contend with a year of COVID-19 restrictions and the impact of these on their mental and physical health.

There has been a significant and largely irreversible deterioration in symptoms experienced by people with dementia with 81% of family carers feeling concerned about a decline in their loved one. Family carers continue to be at breaking point with 54% report a decline in their mental health. Carers' need for practical support has almost tripled compared to July 2020 while over half report needing emotional support. People with dementia report struggling with a lack of routine and activities of daily living. There is also a deep fear of contracting the virus. Both people with dementia and family carers listed loneliness as one of their greatest challenges during COVID-19.

In this presentation, the quantitative and qualitative results of this research and recommendations will be discussed.

P13-02. Psychosocial effects of COVID-19 measures on (pre-)dementia patients during 2nd lockdown

Els Bakker¹, Ingrid van Maurik², Arenda Mank², Marissa Zwan², Lisa Waterink², Susanne van den Buuse², Jennifer van den Broeke², Freek Gillissen², Marleen van de Beek², Femke Bouwman², Philip Scheltens², Wiesje van der Flier²

¹Alzheimer Center Amsterdam, Amsterdam UMC, ²

Background: The COVID-19 pandemic and the associated lockdown measures pose enormous social challenges, especially for people with dementia. In December 2020, the second lockdown started in the Netherlands. We aimed to investigate experienced support and psychosocial effects in Dutch memory clinic patients and their caregivers during second lockdown. In addition, we compared these effects between first and second lockdown.

Methods: We included n=204 symptomatic patients (age=69±7, 38%F; n=119 (58%) dementia, n=85 (42%) mild cognitive impairment (MCI)), n=307 patients with subjective cognitive decline (age=66±8, 41%F; SCD) and n=366 caregivers from the Amsterdam Dementia Cohort who completed a self-designed survey on psychosocial effects of COVID-19. Additionally, n=460 caregivers participated in the study via Alzheimer Nederland (Dutch association for people living with dementia). Survey questions related to experienced support and psychosocial problems. In a subset of patients (n=209) and caregivers (n=178) we were able to compare their answers to answers on a similar survey completed during first lockdown.

Results: The majority of patients and caregivers reported that friends and family (n=155 (77%) MCI/dementia, n=205 (67%) SCD, n=622 (75%) caregivers), practicing hobbies (n=137 (67%) MCI/dementia, n=212 (69%) SCD, n=521 (63%) caregivers), and music (n=122 (60%) MCI/dementia, n=176 (57%) SCD, n=513 (62%) caregivers) helped them coping with COVID-19 times. Compared to the first lockdown, we found that levels of anxiety decreased in both patients (22% vs. 12%, p=0.003) and caregivers (23% vs. 16%, p=0.033). In addition, patients experienced more formal (13% vs. 24%, p<0.05) and informal (40% vs. 79%, p<0.001) support compared to the first lockdown.

Conclusion: Our results suggest that during second lockdown, patients and caregivers adapted to the challenges posed by the lockdown. The majority reported that support from family and friends, hobbies and music helped them cope. Compared to first lockdown, levels of anxiety decreased, while patients experienced more social support.

P13-03. Involving people with dementia in research during the pandemic: challenges and learning

Ana Diaz, Gove Dianne

Alzheimer Europe

Alzheimer Europe set up the European Working Group of People Living with Dementia (EWGPWD) in 2012. Since then, the group has been involved in several Public Involvement (PI) activities in different European research projects. During this time, all PI work had been conducted in face-to-face meetings facilitated by AE staff. During the pandemic, the group has had to change the way it operates. This presentation will reflect on the main challenges and opportunities for people with dementia to work remotely, and will provide recommendations to involve them in PI for research in a meaningful way. Two members of the EWGPWD will also participate in the session and will refer to their personal experiences.

P13-04. The impact of one year of COVID-19 restrictions on lifestyle activities and mental health in older adults: a population-based questionnaire

Lisa Waterink¹, Els Bakker¹, Leonie Visser², Francesca Mangialasche², Mia Kivipelto², Sietske Sikkes¹, Niels Prins¹, Philip Scheltens¹, Wiesje van der Flier¹, Marissa Zwan¹

¹Alzheimer Center Amsterdam, ²Karolinska Institutet

Restrictions during the COVID-19 pandemic influenced the lifestyle and mental health of people across the globe. Particularly in older individuals, unhealthy changes may affect their long-term (brain)health and potentially alter their risk of cognitive decline. We aimed to investigate predictors of lifestyle and mental health changes in older adults during the COVID-19 outbreak.

An online questionnaire was initiated by the World-Wide FINGERS network, and disseminated to registrants aged 50+ of the Dutch Brain Research Registry. 3.195 participants (66±8 years old, 76% female) completed the questionnaire. Participants reported changes in lifestyle and mental health during the COVID-19 outbreak in seven domains (physical activity, diet, sleep, memory, stress and feeling of loneliness or depression). A composite score for overall change was computed, ranging from -7 to 7 where negative scores indicated unhealthy changes. Participants were categorized in three groups: 1) unhealthy (lowest 25%; mean±SD: -2.88±0.95), 2) minimal (middle 50%; -

0.54±0.52) and 3) healthy (upper 25%; 1.10±0.71) overall changes. Multinomial logistic regression analysis related participant demographics, subjective memory complaints and COVID-related factors to healthy or unhealthy changes. Participants that were female (OR 1.45; 95%CI [1.16–1.82]), living alone (1.26; [1.02–1.55]), had subjective memory complaints (2.20; [1.74–2.28]), were fearful of (1.75; [1.46–2.11]) or experienced a COVID-infection (1.96; [1.42–2.71]) were more likely to report unhealthy changes, compared to participants reporting minimal changes. Participants with a good income (0.57; [0.46–0.71]) were less likely to report unhealthy changes. Age <65 was both associated to unhealthy (1.80; [1.50–2.17]) and healthy overall changes (1.19; [1.00–1.42]).

The COVID-19 pandemic differentially impacted the lifestyle and mental health of older adults. To prevent long-term negative health effects, extra attention should be directed to people with reported factors. Future studies should examine how public health policies can promote a healthy lifestyle to counteract the pandemic's negative impact on (brain)health among older adults.

P13-05. Dementia in the Time of Covid

Luisa Bartorelli, Stephanie Levi

Alzheimer Uniti

Objective: The Covid-19 pandemic has caused great changes for families – in the way that people live their daily lives and in their emotional and social relationships. People with dementia have had difficulty accessing their normal cognitive and motor reactivation activities and suffered greatly from isolation. In particular, changes in established routines have contributed to the onset or worsening of psycho-behavioral manifestations and to the accentuation of cognitive disorders, creating a greater burden on caregivers. Conversely, it is known that maintaining a daily routine based on simplified and sequential activities has a reassuring effect both on the PWD and on those around them.

This study investigates the factors that have influenced the resilience of PWD and their families and looks at the harmful effects of social isolation and changing lifestyles which have been caused by the pandemic.

Materials and Method: The study consisted of 160 participants with Alzheimer's (9% with vascular and other kinds of dementia) investigating functional changes in their cognitive, behavioral and motor spheres, whilst also considering the impact on family lives. Social and healthcare professionals stayed in contact with the families by telephone and by sending videos with information on daily activities for cognitive, motor and occupational stimulation. Whenever possible, "bridges" were created for contact with the various doctors and other kinds of assistance.

The assessment was done by a questionnaire given by psychologists on the telephone to caregivers about 100 days into the forced lockdown.

Conclusion: This study shows that distance support produces good results particularly when the caregivers themselves have a high level of general education and a good technological know-how.

A regular routine can decrease the sense of anxiety, uncertainty and precariousness. Finding regular activities that are appropriate restores a sense of security and serenity, providing possible cognitive benefits.

P14. (Parallel session) Intergenerational dementia initiatives

P14-01. The Adoption project: Raising awareness on dementia in primary schools and improving wellbeing in people living with dementia through an intergenerational initiative

Fania Dassen¹, Niels Janssen², Klaasje Voskuil-Peters³, Marjolein de Vugt²

¹Maastricht University - Alzheimer Centrum Limburg, ²Alzheimer Center Limburg, ³Alzheimer Nederland

Background: The Adoption project: Young adopts Old (Dutch: Adoptieproject: Jong adopteert Oud) is an intergenerational initiative that brings together people living with dementia living in care homes and pupils from primary schools, thereby contributing to a dementia friendly society. The initiative was originally developed at the Alzheimer Center Limburg (the Netherlands) and is currently being implemented throughout the Netherlands, in collaboration with Alzheimer Nederland.

Objective: The Adoption project aims at educating pupils from primary schools about dementia and understanding the lived experience, reducing stigmatization and taboo, and open up the conversation about dementia, and include social participation of people with dementia living in a care home.

Methods: Within the Adoption Project, primary schools and care homes are connected using a flexible and tailored approach. Pupils receive an interactive guest lecture on dementia and subsequently visit the care home in smaller groups. During these visits, pupils participate in activities (e.g., baking, reading the newspaper, painting) together with the care home residents. In the upcoming months the Adoption project will be evaluated scientifically using a mixed-methods approach.

Results: Until now, many positive experiences and anecdotes have been reported, highlighting the value of this initiative. Because of COVID-19, in-person visits were not possible, resulting in additional formats allowing for COVID-proof activities (e.g., sending post-cards, exchanging short movie clips, baking something for the residents). By sharing the fundamentals of this intergenerational initiative, and sharing our experiences and lessons learned, we hope to inspire and learn from each other.

Discussion: Especially in times like these due to restrictions and safety measures, intergenerational initiatives are even more important considering the elevated risk of loneliness. Intergenerational initiatives such as the Adoption project contribute to dementia friendly societies and may show mutual benefits, such as increased respect and understanding, and joy and wellbeing, between generations.

Ciara O'Reilly

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

Aim: 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.

Buddy Programme: In the Buddy Programme the PLWD is paired (by mutual interest) with a 16-year-old student for a 6-week intervention. They will meet each week for 1 hour via Zoom. This time affords both the PLWD and the student an opportunity to engage in a shared, meaningful activity relating to their common interest (eg. art, music, sport). Structured activities can be decided in advance but freeform spontaneity is also welcome.

Co-development Process: Three consultations were held to co-develop the initiative with students, family carers and PLWD. These contributors identified the benefits - social connectedness, accessibility, battling ageism and being able to learn from each other - as well as brainstormed ways in which the project could be further developed and rolled out beyond its initial geographic scope (in light of Covid-19).

P14-03. Children Are Learning Dementia

Fusun Kocaman

The fragment of the population that is highly open-minded and responsive to learning about dementia, yet mostly deprived of information, are children; whereas they are at an age where their beliefs and attitudes are remarkably flexible and also workable. Children commonly have a lack of dementia understanding and they develop poor attitudes toward people with dementia, mostly because the parents are buried deeply in their struggle to handle and manage the situation, they often disregard the fact that the children also need to interact with their older relatives. It is crucial to train children for establishing a dementia-friendly society, since they are the potential opinion leaders of the future, and solely “teaching dementia” is enough to change children’s knowledge and attitudes, structured programs are not imminent

Turkish Alzheimer Association has initiated three projects addressing the Intergenerational Dementia Initiative. "Digital Grandchild" incorporates volunteer students contact PwD regularly, by voice and/or video and establish a bond of affection, paint/sing together to improve their visual memory and QoL. The second project named "Children Are Learning Dementia" was launched on April 23rd Children's Day, involving children younger than 14 years of age receiving a specially tailored and animated "Dementia and Communication" training for 30 minutes and answering 10 quiz questions. 278 children have already received dementia-friendly certificates, TAD is working with schools for inserting structured training in their curriculum. The third project "Tell Me a Story" is designed to embrace young students to record their videos while reading a 5-to-6-page-story, with the efforts of acting and personating. These videos are published on TAD web page for PwD to watch and enjoy, improving their QoL.

P14-04. “What if we talk about Alzheimer’s disease?” – An educational booklet for children

Lorène Gilly, Hélène Delmotte

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.

Today, Alzheimer's is the most common neurodegenerative disease. In 2020, 3 million people, people living with dementia and their caregivers, are affected by Alzheimer's disease. 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 also helps them to know how to behave with a person living with dementia and understand the importance of the daily presence of those around her.

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.

P14-05. Young people’s perspectives on parental dementia: a systematic review

Ilaria Chirico¹, Giovanni Ottoboni², Marco Valente², Alessandro Pappadà², Rabih Chattat²

¹University of Bologna, ²

Background: There is extensive literature on the experiences and needs of spouses/partners and adult children of people with dementia. Less is known about the young people’s experience of parental dementia as told by themselves. Hence, the aim of this review was to systematically ascertain the literature on young people’s lived experience of parental dementia and the psychosocial impact of the disease on their development.

Methods: A systematic literature search was performed in CINAHL, PsychINFO, PubMed, Scopus, and Web of Science. A rigorous screening process was followed, and a checklist for qualitative and observational studies was used to evaluate the methodological quality of the studies. Narrative synthesis of the selected articles was carried out.

Results: Twenty-one studies were included and a synthesis of the literature revealed six themes. The first theme concerned the difficulties in dealing with the diagnosis which was often preceded by a long period characterized by uncertainty, confusion, family distress, and conflicts. The second theme discussed changes in family relationships in terms of the role of young people in supporting both parents and keeping family united. The third theme described how young people struggled to reconcile significant caring responsibilities and developmental needs. The fourth theme showed how parental dementia widely affected young people’s personal lives in terms of education/career and the overall life planning. The fifth theme illustrated main adaptation models and coping strategies. The last theme discussed the need for appropriate support and services based on a “whole family” approach.

Conclusions: Findings should promote public awareness about a yet largely neglected topic. Furthermore, they should inform research, practice, program development, and policymakers in the area of collaborative dementia care.

P15. NEURONET - From bench to bedside: preclinical research in IMI ND projects

P15-01. Alzheimer’s Disease-protective Variant of CD33 Increases Microglial Activation

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CD33 is mainly expressed on immune cells of myeloid origin including macrophages and microglia. Upon activation CD33 recruits tyrosine phosphatases, which results in dephosphorylation of key molecules of the immunoreceptor tyrosine-based activation motif (ITAM) pathway such as spleen tyrosine kinase (SYK). Recently, genome-wide association studies identified the CD33 variant CD33^{ΔE2} to decrease the risk to develop late-onset Alzheimer’s disease. However, the mechanism how CD33^{ΔE2} mediates this protective function is still not fully understood.

In this study, a CD33 reporter cell line suitable for ligand screening approaches was developed and putative CD33 agonistic antibodies were validated in human iPSC-derived microglia (iPSdMiG). Furthermore, CD33 knockout and CD33^{ΔE2}-expressing human iPSdMiG were functionally analyzed and compared to isogenic wild type control cells. CD33 knockout and CD33^{ΔE2}-expressing iPSdMiG exhibited increased mRNA levels of inflammatory cytokines and ITAM-containing adapter protein TYROBP, constitutively increased SYK phosphorylation levels as well as an elevated phagocytic uptake of bacterial particles and aggregated amyloid β_{1-42} . Interestingly, CD33 knockout but not CD33^{ΔE2}-expressing iPSdMiG were associated with increased SYK phosphorylation levels after activation of the ITAM pathway and increased phagocytic oxidative burst.

In summary, deletion of CD33 or expression of the Alzheimer’s disease-protective variant CD33^{ΔE2} in human iPSC-derived microglia resulted in putative beneficial microglial activation including phagocytosis of amyloid β_{1-42} . Potential detrimental oxidative burst and exacerbating inflammation was only observed in CD33 knockout iPSdMiG but not in iPSdMiG expressing the Alzheimer’s disease-protective variant CD33^{ΔE2}.

Acknowledgement: This project has received funding from the Innovative Medicines Initiative 2 Joint Undertaking under grant agreement No 115976 (PHAGO). This Joint Undertaking receives support from the European Union’s Horizon 2020 research and innovation programme and EFPIA.

P15-02. Modeling ischemic stroke in a triculture neurovascular unit on-a-chip

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The neurovascular unit (NVU) is made up of multiple cell types responsible for regulating and coupling brain and vascular function, and is impaired in many neurological diseases. Brain stroke is a life-threatening condition that occurs upon disrupted blood flow to part of the brain, resulting in hampered supply of oxygen and nutrients. Approximately 80% of all stroke cases are of ischemic nature, i.e., caused by a blood clot obstructing the blood flow to brain. Alteration of vascular integrity upon stroke can lead to serious complications including haemorrhagic transformation, edema and death. In addition, stroke often co-occurs with other neurological conditions such as vascular dementia and Alzheimer’s Disease. Although in vivo models have served as valuable tools in stroke/NVU research, they are often costly, allow only limited control of experimental conditions, and can have poor translatability

into clinical studies. For this reason, physiologically relevant in vitro models of the NVU are needed to improve our understanding of brain vasculature function in health and disease, and to identify novel therapeutic targets. We present a 3D microfluidic model of the human NVU that incorporates endothelial cells, astrocytes, and neurons. The model displays relevant junctional proteins, expression and function of key transport proteins, and a tight barrier that prevents leakage of small molecules. Ischemic stroke was mimicked in the model by removing glucose, inducing chemical hypoxia, and stopping medium perfusion. Resulting cultures showed a reduction in vascular integrity, mitochondrial membrane potential, and adenosine triphosphate levels, which are common features of ischemic stroke. This NVU on-a-chip model can be used for fundamental studies of NVU function in stroke and other neurological diseases, and for investigation of potential therapies. Due to the platform's high throughput and compatibility with automation, the model also holds potential for drug screening.

P15-03. PD-MitoQUANT: quantification of mitochondrial morphofunction in neuronal cells

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Aim: To quantify mitochondrial morphology and function in neuronal models of Parkinson's disease (PD) using confocal and super-resolution microscopy and high-content image quantification.

PD-MitoQuant Project aims: <https://www.pdmitoquant.eu>

To improve our understanding of mitochondrial dysfunction in PD

To identify and validate molecular drivers and mechanisms in PD

To discover novel potential therapeutic targets for PD

Research goal: Mitochondria in neuronal cells possess a distinct morphology and spatial arrangement within the soma and neuronal network. Evidence is accumulating that mitochondrial morphology and function ("morphofunction") are tightly interconnected. A proper understanding of the role of mitochondrial aberrations in the PD pathomechanism, requires experimental technology for robust and unbiased quantification of mitochondrial morphofunction. Here, we present an integrated experimental strategy to extract this information from 3D microscopy data obtained in neuronal cell models.

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P15-04. Structure-based classification of tauopathies and identification of PET ligand binding sites

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Ordered assembly of tau protein into filaments characterizes multiple neurodegenerative diseases, which are called tauopathies. Aggregated tau can be visualized in living subjects by using position emission tomography (PET). We previously reported that by electron cryo-microscopy (cryo-EM), tau filament structures from Alzheimer's disease, Pick's disease, chronic traumatic encephalopathy and corticobasal degeneration (CBD) are distinct. We now show that the structures of tau filaments from progressive supranuclear palsy (PSP) define a novel three-layered fold. Moreover, the tau filament structures from globular glial tauopathy (GGT) are similar. The tau filament fold of argyrophilic grain disease (AGD) differs from the above and resembles the four-layered CBD fold. The AGD fold was also observed in a case of aging-related astroglialopathy and in inherited cases with mutations +3 or +16 in intron 10 of *MAPT*, the tau gene. Tau filament structures from cases of familial British dementia and familial Danish dementia were the same as those from Alzheimer's disease and primary age-related tauopathy. These findings suggest a hierarchical classification of tauopathies based on their filament folds, which complements clinical diagnosis and neuropathology, and allows identification of new entities, as we show for a case diagnosed as PSP, but with filament structures that were intermediate between those of GGT and PSP. Finally, we used cryo-EM to determine the binding sites of APN-1607, a second-generation PET ligand, in the core of tau filaments from Alzheimer's disease. We identified two major sites in the β -helix of paired helical and straight filaments and a third major site in the C-shaped cavity of straight filaments. Knowledge of the binding modes of APN-1607 to tau filaments may lead to the development of new ligands with increased specificity.

P16. INTERDEM: Sharing best practice e-health interventions in dementia

P16-01. The JAIN challenge: lessons learned from the Dutch version and call for the World JAIN challenge

Franka Meiland¹, Hans Arnold²

Background: The last three decades, more and more assistive technologies (AT) have been developed in dementia care. Even though benefits have been reported for persons with dementia, informal and professional caregivers, the implementation and actual use in practice is laying behind. Various barriers are recognized, such as technologies not attuned to needs, ethical issues, lack of information about which AT exist and are useful for which target group, lack of training in the use of AT and lack of proper business models. The Joint Artificial Intelligence Network (JAIN) aims to break down some of these barriers by setting up collaborative networks with all relevant stakeholders involved. The goal is to improve the Quality of life of persons with dementia and their caregivers with the use of AT.

Method: A National (Dutch) JAIN Challenge was organized for promising prototypes and market-ready products in dementia care. Twenty-six companies applied for the challenge. From May 2021 on, the World Challenge has started. Also, other initiatives are set up, like a joint European research proposal, setting up field labs and collaborative networks in countries around the world.

Results: The National JAIN Challenge, resulted in three selected prototypes and three products. In the category 'Prototype', TOOLOBA won and in the category 'Market Ready Product', the video calling app 123Family took the prize. These will be shortly presented, as well as further activities of JAIN.

Discussion: The time seems right to involve all stakeholders and bridge the innovation gap by collaborating worldwide in development, evaluation and implementation of AT. In doing so, we may maintain and improve good quality care for people with dementia and their carers.

P16-02. Setting up Field labs: pilot in SPAIN

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Dependency ratio in Europe is expected to almost double from 29.6% in 2016 up-to 52.3% in 2080. So, demand for long-term care in older people will rise and put a strain on the sustainability of healthcare systems. Consequently, European policies are focusing on allowing older adults to live safely and independently at home.

Technological advancements provide a good opportunity to address the challenges of promoting independence, health, and personal well-being in people with dementia. However, the use of ICT solutions for PWD is very low despite the public funding of projects aimed to stimulate its development. Unfortunately, most of technological solutions to apply psychosocial approaches are seldom fully developed, only reaching a pilot phase, and the route to implementation and sustainability into clinical practice is scarcely considered. So, few digital tools on psychosocial care have been successfully used in the real-world. It's necessary to move forward in the implementation and uptake of ICT solutions for PWD.

"Living labs are defined as user-centred, open innovation ecosystems based on systematic user co-creation approach, integrating research and innovation processes in real life communities and settings"[1]. The advantage of this strategy is to develop and implement technology almost simultaneously involving final users in the process. We present the development of a living lab in Spain and we describe the main features of it. The key point is to develop it from the beginning involving researchers, final users and health workers. All potential stakeholders will be involved actively in the development of the platform from the design stage, assessing their satisfaction, the impact and its acceptability and usability.

Finally, the project aims to demonstrate how it can be used with a ICT platform, being able to respond to the PWD, MCI and their carers needs. Besides, an international network like Jain can promote this approach.

P16-03. The role of people with dementia and family carers in creating and assessing AI solutions enhancing quality of life

Marco Blom

Alzheimer Nederland

In several - if not all - phases of the development of technological solutions people living with dementia and their family carers play a crucial role as primary end users. First of all, their needs and problems should be the main focus of the development to make sure that the innovation is not solely tech-driven. In assessing needs and problems a societal approach can be of added value if there is also a focus on impact. Technological solutions with a focus on domains that are relevant for (1) many end users, (2) during a long period of time, (3) with high effectiveness on (4) crucial needs/problems will have a greater impact. These solutions should also be highly acceptable for different groups of end users (inclusiveness) and easily integrated/adopted in their daily life. This could mean that certain aspects - sometimes innovative or related to the design - of the solutions need to be adapted in order to reach out to as many end users as possible.

P16-04. Artificial Intelligence and the Challenges of Living with Dementia: An interdisciplinary, multi-lab approach to design smart care solutions

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Living with dementia, even at an early stage, may significantly impact the quality of life of individuals with dementia and their family. Powerful and adaptive technologies, such as artificial intelligence, may offer previously unimagined benefits to enhance quality of life, but their match to the needs of individuals and their successful implementation in practice remain significant challenges. In order to address these, we are in the process of developing a unique international, interdisciplinary, and multi-lab approach, where we are harnessing the learning and predictive powers

of AI, and transforming them into warm, smart care solutions that can meaningfully impact quality of life in 3 key domains:

- health, safety, and quality of care.
- social participation and social contact.
- autonomy, meaning, and self-respect.

Our approach is based on the notion of Warm Technology: person-centred and meaningful designs developed together with individuals with dementia, their relatives, informal caregivers, and healthcare professionals. Our work is situated within, and dependent upon, an open ecosystem of co-creation with field labs and academic workplaces at its heart, allowing us to iteratively implement knowledge/innovations into practice and provide a long-term responsive learning environment on dementia and technology in a unique interdisciplinary and international collaborative network.

P17. (Parallel session) New ways of diagnosing dementia and of recruiting and assessing research participants

P17-01. The (non)sense of computer tools in memory clinics – an international survey study assessing the views of professionals, patients and care partners.

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Introduction: Computer tools based on artificial intelligence could aid clinicians in memory clinics by supporting cognitive testing at home, diagnostic decision-making, and communicating diagnosis and prognosis. We aimed to identify preferences, main barriers, and facilitators for using computer tools in memory clinics of all end-users, i.e., clinicians, patients, and care partners.

Methods: Between July and October 2020, we invited clinicians to participate in our online survey, using the European Alzheimer's Disease Centers network and Dutch Memory Clinic network. A total of 109 clinicians participated (45±10y, 49%F). A second survey was created for patients and care partners. They were invited via Alzheimer Europe, Alzheimer's Society UK, the Amsterdam Dementia Cohort, and the Amsterdam Ageing Cohort. A total of 50 patients with subjective cognitive decline (SCD), mild cognitive impairment (MCI), or dementia (73±8y, 34%F) and 46 care partners (65±12y, 54%F) participated.

Results: The vast majority of clinicians reported willingness to use diagnostic and prognostic computer tools. User-friendliness and increasing diagnostic accuracy were reported as the main factors to stimulate the adoption of a tool. Tools should also be time-saving and provide clear information on reliability and validity. Inadequate integration with electronic patient records and fear of losing important clinical information were most frequently indicated as barriers. Patients and care partners were equally positive about the use of computer tools by clinicians, both for diagnosis and prognosis. In addition, most of them thought favorably of the possibility of using tools themselves.

Discussion: This study shows that most end-users positively value computer tools in memory clinics. Computer tools can pave the way for remote testing, which might be of particular importance in times of social distancing. With the further development and implementation of tools, it is essential to overcome technical and practical barriers whilst paying utmost attention to reliability and validity.

P17-02. Remote telephone-based assessment and the additional clinical use of speech features in the Semantic Verbal Fluency task

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Background: The COVID-19 pandemic has accelerated the transition to remote neuropsychological assessment, meaning patients do not have to visit hospitals, which reduces the burden in patients, saves time, and reduces costs. However, the accuracy of a remote telephone-based administration remains unclear. We investigated the accuracy of the Semantic Verbal Fluency (SVF) task and related speech and linguistic features in the diagnostics of cognitive disorders in a face-to-face and semi-automated telephone assessment, and we examined the user-experience of both modalities.

Method: In the DeepSpA project, 134 participants were recruited from the memory clinic of the MUMC+ (Maastricht, the Netherlands). All participants underwent a face-to-face neuropsychological assessment at baseline and a semi-automated telephone-based assessment (after 6 months), both including the SVF task (animals and groceries, 60 seconds) which was administered via the Delta application (Ki-elements). The relation between speech and linguistic features, such as mean word frequency, temporal and semantic clusters etc., and clinical diagnosis, were investigated using stepwise regression analyses, corrected for age, education level and gender. Questionnaires on user-experience were administered after each assessment. The questionnaires were analysed with an independent samples t-test comparing the face-to-face with the semi-automated telephone assessment.

Results: Compared to the commonly used SVF total score, automatically derived speech and linguistic features had an additional value in the differentiation between people with and without cognitive disorders in both the face-to-face assessment ($R^2=0.551$, R^2 increase 11%), as in the telephone-based assessment ($R^2=0.329$, R^2 increase 17%). The user-experience ratings of simplicity, conceivability, comfortability of the assessment and wanting to repeat the assessment were comparable for both assessment modalities.

Conclusion: Automatically derived speech and linguistic features of the SVF task have an additional value in the early diagnostics of cognitive disorders. A telephone-based assessment could be considered as an easy tool to follow patients remotely over time.

P17-03. Reviewing the impact of the COVID-19 pandemic on Join Dementia Research volunteer registrations and study recruitment in the United Kingdom

Adam Smith, Martin Rossor

University College London

Since its launch in February 2015, Join Dementia Research (JDR) has played a key role in delivering the UK Government's Challenge on Dementia. This had a stated ambition that England should be the best country in the world for dementia care and support, and for research into dementia and other neurodegenerative diseases.

By entering basic demographic and health information, JDR matches members of the public to research studies, making it easier to participate in research, as well as streamlining the recruitment process for researchers. Anyone aged over 18 can volunteer, people with and without dementia and carers. Studies recruiting through JDR range from clinical trials of new treatments to surveys identifying improvements to the quality of life of people with dementia.

JDR relies on a flow of new volunteers' registrations, to provide researchers and their studies with sufficient participants. The service is promoted in various ways, however the primary source of referrals for people living with dementia is NHS Memory Clinics.

Since launch the service has enjoyed steady growth; in December 2019 the service had reached a monthly average of 103 volunteers with dementia and 504 without. With a one month maximum of 160 people with dementia and 1000 people without. Since January 2020, when the impact of the pandemic was first being felt, registrations fell to a monthly average of 50 people with dementia and 250 without – representing a 50% decrease.

Despite the decrease in new volunteers, study recruitment from the service increased in 2020 particularly to observational studies, and large survey studies.

In this presentation we present new data, to demonstrate the impact of the COVID-19 pandemic on research volunteering and study recruitment and consider the increasing importance of JDR and similar services in a changing landscape which is moving towards remote and digital delivery

P17-04. Impaired central recognition of non-verbal environmental sounds in mild Alzheimer's disease and MCI

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Background: Recently, studies have emerged showing that the recognition of not only verbal but also non-verbal sounds might be affected in patients living with Alzheimer's disease. Impairment of central auditory processing has serious implications for everyday living. The aim of our study was to investigate environmental sound recognition in a well-defined population with Alzheimer's Disease (AD).

Methods: Cognitive functioning of 51 patients with prodromal and mild AD and 27 age- and gender-matched cognitively healthy controls (HC) was evaluated using CERAD neuropsychological test battery. Intact peripheral hearing was ensured via a headphone-administered hearing-test. A sound recognition test containing 20-items of non-verbal environmental sounds of increasing difficulty and different categories was administered. Participants completed the sound test 5 times with sounds becoming increasingly louder. In the penultimate and last trial picture and word clues were presented, respectively, to ensure effects were not due to naming difficulties.

Results: HC performed significantly better at CERAD measures. Patients with dementia performed significantly worse in the sound test in comparison to HC. Whilst HC correctly identified 16.85 +/- 1.83 out of 20 sounds in the first trial, patients only recognised 15.75 +/- 2.56. Multivariate analysis revealed significantly better HC performance regardless of sound difficulty or category. Wilcoxon rank-sum-test showed that over 5 trials HC performed significantly better than AD and MCI ($Z = -2.422$, $p = 0.015$).

Conclusion: Our results show that recognition of daily environmental sounds is already significantly impaired in prodromal and mild AD. This is interpreted as an indicator of dysfunctional central hearing. Our results suggest that sound tests could aid as a swiftly administrable early diagnostic tool and show promise as being implementable via telemedicine.

P17-05. Digital Biomarkers for Alzheimer's Disease in a Real-Living Smart Home Environment: the RADAR-AD Tier 3 Study

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Background: Digital biomarkers constitute new ways for efficient, accessible and remote monitoring of functional and cognitive decline in Alzheimer's Disease (AD), even during a pandemic, as explored in the on-going 'Remote Assessment of Disease and Relapse – Alzheimer's Disease' (RADAR-AD, <https://www.radar-ad.org/>) international study, organized in three Tiers. While Tier 1 focuses on wearable devices and apps, and Tier 2 on a few sensors installed at participants' homes, Tier 3 aims for more holistic and pervasive monitoring at a real-living smart home environment.

Methods: We conducted literature and market research to select technology for the Tier 3 smart home. A technology platform for data retrieval and uniform representation was developed, coupled with Artificial Intelligence (AI) methods to extract events and activities from raw data. A Patient Advisory Board (PAB) of patient and carer representatives was organized to discuss acceptance and identify pitfalls.

Results: The Tier 3 device selection includes wearables and apps from Tier 1 and the home sensors from Tier 2. Infrared motion, power consumption and magnetic sensors, in greater quantities will detect presence in every room, appliance and door use respectively, extended by water level sensors to monitor use of the flush, shower and sinks and a button to press on emergency. The system transforms raw sensor data into events (e.g., power to appliance on/off) and combines them into user activities (e.g., watching TV, cooking or doing chores). The PAB confirmed willingness to participate in Tier 3.

Conclusion: The RADAR-AD Tier 3 study at a real-living smart home installation can provide clinically relevant detailed monitoring for dementia assessment. Due to its novelty, healthy participants (N=10) and partners are recruited for the study to start soon.

This work has received support from the EU/EFPIA Innovative Medicines Initiative Joint Undertaking RADAR-AD (grant No 806999) and their associated partners.

P18. (Parallel session) Young onset dementia

P18-01. For people with young-onset dementia and their caregivers advance care planning should focus on ‘what matters to them now and in the future’

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End-of-Life Care Research Group

Background: Advance care planning (ACP) has been conceptualized as a process of communication between patients, family and professionals to explore preferences for future care, including end-of-life care. Although the significance of ACP is widely acknowledged for people living with dementia, its uptake in this population is particularly low. Moreover, ACP research in young-onset dementia (YOD) is nearly non-existent. This study's research question is: "What are the experiences with and the views on ACP of people with YOD and their family caregivers?"

Methods: We conducted semi-structured, in-depth interviews with 10 people with YOD and 10 of their respective caregivers, in Belgium. Transcribed interviews were analyzed through the qualitative method of constant comparative analysis.

Results: Respondents lacked awareness of the concept of ACP, particularly as a communication process, and had very limited experience in planning medical care, for which they provided both personal (e.g. attitudes) and circumstantial (e.g. lacking information) reasons. Nonetheless, respondents formulated hypothetical emotional benefits of ACP, especially for caregivers. When discussing ACP as a communication process, participants elaborated on 'what matters to them' and paid a lot of attention to non-medical aspects, i.e. values they find important within care (e.g. dignity and an orientation towards family), the need for high-quality care provision, and the taboo associated to (young-onset) dementia.

Discussion: Respondents discussed their views on care in a concept that did not compartmentalize medical, social and mental health. The current image and implementation of ACP might, as such, be too medicalized and not accommodating to respondents' overarching focus on 'what matters to them now and in the future'. Therefore, we suggest practice to pay attention to patients' and caregivers' 'bigger picture' and strive to make ACP more of a dynamic, holistic process. Further, high-quality care and adequate information on both YOD and ACP emerged as preconditions for ACP engagement.

P18-02. Working post diagnosis of dementia: the development of a collaborative approach to research involvement.

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People living with dementia have the right to be involved in research in meaningful ways. This not only benefits the individual, but improves the research process and ensures the outcomes of the research are useful and accessible, with the potential to improve the lives of people living with dementia. This presentation aims to reflect on the development of a collaborative approach to research involvement between researchers at University of the West of Scotland and the members of the Scottish Dementia Working Group.

We will draw on our experiences of a new research project which aims to develop and test a new intervention using career guidance approaches to support people diagnosed with dementia whilst in employment. Our research has demonstrated that there is a lack of support services for people who are working when they develop dementia. Many people report having a negative experience of work after their diagnosis and experience poor mental health after leaving work. Career guidance can provide individuals with the tools to recognise their abilities, experience and transferrable skills. It assists them with decisions throughout their career, from leaving school until after they retire. Understanding the experiences of people living with dementia has been instrumental in the development of this research project and it has been designed to ensure that their expertise can inform the research throughout the three-year project.

This presentation will describe our collaborative work in developing a co-researcher model which provides meaningful, paid opportunities for involvement throughout the research process. Drawing on perspectives of the research team and from members of the Scottish Dementia Working Group we will present our working agreement and address the opportunities and barriers faced along the way as well as our hopes and aspirations for our future working relationship.

P18-03. Peer support through Zoom: experiences of people with Young Onset Dementia

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Background: 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. However, access to in-person peer support groups varies across the UK, and the Covid-19 pandemic forced in-person peer support groups to move online.

Methods: A literature review showed that people with YOD use online platforms, such as Facebook and Twitter, for peer support. During the pandemic Zoom became increasingly popular. However, little is known about people's experiences with peer support in such online settings. Based on the literature review and informal consultations with people with YOD, a focus group study was developed. The target group was people with YOD attending existing peer support groups that meet online. The data was analysed thematically by two independent researchers, using an inductive approach.

Preliminary results: Four focus groups with existing peer support groups were conducted, including 18 participants. Participants represented a wide geographical area, from the south of England up to Scotland. Participants were able to build friendships during the pandemic, which would not have been possible without the online platform. They overcame challenges related to technology, living with YOD, and the pandemic. While going through an extremely difficult time and not being physically close, participants developed new technological skills and supported each other.

Implications: This study provides insights into how people with YOD experience and use online peer support and how it impacts their life. It also shows what coping skills they use to manage challenges related to technology and living with YOD. These findings can be used to better support people with YOD in accessing online peer support, and to create new and strengthen existing online peer support opportunities.

P18-04. Living with a diagnosis of frontotemporal dementia: What helps and hinders?

Suzanne Gray

NHS Tayside

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

Aim: The aim of this study is to explore the lived experience of FTD from the person's perspective and to identify what helps and hinders people to live well.

Methodology: Interpretative phenomenological analysis (IPA) was selected due to its commitment to exploring how people make sense of life experiences and its usefulness in under-researched areas.

Methods: Seven people with FTD took part in individual interviews. Data was collected from thirteen interviews and analysed using IPA guidance. A reflective journal informed and refined the development of emergent themes.

Findings: 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 overarching 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 and are represented in the framework entitled 'the person led framework for understanding the experience of FTD'.

Conclusion: This study addresses a gap in knowledge about the person's lived experience of FTD. The study informs clinicians in relation to supporting people with FTD, involving people with FTD in decision making, and in future research.

P18-05. Worldwide prevalence and incidence of young-onset dementia

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Background: Young-onset dementia (YOD), with a symptom onset before the age of 65 years, heavily impacts affected persons with YOD and their caregivers. However, data on the epidemiology of YOD is scarce. Insight in prevalence estimates is crucial for healthcare policies to provide tailored services and care. Information on incidence facilitates further research on the etiology, mechanism, and risk factors of YOD. Both are needed to raise awareness of YOD. Therefore, we conducted 2 systematic reviews and meta-analyses on the worldwide prevalence and incidence of YOD.

Methods: The literature search was conducted in PubMed, Embase, PsychINFO, and CINAHL. Eligible studies were population-based studies reporting on incidence or prevalence of dementia before the age of 65. Random-effect meta-analyses were performed on 5-year age bands for prevalence and incidence separately. Results were standardized for the World Standard Population. Subgroup analyses and meta-regression were used to identify factors influencing heterogeneity between studies. The study is registered with PROSPERO, CRD42019119288.

Results: 145 eligible studies were found, 95 targeting prevalence, and 50 targeting incidence. Total age-standardized results for the age-range 30-64 years showed a prevalence of 119/100,000 population, and an incidence of 10/100,000 person-years. Subgroup analyses showed that both prevalence and incidence were similar for men and women, and were highest for Alzheimer's disease, followed by vascular dementia and frontotemporal dementia. Meta-

regression showed age range, sample size and study methodology significantly influenced heterogeneity in the prevalence studies, whereas geographic location significantly influenced heterogeneity in the incidence studies.

Conclusion: The worldwide prevalence and incidence of YOD are considerable, with a worldwide prevalence of 3.9 million people, and an incidence of 350,000 new cases each year. This shows tailored healthcare and more research into YOD is necessary. Still, there are knowledge gaps to address in future research, such as differences in ethnicity and subtypes of dementia.

P19. (Parallel session) Fluid biomarkers as strategic tools for counteracting dementia

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Alzheimer's dementia, Lewy body dementia, and frontotemporal dementia (FTD) are amongst some of the most common forms of dementia. Each type is caused by different biological factors, and therefore they will likely require different specific treatments targeting these factors. To be able to develop such effective treatments, it is important to correctly diagnose each dementia type, at the earliest possible stage.

The bPRIDE project (blood PRotein Identification to Discriminate dEmentias) aims to generate and validate blood tests for early and specific diagnosis of the major dementia types. To successfully achieve these aims, bPRIDE will analyse more than 1,000 blood proteins in over 1,000 patients, who are at different stages of these different dementia types. This will be done using novel and extremely sensitive technologies.

MIRIADE (Multiomics Interdisciplinary Research Integration to Address DEmentia diagnosis) aims to train a new generation of scientists able to optimise and accelerate development of novel biomarkers for dementia. It is expected that this new generation of researchers will develop reliable tests to detect the underlying cause of different dementias years before the symptoms begin. The focus of the project is on the best possible education of these young researchers and on the discovery of new dementia markers and their application in the clinic.

The tools developed within both projects could ultimately help to provide specific and early/timely diagnoses, which will empower people with dementia. It will also allow to assign the most suitable novel treatments to the right people, which could strongly facilitate development of successful therapies.

This session is organised by bPride and MIRIADE

P20. (Parallel session) Joint EADC/EAN Symposium on MCI: diagnosis, disclosure and management

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The concept of mild cognitive impairment (MCI) was coined in the 1980s and has since evolved to denote a population of patients with a syndrome of cognitive impairment, as well as a certain stage in the disease trajectory of neurodegenerative dementia disorders, most notably Alzheimer's disease. Despite the fact that the concept is widely used in clinical practice, a number of considerations surrounding MCI remain problematic. Firstly, patients with MCI constitute a very heterogeneous population with varying prognosis, underlying pathology and treatment perspectives. Secondly, explaining a diagnosis of MCI and the underlying cause to patients and caregivers may be difficult. Thirdly, the diagnostic utility of biomarkers in the MCI stage of a possible progressive, neurodegenerative dementia disorder is uncertain on the individual patient level, which further compounds the difficulties for clinicians to determine which patients should undergo biomarker sampling. Fourthly, such issues raise a number of ethical questions surrounding the use of the MCI diagnosis, which clinicians need to be aware of and take into consideration when counselling individual patients. These aspects have become even more relevant since the approval by the FDA of Aducanumab, a mono-clonal beta-amyloid antibody, for AD. As it is likely that the treatment may be more effective e.g. in the MCI stage versus the dementia stage and require the presence of beta-amyloid in the brain of patients, biomarker-based diagnoses will become increasingly more relevant.

This session is organised by EAN and EADC

P21. (Parallel session) Telecare and counselling

P21-01. Improving Communication between Staff and Family of Non-Communicative Patients at Israeli Geriatric Facilities by Using a Mobile App also during the COVID-19 Outbreak

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Family caregivers (FCs) of non-communicative persons institutionalized at geriatric facilities present significant unmet communication needs regarding receiving regular updates about their loved one's condition and having available healthcare professionals (HPs) to approach when needed. We developed and tested a mobile app for staff-family communication with both parties having active roles in app planning to tailor it to their needs and abilities. The app

includes a daily-update module for FCs and a chat option for FCs and HPs. App use was piloted at one geriatric medical center for 15 months (unit-level randomization resulted in one complex-care and one assisted-ventilation unit in each group- intervention and control) and one single-unit nursing home for three months during the COVID-19 outbreak. Participants were 55 FCs (28 from intervention group and 27 FCs from control group) of patients who were reported to have dementia or major cognitive impairment (85.2% - intervention group and 59.3% - control group). Personal interviews were conducted with the FCs before and after app use (with mean duration of use 1.6[S.D.=.6] months). Most participants were women and the children of the patients; their mean age was 55.9 years (S.D.=12.4). Repeated measures Analysis-of-Variance for the end-of-life communication sub-scale on the Quality of Communication questionnaire yielded a main effect for time ($F_{(1,53)}=8.31$, $p=.006$) with both groups' ratings increasing over time and an interaction effect ($F_{(1,53)}=4.78$, $p=.033$) with a greater increase for intervention group compared to control group. Intervention group participants rated the app as convenient to use. Qualitative data revealed that FCs perceived app use as improving quality of communication with the HPs who used it and improving their own well-being. The app offers a feasible and an effective mode of communication that incorporates technology in daily communication between FCs and HPs while addressing FCs' unmet needs.

P21-02. Financing the sustainable implementation of eHealth interventions for caregivers of people with dementia: Lessons from nine Dutch case studies

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Background: Due to the COVID-19 pandemic, there is a greater need for remote support options for dementia than ever, as many traditional face-to-face services have been suspended. Moreover, the pandemic has created an increased enthusiasm for online support in care professionals and patients alike. Unfortunately, these online (eHealth) interventions seldom find their way from research into clinical practice. The goal of this study was to map which strategies are used to facilitate the desirability, feasibility, viability, and sustainability of eHealth for dementia that is already used in practice.

Methods: Experts (N=483) in the areas of dementia and eHealth were asked to suggest interventions that met the following criteria: delivered via the internet; suitable for informal carers of people with dementia; accessible in the Netherlands; and used in practice. Subsequently, contact persons from the recommended interventions were interviewed via telephone. These interviews were analyzed using multiple case study methodology.

Results: Twenty-one eHealth interventions for carers of people with dementia were suggested. Nine of these 21 interventions met all four criteria. Four of these interventions had developed sustainable business models and five were implemented in a more exploratory manner, although some had also developed preliminary business models.

Conclusions: These findings indicated that intervention origin was important, as eHealth interventions that were developed in the research context found their way to sustainable implementation less often. Successful implementation was linked to integration into larger organizations, internal ownership and content creation, external development of information and communication technology support, and fixed, low pricing. These insights will help bring evidence-based interventions into practice through sustainable financing, independent of research grants. This will help meet the increased need for more remote support options for dementia, and take advantage of the elevated enthusiasm to digitizing dementia care.

P21-03. Keeping physically active through tele-rehab during the pandemic: Results from the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) study

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Background. Restrictions introduced in response to the COVID-19 pandemic led to increased risk of deconditioning in the general population. No empirical evidence of this effect however has been gathered in people living with dementia.

Methods. This is a longitudinal phenomenological qualitative study. Participants living with dementia, their caregivers and therapists involved in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) process evaluation during the COVID-19 pandemic were qualitatively interviewed at two time points: the baseline two months after the national lockdown was imposed in England (i.e., May 2020), the follow up two months after the first set (i.e., July 2020). The data were analysed through deductive thematic analysis.

Results. Twenty-four participants living with dementia, 19 caregivers and 15 therapists took part in the study. A self-reinforcing pattern was identified among the participants, whereby lockdown made them apathetic, demotivated, socially disengaged, and frailer. This reduced activity levels, which in turn reinforced the effects of deconditioning over time. Without external supporters, most participants lacked the motivation / cognitive abilities to keep active. Provided the proper infrastructure and support, some participants could use tele-rehabilitation to break the vicious cycle and combat deconditioning.

Conclusion. The added risks and effects of deconditioning on people with dementia require considerable efforts from policy makers and clinicians to ensure that they initiate and maintain physical activity in prolonged periods of social distancing. Delivering rehabilitation in the same way as before the pandemic might not be feasible or sustainable and innovative approaches must be found. Digital support for this population has shown promising results, but remains a challenge.

P21-04. eHealth interventions for dementia in times of Covid-19: using WordPress plugins as a flexible dissemination for dementia service providers

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Background: In times of Covid-19, digital interventions can be a valuable resource to support informal caregivers. However, there is a lack of digital interventions that have been successfully put into practice in the dementia landscape, particularly interventions that have been scientifically evaluated. Evaluated and effective digital interventions exist, but they often don't find their way from research to practice or remain at a low implementation readiness.

Method: In the project digiDEM Bayern a digital intervention for informal caregivers, the 'Angehörigenampel' (dementia caregiver traffic-light) was developed. The intervention allows informal caregivers to assess their physical and psychological burden of caregiving. Based on the assessment results, appropriate recommendations are provided. The intervention is based on the short version of the Burden Scale for Family Caregivers (BSFC). The digital intervention 'Angehörigenampel' was developed as a WordPress plugin and integrated into our digiDEM Bayern platform.

Results: The development of the digital intervention as a WordPress-plugin was kept generic so that it can easily be installed and adapted on further websites. Initially, the intervention was published in four languages (German, English, Turkish, Russian). Due to the multi-language approach, an adjustment of the recommendations or adding a new language is possible without programming knowledge. For an own implementation only a WordPress installation is needed, the customization of all text modules (introduction, questions, answers, recommendations, reminder & feedback section) is easily possible.

Conclusion: The 'intervention as a plugin' approach demonstrates an easy and flexible way of deploying eHealth interventions to other service providers. The implementation barriers for other service providers are low enough to easily integrate the intervention on their website, enabling more caregivers to benefit from the disseminated intervention.

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P21-05. Ask us About Dementia – a Pilot Study

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Background: The COVID-19 pandemic has placed increased pressures on both care services and family carers. In the community unpaid carers have received less support due to staff shortages and removal day centres and community support groups. Dementia helplines have reported an increase in calls reporting: stress & distress; progression in dementia symptoms; difficulty contacting local healthcare services. Interventions that include carer support with problem-solving and coping strategies are known increase carer resilience.

Aims:

- Provide timely access to expert advice and signposting on dementia care using telehealth
- Increase awareness of the Allied Health Professions and improve access to their expertise
- Support peer learning between health and social care practitioners

Methods: Health and Social Care Wales partnered to design and pilot an innovative national dementia support service, Ask us About Dementia (AUAD), in conjunction with TEC Cymru's Video Consultation programme. Pilot sites included: care homes, domiciliary care providers, local carer centres and national dementia helplines. Health and social care practitioners with expertise in dementia were identified via professional networks to take calls following a coaching model. The national outcomes framework for care and support in Wales is used to evaluate calls. A mixed methods approach was used for evaluation with focus groups, telephone interviews and an online survey. The pilot follows a Quality Improvement approach; regular meetings were established so stakeholders can contribute to continuous improvement.

Results: To date, all calls have been resolved and the key area of impact is on physical, mental health and wellbeing. Practitioners have reported a positive experience with the formation of a national network providing opportunity to learn and share skills.

Conclusions: AUAD has shown cross-organisational and cross-disciplinary ambition, design, and working can happen quickly when telehealth is applied creatively. Through providing quicker and fluid access to advice carers are identifying and de-escalating potentially unnecessary referrals.

P22. (Parallel session) Risk factors and prevention

P22-01. Reasons of patients and their care partners for visiting the memory clinic: the ABIDE project

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Introduction: There is great practice variation in the diagnostic work-up offered at memory clinics. Likewise, there may also be large variation what patients expect from their visit. We aimed to investigate the reasons of patients and their accompanying care partners for visiting a memory clinic.

Methods: We conducted an observational study at eight memory clinics, combining survey data with audio-recordings of diagnostic clinician-patient consultations. The survey on reasons for visiting a memory clinic was completed by 115 patients and 95 of their care partners after their first memory clinic visit. Of 63 of these patients, audio-recordings were available of their consultations with the clinician/physician during the diagnostic trajectory. Two researchers used a study-specific coding scheme to independently categorize if and which reasons were expressed during those consultations.

Results: The majority of patients (70/115; 61%) reported in the survey that they want(ed) to find out what is causing their symptoms. A considerable number of patients (22/115; 19%) reported other reasons, such as aiming for treatment or care, or wanting more information, for example about the future. The majority of care partners reported confirming the presence or absence of dementia as the main reason (56/95; 60%). The audio-recordings showed that over half of patients (34/63; 54%) and care partners (36/63; 57%) never voiced their reason for visiting the memory clinic.

Discussion: When visiting a memory clinic, most patients aim to get clarity about the cause of symptoms, while most partners want to know explicitly whether there is dementia. Yet, one in five patients has another reason. Since most patients nor care partners do not discuss their reason with their clinician, current diagnostic care might not match their needs. Deliberately engaging in a conversation on reasons at the start of the diagnostic trajectory, allows expectation management and tailoring of care after the diagnosis.

P22-02. Attitudes and views on healthy lifestyles for the prevention of dementia and cardiovascular disease among older adults with low socioeconomic status: a qualitative study

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Background: Individuals with a low socioeconomic status (SES) have an increased risk of cardiovascular disease (CVD) and dementia, partly due to the high prevalence of unhealthy behaviours in this population. Interventions targeting lifestyle-related risk factors can potentially delay or prevent CVD and dementia onset. In this study, we explore the attitudes, experiences and views of low SES older adults on healthy lifestyles for the prevention of CVD and dementia. We also aim to study the potential role for coach-supported mobile health (mHealth) use, facilitating the development of the Prevention of Dementia using Mobile Phone Applications (PRODEMOS) intervention.

Methods: We performed semi-structured interviews with Dutch adults aged ≥ 55 , at increased risk of dementia, who possess a smartphone. Recruitment took place through general practices. Participants were purposively sampled on age, sex, and history of CVD and diabetes. We used thematic analysis to analyse the data.

Results: Between May 2018 and June 2019, we performed 19 interviews. Five main themes were identified: 1) participants perceived little influence on their future health, 2) the sacrifices of healthy lifestyles outweighed the potential benefits, 3) physical complaints or disease could prompt behaviour change, 4) participants perceived limited self-efficacy to change their behaviour, and 5) the social network had an important role in behaviour change. Needs regarding mHealth support were an easy-to-use smartphone application with trustworthy health information that is provided in a non-obligatory way.

Conclusions: Low SES older adults may benefit from lifestyle interventions that aim to improve self-efficacy levels by (remote) human support. Appropriateness and attractiveness of such interventions may increase when taking into account the participant's own autonomy, and when emphasizing the direct gains of lifestyle changes for daily life. Moreover, involving the social network may be a valuable approach when developing lifestyle interventions for low SES older adults.

P22-03. Dementia attributed to air pollution exposure: monetary burden in Sweden

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Alzheimer's disease (AD) and other dementias correspond to the fifth most common cause of death in the world. Air pollution has emerged as a plausible risk factor for AD, but monetary estimates of AD incidence attributed to fine particulate matter (PM_{2.5}) or other air pollutants are lacking.

The aim of the present study was to estimate dementia cases attributable to air pollution in the Swedish population above 60 years of age and resulting monetary costs. To do so, we used a concentration response function based on ten longitudinal cohort studies. We furthermore added data on average population-weighted exposure to ambient PM_{2.5} for the entire population of Sweden. To estimate the monetary burden of attributable cases, we calculated total costs related to dementia, including direct and indirect lifetime costs and intangible costs by including quality-adjusted life years (QALYs) lost. Two different monetary valuations of QALYs in Sweden were used to estimate the monetary value of reduced quality-of-life from two different payer perspectives.

The annual number of dementia cases attributable to PM_{2.5} exposure was estimated to be 820, which represents 5% of the annual dementia cases in Sweden. Direct and indirect lifetime average cost per dementia case was estimated to correspond € 213,000. A reduction of PM_{2.5} by 1 µg/m³ was estimated to yield 101 fewer cases of dementia incidences annually, resulting in an estimated monetary benefit ranging up to 0.01% of the Swedish GDP in 2019.

This study estimated that 5% of annual dementia cases could be attributed to PM_{2.5} exposure, and that the resulting monetary burden is substantial. These findings suggest the need to consider airborne toxic pollutants associated with dementia incidence in public health policy decisions.

P22-04. The effects of exercise programs on cognition, activities of daily living, and neuropsychiatric symptoms in people with dementia - A systematic review

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Background: The prevalence of dementia is expected to increase dramatically. Due to a lack of pharmacological treatment options for people with dementia (pwd), non-pharmacological treatments such as exercise programs, have been recommended to improve cognition, activities of daily living (ADLs), and neuropsychiatric symptoms. However, inconsistent results have been reported across different trials, mainly because of high heterogeneity of exercise modalities. Thus, this systematic review aims to answer the questions whether exercise programs improve cognition, ADLs as well as neuropsychiatric symptoms.

Method: Eight databases were searched for articles published between 2016-2021 (ALOIS, CENTRAL, CINAHL, Embase, Medline, PsycINFO, PubMed, Web of Science). RCTs evaluating the effects of any type of physical activity on cognition, ADLs or neuropsychiatric symptoms in people with a formal diagnosis of dementia were included in this systematic review. Two authors independently assessed eligibility and quality of the studies. The methodology was in line with the PRISMA guidelines.

Results: Seven trials were included in this review with the majority investigating either a combination of strength and aerobic exercise or aerobic exercise alone. This review revealed that there is no clear evidence for the beneficial effects of exercise on cognition. None of the included trials found an impact on ADLs. Although different RCTs reported inconsistent results, one trial indicated that especially aerobic exercise may improve neuropsychiatric symptoms.

Conclusion: Our systematic review did not confirm the impact of exercise on cognition and ADLs in pwd. The results suggested that aerobic exercise might be effective to reduce neuropsychiatric symptoms. Well-designed trials with strict intervention criteria, large samples and long-term follow-up are needed to improve the scientific evidence on the best type of exercise modality.

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P22-05. Examining the relationship between fear of dementia and modifiable risk factors in mid-life

Francesca Farina

Global Brain Health Institute

Dementia is the most feared disease associated with aging. If left unaddressed, these fears can be harmful. Experiencing high levels of fear about dementia has been associated with increased memory failures and lower quality of life in older adults. The aim of this study was to replicate and extend these findings by examining the relationship between fear of dementia and a broader range of psychosocial factors, including depressive symptoms, sleep disturbance and social functioning.

Older adults ($n = 230$, 55+ years) with and without a family history of dementia completed a verbal memory test and a series of online questionnaires measuring dementia-specific fear, self-reported memory failures, quality of life, anxiety and depressive symptoms, sleep disturbance and social functioning.

Hierarchical regression analysis indicated that dementia-specific fear was significantly associated with increased self-reported memory failures, lower quality of life and reduced social functioning (all p s $\leq .002$) – after adjusting for general anxiety and objective memory performance. Dementia-specific fear was not associated with depressive symptoms or sleep disturbance after adjusting for general anxiety. People with a family history of dementia (i.e. first-degree relative with a diagnosis) reported significantly higher fear compared to those without ($p \leq .02$).

Findings provide supporting evidence for the link between fear of dementia and psychosocial functioning in older adults. Results also support a fear-avoidance model of dementia-specific fear, whereby experiencing high levels of fear may influence lifestyle risk factors for dementia, as people withdraw from valued social activities. This model provides hypotheses for future research and potential strategies for intervention.

P23. NEURONET - Looking to the future: Impact of the IMI ND portfolio

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The primary objective of Neuronet is to establish an efficient platform to drive synergy and collaboration across Innovative Medicines Initiative (IMI) neurodegenerative disease (ND) projects, multiplying their impact, increasing their visibility and facilitating coordination with related initiatives both in Europe and globally. In order to achieve this

objective, various activities have been carried out to map the landscape of ND research, establish a framework to assess the impact of the projects and understand gaps in ND research.

To overcome research fragmentation, accelerate innovative research and amplify the impact of the IMI ND portfolio, different tools and initiatives were established by Neuronet. These include the Knowledge Base, a dashboard that provides a summary of the projects in the portfolio in addition to an asset map that gives an overview of the key assets generated by projects in the IMI ND portfolio. Furthermore, the NEURO Cohort; a coalition of research and clinical sites across 13 countries in Europe has been recently initiated.

To inform future ND research, a series of workshops were held by Neuronet to understand the priorities and gaps of ND research from the perspective of different stakeholders. The stakeholders consulted were people with dementia and their supporters, academic and industry researchers, regulators and health technology assessment bodies. Feedback received in the workshops was analysed to identify gaps and priorities for further research.

In this roundtable session, Neuronet project leader Lennert Steukers will moderate a discussion on the outlook of the IMI's ND portfolio and the plans to ensure its continued impact and contribution to the ND landscape. The session will start with two presentations. The first presentation will provide an overview of themes identified across the mapping and priority-setting workshops. The second presentation will provide an overview of the Neuronet Knowledge Base, asset map and the NEURO Cohort.

P24. INTERDEM: Training next generation in psychosocial care in Dementia

P24-01. SiDeCar Project, a curriculum of studies in dementia care for the next generation of European Higher Education

Giovanni Ottoboni¹, Ilaria Chirico², Niels Janssen³, Marjolein de Vugt⁴, Maria Cruz Sanchez⁵, Juanjo Mena⁵, Manuel Franco⁵, Pavla Povolná⁶, Tereza Pecankova⁶, Iva Holmerová⁶, Rabih Chattat²

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Introduction: Despite the increasing body of evidence on the usefulness of psychosocial approaches in supporting and fostering the quality of life of people with dementia and formal and informal carers, the knowledge transfer rate needs to increase. The SiDeCar project is a European Erasmus+ program project- KA2 asset- aimed to impact on European higher education system and educate the next generation of professional's keen to work in welfare and health dementia services.

Method: The partnership adopted a collaborative policy to secure three intellectual outputs.

Results: The first output regarded a cumulative analysis of European higher education curricula and policy documents. Based on the analysis' results and relying on the most solid scientific evidence, the partnership developed the second project output: a curriculum of 3 modules. One module deals with topics informing about aspects featuring the life of people with dementia, as their care needs, the psychosocial interventions they can benefit from, ethical and legal considerations, recommendations concerning risk factors and lifestyles, barriers and opportunities offered by technology. The second and the third modules regard respectively informal and formal carers' extents. They summarise European care policies, suggest assessments and interventions tackling caregiving impacts, comment on cultural diversity and transversal skills. Moreover, theoretical commentaries introduce each module. The third output regards the editing of guidebooks aimed at facilitating curriculum adoption from schools and faculties. All the reported material is available at <https://sidecar.grial.eu/login/>

Discussion: The feedback we gathered indicates the curriculum to be a training tool very responsive to students and professionals' expectations.

Conclusion: SiDeCar aimed to facilitate the education of new workforces about supporting people living with dementia, informal and formal caregivers during their life or work. By systematising the timely scientific and practical knowledge, the curriculum represents an ultimate solution for those universities and institutes seeking to enhance their training offer.

P24-02. INDEED online: an educational intervention for professions involved in dementia care

Alexander Kurz

Technical University of Munich

The INDEED online platform is an educational intervention which addresses all professions involved in dementia care including physicians, nurses, social workers, occupational therapists, speech and language therapists, physical therapists and others. The goals of the intervention are to expand professional competence and know-how, complement occupation-specific trainings, foster collaborative skills, stimulate interprofessional networking, and promote entrepreneurial activity for novel dementia services. It provides a common, scientifically up-to-date knowledge base about dementia and conveys a comprehensive biopsychosocial, person-centred concept of dementia care in a non-technical language style. Specific emphasis was placed on quality of life, early diagnosis, non-pharmacological interventions, dementia-friendly environments, interprofessional management with the person at the centre, and advice on business plan development from idea to implementation with a range of good practice examples. In order to make the intervention attractive and engaging we built in multiple media formats such as infographics, cartoons, animated videos, case vignettes, short expert interviews and quizzes.

The programme is currently available in five languages (English, Bulgarian, Romanian, Slovakian, Slovenian). An evaluation in four countries showed excellent feedback from 120 participants. Efforts regarding sustainability and rollout to care practice are ongoing.

P24-03. Interdem Academy. European network for training of early stage researchers involved in psychosocial research

Fania Dassen, Marjolein De Vugt, Frans Verhey

Netherlands

Introduction: INTERDEM Academy is a European training network for early stage dementia researchers. INTERDEM Academy was established in 2014, and has grown in recent years to around 200 members from 20+ different countries. The aim of INTERDEM Academy is to develop the careers and to build capacity of young researchers working on psychosocial interventions under supervision of INTERDEM seniors. INTERDEM Academy want to support the early stage researchers in their pathway to senior (academic) posts in the field.

Method and results: To achieve this, INTERDEM Academy organizes expert workshops and masterclasses to develop ideas and methodological expertise. The INTERDEM Academy offers travel fellowships allowing the early stage researcher to spend 3-6 months in another INTERDEM research center. The goal is the exchange of knowledge and experience between the INTERDEM centres. New is the annual publication award. The purpose of this prize is to create a platform in which young scientists not only take note of each other's plans, but also inform each other and the senior INTERDEM-members about their results. Another new initiative is the 'INTERDEM Academy Café'. We plan to have this networking event three times a year in an online setting. Every Café-session will have a specific topic, and a chance to network and exchange experiences with your fellows. Discussion. The INTERDEM academy offers the opportunity to share expertise, create awareness for Academy talent and stimulate collaboration. The Academy links to educational networks such as INDUCT, DISTINCT and SiDeCar to improve dementia care knowledge and competency in a stimulating international and collaborative environment.

P24-04. The INTENSE project: improving dementia care through self-experience

Valentina Conotter¹, Louise Hopper², Marjolein De Vugt³, Gabriele Meyer⁴, Marianna Riello⁵

¹, ²DCU, ³Maastricht University, ⁴Halle University, ⁵SPES

As the prevalence of people with dementia increases, it becomes crucial to better understand the needs of people living with dementia and to create environments where they can get the best care. The EC is concerned about the growing shortage of health care professionals to care for dementia. Although specialized dementia education programs have begun to appear in recent years, a lack of consistency and adequate level of knowledge of dementia to anticipate the required treatment remains across Europe.

The Improving dementia care Through Self-Experience (INTENSE) project will educate, equip and train health and social workers to better support people with dementia through innovative learning approaches and the use of ICT tools that explore the lived experience of the person with dementia. INTENSE will support the creation of skills improvement paths for professionals across Europe that incorporate and promote successful self-experience methodologies and practices to increase knowledge and understanding of the lived experience of dementia (e.g., Virtual Dementia Tours (VDT), role plays and practices of theater workshops).

Purposes of the project are to: strengthen cooperation and exchange of experiences between organizations working in the field of dementia care by developing a new permanent network of collaborating professionals; improve social awareness of the ability of self-experience to improve dementia care; promote the integration of self-experience practices in the daily activities of current professionals.

Dr. Valentina Conotter, PhD is the coordinator of the INTENSE project, leveraging large experience in Eu projects for the development of innovative ICT solution for the social and healthcare sector. The solid partnership of INTENSE (Maastricht, Halle and Dublin University, SPES Group, SIT), affiliated with relevant and complementary networking is currently granting the required expertise for the smooth implementation of the INTENSE project.

Special Symposium

SS1. (Special Symposium) REspectful CAring for the AGitated Elderly: an overview of the RECAGE project

Sara Fascendini¹, Carlo Alberto Defanti², Maria Cristina Jori³

¹FERB ONLUS, ²FERB onlus, ³Mediolanum Cardio Research

Introduction: this Project aims at validating, adapting and upscaling the Special Care Unit for Behavioural disturbances of people with dementia (SCU-B). The first phase of REcage is a multicenter, prospective observational study aimed to assess the short- and long-term efficacy of the SCU-B. REcage started in January 2018 and will end on 30th December 2022. COVID 19 created serious problems during the follow-up period. An additional analysis, after the conclusion of the trial, will explore the effects of the pandemics on the trial results.

The REcage Clinical Trial: Main characteristics and an overview of the study progress will be presented. 500 community-dwelling patients with a diagnosis of mild-moderate dementia of any etiology and significant BPSD were to be enrolled: 250 in five centres endowed with a SCU-B and 250 in six centres lacking this facility. Patients are followed over a 36-month period according to routine of the centres. The primary endpoint is the comparison of the change of BPSD between the cohorts. Quality of life of patients and carers, cost-effectiveness of the intervention and

time to definitive admission to nursing home are the main secondary endpoints. Enrolment was completed on September 30th, 2019 with a total of 518 patients, 266 in the SCU-B cohort and 252 in the non SCU-B.

Preliminary data on the concomitant qualitative study: The difficulties of implementing a European multicentric, multi-country Research Project aiming at validating, adapting and upscaling the Special Care Unit for patients with dementia and BPSD, are briefly described. We underline the significant differences across the healthcare systems of the participating countries and we are presently investigating the social context of the intervention through a qualitative study (focus group technique). The data of this qualitative study will be useful for the interpretation of the results of the clinical trial (ongoing).

This session is organised by RECAGE

SS2. (Special Symposium) EWGPWD: Resilience and dementia

This session is organised by EWGPWD

SS3. (Special Symposium) Building Resilience in Health Systems for People with AD: Early Detection and Timely Diagnosis in a COVID-19 World

Why does Alzheimer's disease (AD) continue to be undiagnosed or diagnosed too late, and how has this been exacerbated during the pandemic? What is the impact of delayed detection and diagnosis of AD? How does the care of people living with Alzheimer's need to change? Will the availability of disease-modifying therapies change how we detect and diagnose AD?

During this symposium, experts from the AD community will bring perspectives from primary care, secondary care, carer and industry on how we will ensure timely and appropriate diagnosis, treatment and care for people living with AD in a COVID-19 world. Questions for our panellists will be posed by members of the European Working Group of People with Dementia.

We will hear how the detection and diagnosis of AD has been impacted by the pandemic, and discuss ways, as an AD community, we can work together to develop solutions and move forward in a changing world.

Join us and be part of the discussion.

This session is organised by Roche

SS4. (Special Symposium) The road behind and the road ahead: measuring the performance of 10 European governments on Alzheimer's disease

Michael Hodin, Sagar Sane

Global Coalition on Aging

The Global Coalition on Aging's symposium will feature insights and actions highlighted in the 2021 Alzheimer's Innovation Readiness Index (AIRI). The comparative report evaluates how the governments and healthcare systems of 10 European countries are addressing prevention, diagnosis, treatment, and care for Alzheimer's disease.

The Index, which was developed in partnership with Alzheimer's Disease International (ADI) and funded by Biogen, scores countries based on how they perform across 5 categories critical to sustaining Alzheimer's disease efforts: strategy & commitment, early detection & diagnosis, access to care (medical), awareness & monitoring, care standards & settings.

During this session, attendees will first hear from GCOA CEO Mike Hodin and from ADI CEO Paola Barbarino, who will deliver introductory remarks. Afterwards, Sagar Sane from GCOA will provide an overview of topline results and findings from the report. Next, GCOA CEO Mike Hodin will moderate a panel discussion with expert contributors on some of the key findings and recommended actions for European leaders. After the panel discussion, attendees will have the opportunity to ask questions as part of a short Q&A.

Debbie Abrahams, MP

MP for Oldham East and Saddleworth since 2011, Debbie Abrahams is the Co-Chair of the All-Party Parliamentary Group on Dementia (APPGD).

Lorène Gilly, France Alzheimer

Lorène Gilly's is responsible for monitoring public policy at France Alzheimer, a leading association focused on improving the lives of those living with Alzheimer's and supporting their families and caregivers.

Dr. Pablo Martínez-Lage, Fundación CITA-alzhéimer

Director of neurology at the CITA Alzheimer's Foundation, Dr. Pablo Martínez-Lage has worked with the nonprofit for over a decade and was on the committee to develop the National Plan on Alzheimer's.

Helen Rochford-Brennan, European Working Group of People with Dementia

Helen Rochford-Brennan is a member of the European Working Group of People with Dementia (EWGPWD).

This session is organised by GCOA

SS5. (Special Symposium) The Importance of Sharing Global Alzheimer's Disease Data in Search of Novel Treatments and Cures

No submitted abstract.

This session is organised by ADDI

SS6. (Special Symposium) The Importance of Brain Health and its impact on Alzheimer's Disease

Alzheimer's disease is a complex, challenging, and devastating condition. However, over the last ten years our understanding and knowledge has greatly increased, and we now have hope for a better tomorrow for all of those affected. By uncovering the science behind Alzheimer's disease, and the benefits of looking after our brain health, we're heading towards a new era in Alzheimer's disease prevention and management.

It's crucial to increase awareness of the importance of brain health and the impact it can have on our future, in the same way we might think about cardiovascular health or lung health. So, let's make brain health top of mind.

The Biogen symposium at the Alzheimer's Europe Conference will provide first-hand insights into how one of the most influential US patient advocacy organizations decided to approach brain health and stigma and built the Be Brain Powerful campaign, designed to change the behaviours of families, communities, policy makers and payers, to make brain health a priority, and to alter the trajectory of Alzheimer's disease. Join us to learn more about the strategy and tactics that made this campaign raise brain health on the public agenda. A range of topics will be covered, including the importance of cutting through stigma, promoting equal access for brain health initiatives, and awareness around the benefits of early detection and diagnosis.

The meeting will be moderated by Karin Hellsvik, Head of Corporate Affairs, Alzheimer's Disease Business Unit at Biogen and presented by Brooks Kenny, Vice President, Consumer Engagement and Partnerships, UsAgainstAlzheimer's and will be held from 13:00 – 14:00 CET on 1st December 2021.

The session is sponsored by Biogen.

SS7. (Special Symposium) Late-stage clinical trial conduct during COVID-19: challenges, lessons, and the future for Alzheimer's disease management

Sonya Miller¹, Serge Gauthier², Bjoern Schelter¹, Linda Sommerlade³

¹TauRx Therapeutics, ²Alzheimer Disease and Related Disorders Research Unit of the McGill Center for Studies in Aging, Douglas Hospital, ³GT Diagnostics

TauRx launched a pivotal phase 3 clinical trial in Alzheimer's disease in 2019 with top line results expected in mid-2022. During the trial recruitment phase much of the world was in some form of lockdown due to the COVID-19 pandemic. Despite this, the trial fully recruited swiftly. The pandemic presented various challenges to TauRx, the sites, the participants, and their study partners. Overcoming these challenges required flexibility and adaptability with many lessons learned along the way.

At the same time, GT Diagnostics, a joint venture between Genting Berhad and TauRx, forged ahead with its development of novel diagnostic tools targeting a diagnosis at very early stages of the disease. These tools are being developed with a view to eventually support remote administration, an important feature as further evidenced by the pandemic.

This session will discuss the entire patient journey, ranging from our vision of home administered assessment and monitoring tools enabling access to treatment, whilst ensuring the safety of patients. Our panel will also consider how lessons learned from our trial, including the impact of COVID-19 on people with Alzheimer's disease, and advances in diagnostics should translate into benefits in clinical practice.

It is a privilege to be joined by Professor Gauthier, Professor in the Departments of Neurology & Neurosurgery, Psychiatry, Medicine, at McGill University, and Director of the Alzheimer Disease and Related Disorders Research Unit of the McGill Center for Studies in Aging, Douglas Hospital.

Symposium chair: Professor Serge Gauthier

Introduction: the shifting patient pathway in AD; Professor Serge Gauthier

Conducting a phase 3 trial in a global pandemic – how we managed our trial; Dr Sonya Miller

New diagnostic tools for early detection and monitoring of dementia; Dr Linda Sommerlade

Data collection during COVID-19 and dementia insights; Professor Bjoern Schelter

This session is organised by TauRx

Quick Oral Presentations

QOP1. (Quick Oral Presentation) Resilience and COVID-19

QOP1-01. Lived experiences of nurses working in dementia units during the COVID-19 pandemic: lessons learned

Anthony Scerri¹, Christian Borg Xuereb², Charles Scerri²

The COVID-19 pandemic had a negative impact on residents living with dementia and on frontline caring staff. This study sought to explore the lived experiences of nurses working in dementia units during the pandemic using a qualitative, interpretative phenomenological approach. Nine Maltese nurses working in these units were interviewed during the month of February 2021, a year after the first infected cases were formally registered in Malta. Following analysis of the transcripts, three superordinate themes were identified; 'challenges faced by the participants due to the pandemic', 'a roller coaster of emotions' and 'factors influencing the experience of the pandemic'. Participants experienced several challenges associated with the mitigation measures adopted by the organisation such as stopping/restricting family visits and quarantining COVID-19 positive residents. Although these generated negative emotions, some participants managed to find positivity during these times. Appraisal of their experience depended on their coping strategies, how they negotiated infection control measures with the residents' quality of life and how they felt their organisation was resilient pre-COVID-19. The lessons learned can help in developing strategies aimed at improving the services provided to persons living with dementia, post-COVID-19.

QOP1-02. The work of associations in times of COVID

Pablo Baldomir Puga¹, Isabel Gey Pérez², Javier Hermida Porto¹, Pablo Baldomir Puga¹

¹Federación Alzheimer Galicia, ²Federación Alzheimer Galicia

Objectives:

- Bring the stimulation services closed due to COVID to the home
- Maintain or slow down the progression of the disease
- Offer a break time for caregivers
- Facilitate communication between professionals, family members and people with dementia

Method: In order to minimize the impact of the closure by COVID19 of the therapeutic centers for people with dementia, the interdisciplinary team was initially trained in health protocols and then brought the activities that had been carried out before the internment to the homes of the users. Several professionals came to each home weekly to perform person-centered cognitive and functional stimulation therapies adapted to the needs of each user. Services were provided to caregivers: training, psychological support, mutual help groups ...

To maintain a daily routine, both people with dementia and caregivers were provided with the necessary means to complement the required care through material adapted to be carried out in their own homes as well as through telephone calls, video calls, applications of cognitive stimulation ...

Results:

- Participating associations: 15
- People's participation in services at home and weekly duration per person:
- Cognitive stimulation therapies at home: 1.630 (1 hour and a half)
- Nursing: 57 (1 hour and a half)
- Physiotherapy and occupational therapy: 123 (1 hour)
- Active aging at home: 642 (2 hours)
- Psychological Support: 692 (1 hour)
- Training for caregivers: 243 (50 total hours)
- Training for professionals: 300 (50 total hours)
- Professional participation: psychology, social work, occupational therapy, social education, physical therapy, assistant geriatrics, nursing ...
- Higher cognitive abilities were maintained and residual functional capacities prior to confinement.
- Caregivers saw reduced psychological and behavioral symptoms associated with dementia neurodegenerative.

Conclusions: Given the success of the program, a proposal for a home stimulation model has been presented to the autonomous government as a dependency prevention measure for people with dementia.

QOP1-03. The experiences of people living with dementia and their care partners in the North West of England during the lockdown and as restrictions are eased

Anthea Innes, Siobhan Kelly, Sophie Bushell

Salford Institute for Dementia

Living well with dementia and retaining independence can be challenging. COVID-19 and the UK Government 'lockdown' and social distancing measures led to people living with dementia and their care partners losing vital access to support networks and services that promote their wellbeing and independence. This paper will report on two small-scale rapid research studies conducted in the summer of 2020 and the summer of 2021. The first considered the impact of COVID-19 from the perspective of people living with dementia and their care partners, the second considered the impact of the return to in-person groups and meetings following the ease of lockdown restrictions.

Our summer 2020 research found that the lack of opportunities for social engagement and enjoyable activity had a detrimental effect on the mental health and wellbeing of people living with dementia and their care partners that recent policy and practice has strived to address. Participants reported; feeling lonely, isolated and experiencing low mood, a loss of confidence and a perceived deterioration of their cognitive ability.

We will also report on our summer 2021 research where we explored people living with dementia and their care partners views and experiences of returning to a group setting they had enjoyed attending prior to lockdown. We will compare the experiences of people during and as lockdown restrictions ease. Particular attention will be drawn to the impact on mental health, resilience and self-reported strategies to support people living with dementia moving forward. It is vital that people living with dementia and their care partners are supported whether or not there is a health pandemic. Covid-19 demonstrates the need to do so in new and creative ways, using methods tailored to individual preferences, while finding ways to develop skills (for example ability to access technology) to enable future resilience.

QOP1-04. "I felt even more alone": impact of COVID19 restrictions on loneliness and social needs from the perspective of residents, family members and volunteers in nursing homes

Suzie Noten¹, Nina Hovenga², Katrien Luijkx²

¹Tilburg University, ²

Background: During the COVID-19 outbreak in March 2020, restrictive measures (e.g. prohibiting physical visits and group activities) were applied in nursing homes to protect older residents. Although the importance of social activities and social contacts to avoid loneliness is known, this was challenged during the pandemic. To gain insights into the impact of restrictive measures on loneliness and social needs and what lessons could be learned, this multicentre qualitative study specifically focused on how residents, family members and volunteers in nursing homes experienced the restrictive measures in retrospect.

Methods: 30 semi-structured, face-to-face interviews with residents and family members, and one online focus group with ten volunteers were conducted. Recruitment took place at psychogeriatric and somatic units in two regions in the Netherlands and in Flanders, Belgium. The interviews and focus group were transcribed verbatim, and an open, inductive approach was used for analysis.

Results: Overall, residents and their partners reported an increase in experienced loneliness. To a lesser extent loneliness was reported among other family members and volunteers. In general, participants reported it was a difficult time for everyone, indicated by feelings of sadness, fear and feelings of powerlessness. Alternative ways of contact such as video calling, where not in all cases successful. Moreover, sometimes enlarged feelings of loneliness. Overall, negative experiences were influenced by variations in local restrictions and the number of COVID-19 infections and deaths in the nursing homes.

Lessons learned: To reduce the impact of the restrictions, participants recommended policy makers to fine-tune the balance between safety and wellbeing, by paying more attention to the social aspects, and including their wishes and needs. During the presentation, we will elaborate on how we translated our findings into practice together with relevant stakeholders from this study, as well as care professionals, policymakers and trainers within education.

QOP1-05. Resilience in Admiral Nurses during the COVID-19 pandemic

Gayle Madden¹, Karen Harrison-Dening¹, Kay de Vries²

¹Dementia UK, ²De Montfort University

COVID-19 has meant that people, organisations and governments have had to make huge changes to lives and ways of working. This study explores the impact on Admiral Nurse (AN) practice (specialists in dementia care who support families affected by dementia) (Aldridge et al, 2019).

During the pandemic families living with dementia have felt less supported than during normal times (Wang et al, 2020). ANs have proved to be an adaptable and flexible workforce in these challenging times. In such unprecedented circumstances it is important to examine how a workforce adapts its practice and also how they feel about this. Such knowledge is of value in ensuring they are equipped in future pandemic situations and to ensure their resilience in supporting families affected by dementia.

The research used qualitative, semi-structured interviews to explore the experience of working during COVID-19 from the ANs perspective. Purposive sampling was used in order to ensure the final sample was represented by ANs from all settings; community, acute hospital, hospice and care home. 19 ANs were interviewed during July/August 2020. Interviews were audio recorded using the Microsoft Teams platform, transcribed verbatim and anonymised. Interviews were analysed using a theoretically flexible thematic approach (Braun & Clarke, 2006).

The findings identify that during the first wave of COVID-19, Admiral Nurses negotiated a journey from temporary impotence, through processes of transition, to a new world. They demonstrated resilience through reflection, learning and adaptation. Understanding this experience helps the Dementia UK AN Practice Development Team to continue to target education and resources in support of ANs post COVID-19. It is believed that the learning from this study can be applied to other roles and models of dementia care and support.

QOP1-06. From Plan to Impact IV: Progress towards targets of the WHO Global action plan on dementia

Lewis Arthurton, Chris Lynch

Alzheimer's Disease International

COVID-19 has exposed inadequacies in the preparedness of governments to care for and support those living with dementia and their carers. This, compounded with the stigma and discrimination that still surrounds dementia, has resulted in this constituency being disproportionately impacted, highlighting the need for robust and effective national dementia plans as an indispensable component of any future preparedness plans.

The WHO Global plan of action on the public health response to dementia 2017-2025 was universally adopted by Member States in 2017. Every year since, Alzheimer's Disease International has produced the report 'From Plan to Impact' reviewing progress and barriers towards the goals of the plan, including the development of national dementia

plans worldwide and shining a light on the challenges, responses and innovation around the COVID-19 pandemic. At this half-way stage of the plan, only 32 Member States (40 countries globally) out of 194 have developed national dementia plans. To achieve the WHO target of 75% of Member States (146) with a funded national dementia plan, 28 new plans will be required each year until 2025. Presently, there are 21 countries developing dementia plans or are incorporating dementia within a wider health plan.

Between the period of May 2020-2021, four countries launched new national dementia plans (China, Dominican Republic, Germany and Iceland) and three have been evaluated and updated. To date, there remains only one national dementia plan in the WHO regions of the Eastern Mediterranean and South-East Asia, in Qatar and Indonesia respectively; there are currently no plans in existence in sub-Saharan Africa.

The results of the report highlight the need for a robust and concerted effort by all WHO Member States if the targets of the Global plan are to be met. This is especially important for the more than 50 million people living with dementia globally.

QOP1-07. Counselling and dialogue ethical unit

Lorène Gilly, Frédéric Maynier, Kevin Rabiant

France Alzheimer

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. It is also a question of listening to the explanations of all stakeholders, in order to defuse the conflict, to find a consensus and the best option for the wellbeing of the resident.

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, at the end of which they draw up a report and send it to the Regional Health Agency.

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.

QOP1-08. Dementia and COVID-19 - exchange of experiences and chances for the future

Alice Edtmayer

Gesundheit Österreich GmbH

Background: The annual conference 2020 by the Austrian Dementia Strategy was originally planned to focus on the needs of relatives of people living with dementia. Due to the pandemic, the conference had to be reorganised and the focus was shifted on challenges and chances for people living with dementia in the context of the COVID-19 pandemic.

Methodology: Four online talks were held between September and November 2020. For each talk, a specific audience was invited to talk about their experiences during (March 16th – May 1st) and after the first lockdown in Austria. In the first talk, the target groups were people living with dementia themselves as well as their relatives, partly represented by support groups. The second talk focused on the view and experiences of institutions that provide either care for people living with cognitive impairment or have an advocacy role for those. In the third talk, chances for the future with a focus on digitization were discussed: this included a presentation of a recent study regarding dementia and digitization, conducted by the university of Vienna. Within the last session, a summary of all talks and the derivation of needs for action, also in accordance with results from the currently running reform in long-term-care, were made.

Results: It was reported that the first lockdown had positive as well as negative effects on people with cognitive impairment and their families. For support groups, a lot of reorganisation was necessary – partly new ways of supporting people were successful, partly they were not. Institutions talked about the challenges in the provision of care for people with cognitive impairment. Concerning dementia and digitization, the results of the presented study showed that under certain conditions, digital tools can be supportive in everyday life. That was also confirmed by people with dementia who joined the talk.

QOP1-09. Influence of the obligatory quarantine related to COVID-19 pandemic on caregivers of people with dementia

Petya Nikolova¹, Ivo Popivanov²

¹Alzheimer Bulgaria Association, ²Department of Cognitive Science and Psychology, New Bulgarian University & Diagnostic and Consultative Centre "Alexandrovska"

This study was focused on caregivers of people with dementia who were especially vulnerable in the condition of quarantine because of spreading of COVID-19 in Bulgaria. Caregivers were facing many challenges in this situation,

however because of the stigmatisation of dementia, ignorance or other socio-cultural factors in Bulgaria, there was lack of necessary support to this social group.

The main aim of the study was to describe how the perceived stress, depression, caregiver burden and self-esteem were changing during the condition if forced quarantine. There was also a comparison with a matching control group.

According to our expectations, caregivers showed higher levels of perceived stress and depression, as well as a tendency for lower self-esteem compared to the participants from the control group. Correlation analysis confirmed the results from previous studies in other countries, showing relationship between high levels of burden, depression, perceived stress and low self-esteem. Moreover, some demographic factors were found to influence those levels too. E.g., the higher age of the caregivers as well as the fact that they live with the person with dementia could be related to higher levels of depression. On the other hand, the number of people who are taking care of the person with dementia influenced the burden and depression ratings. Finally, the levels of burden and depression were higher during the initial and late stages of dementia in comparison to the middle stages.

In conclusion, our data shows reduced quality of life in caregivers of people with dementia. It also shows how important is to support such vulnerable groups of the society in extreme conditions, such as quarantine due to spreading of COVID-19.

QOP1-10. Social health among German care recipients with dementia during COVID-19, and the role of technology to promote social participation

Viktoria Hoel¹, Karin Wolf-Ostermann²

¹Universität Bremen, ²University of Bremen

Background: A large proportion of care recipients with dementia are treated with pharmacological therapies for Behavioural and Psychological Symptoms in Dementia (BPSD), although research suggest that psychosocial interventions can be effective in decreasing BPSD without the side-effects that come with pharmaceuticals. However, in-person psychosocial interventions have been impeded during COVID-19, making technological solutions a viable option. The impact of COVID-19 on clinical outcomes for care recipients with dementia, the available social activities and the role of technology in promoting social participation was explored as a part of the Marie-Curie Innovative-Training-Network action, H2020-MSCA-ITN, grant agreement number 813196.

Methods: Cross-sectional data collected from a larger survey conducted in care facilities throughout Germany. Descriptive statistics of closed-end questions as well as inductive thematic analysis of open-ended questions were performed.

Results: An overall increase in pharmacological treatment for care recipient with dementia was reported by respondents, as well as an increase in observed BPSD – anxiety and depression most frequently occurring. A large proportion of the respondents reported that social activities for care recipients with dementia were cancelled during the pandemic, but few had established procedures to promote social participation for these care recipients using technology. Requirements to promote social participation for care recipients using technology identified at the micro-, meso-, and macro-level. Technology requirements permeated all three levels.

Conclusion: During and beyond the COVID-19 pandemic, nonpharmacological treatments such as technology-driven solutions to promote social health among care recipients with dementia should be an integrated part of caregiving procedures. This requires solutions at the societal-, organizational- and individual levels. Participation in meaningful activities is an important part of social health, and the sudden absence of social activities for care recipients with dementia can increase BPSD, ultimately resulting in increased use of avoidable pharmacological measures.

QOP1-11. Dyadic coping through COVID-19 with and without social technology: Experiences from community-dwelling people with dementia and their spouse

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Background: People with dementia and their caregiving spouse (dyads) faced multiple impacts of the COVID-19 pandemic, including restricted social support services and social isolation. With limited opportunities for couples living with dementia to participate in social activities during the pandemic, social technology can potentially support social participation and dyadic relationships. As a part of an ongoing feasibility trial, this study assesses how COVID-19 has impacted community-dwelling dementia caregiving dyads. The dyads use of social technology and their motivation for inviting technology into their social interactions is also explored as a part of the Marie-Curie Innovative-Training-Network action, H2020-MSCA-ITN, grant agreement number 813196.

Methods: A pilot case study (nested within a larger feasibility trial), employing baseline interview data from caregiving dyads. Each dyad consisted of a person with a dementia diagnosis and their spouse who performed most caregiving tasks. Interviews were audio recorded, transcribed verbatim and subjected to thematic analysis. Two researchers independently coded the data, and collated the codes and themes collaboratively.

Results: Dyads who were socially active pre-COVID-19, and who managed to make good use of technology to facilitate and maintain their social engagement during COVID-19, reported to have been less negatively impacted by COVID-related social restrictions. Several themes and subthemes related to living with dementia during COVID-19 and the role of technology were identified.

Conclusion: The dyads differed in how COVID-19 restrictions impacted their lives and how they coped with dementia, revealing different motivations for wanting to invite technology into their social interactions. Social technology can be a valuable tool for promoting social participation when in-person contact is limited. Successful uptake of social technology depends on customization to individual's needs and conditions. Efforts are needed to tackle barriers that exists for older adults in using such technology.

QOP1-12. Designing and implementing an IT architecture for a digital multicenter dementia Registry: digiDEM Bayern

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Background: Registries are an essential research tool to investigate the long-term course of diseases and their impact on the affected. The project digiDEM Bayern is setting up a prospective dementia registry to collect long-term data of people with dementia and their informal caregivers in Bavaria (Germany) supported by more than 300 research partners. For an effective management of a dementia register study, an information technology-based architecture to support the study processes is essential. Measures to ensure high data quality, study governance, along with data privacy and security are to be included in the architecture.

Method: The architecture was developed based on an iterative, stakeholder-oriented process. We gradually moved from a general to a detailed understanding of both the requirements and the design through a series of iterations. The experience learned from the pilot phase was integrated into a further iterative process of continuous improvement of the architecture.

Results: The infrastructure provides a standardized workflow to support the electronic data

collection and trace each participant's study process. Therefore, the implementation consists of three systems: (1) electronic data capture system for web-based or offline app-based data collection; (2) participant management system for the administration of the identity data of participants and research partners as well as of the overall study governance process; (3) videoconferencing software for conducting interviews online. First experiences in the pilot phase have proven the feasibility of the framework.

Conclusion: This approach outlines an architecture to integrate a registry and participant management in a dementia research project. Due to its adaptability of used software systems, a transfer to other projects should be easily possible.

Funding: This research is funded by the Bavarian State Ministry of Health and Care (StMGP) as part of the Bavarian Digital Registry – digiDEM Bayern (funding code: G42d-G8300-2017/1606-83).

QOP1-13. Community Makers Project

Natasha Morgan¹, Shirley Evans²

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This presentation will provide an overview of the Community Makers project – Alzheimer's Society's innovation team's immediate response to the Coronavirus pandemic.

In April 2020, Alzheimer's Society's Innovation team issued an open call for challenges that people affected by dementia were facing due to COVID-19. A growing body of evidence indicated that lockdown-induced isolation was having a negative impact on wellbeing and dementia symptoms[1]. The team formed a collaboration with the UK Dementia Research Institute Care Research and Technology Centre (UKDRI CRT) and The Association for Dementia Studies (ADS) to harness technology to help people affected by dementia feel less isolated and better supported.

Community Makers is a network of community groups from across the UK supporting people affected by dementia to reconnect during COVID-19 related isolation and beyond. Together, we are exploring the role of technology in helping groups get connected, and creating a knowledge exchange network to share experiences and advice.

The network has been instrumental in the building of a prototype toolkit (<https://communitymakers.co>) of creative ideas to inspire groups with different approaches to digital involvement, including reducing digital exclusion. A Slack workspace and monthly zoom meetings provide an open forum for community organisers to support each other by sharing challenges and insights from their work.

As the impacts of the pandemic shifted, so did the role of Community Makers. Increasingly Community groups were entering a hybrid world, making the most of physical and digital connection and building an emerging role in helping isolated people use technology.

Now, in June 2021, as restrictions start to lift in the UK, the project is pivoting to focus on testing these hybrid models of support to connect those who are most excluded to their local community. We plan to launch a small number of pilot sites later in the year.

[1] <https://www.alzheimers.org.uk/sites/default/files/2020-09/Worst-hit-Dementia-during-coronavirus-report.pdf>

QOP1-14. A future for personalised care - discussion paper

Morgan Griffith-David, Jo Baxter

Alzheimer's Society

During the Covid-19 pandemic, many people with dementia experienced a worsening of symptoms, with increasing need of support from domiciliary care or care homes. Prior to the pandemic, decades of underfunding and neglect had led to a care system where people struggle to access the care they need. These challenges have now been exacerbated with new challenges added. We need to ensure a legacy of the pandemic is the creation of a care system capable of giving people the support they need and deserve.

Our discussion paper, A future for personalised care, examines what good quality care means for people with dementia. We looked at evidence from legislation, guidance, standards and frameworks that 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 to discover what has the greatest impact on people's wellbeing.

We found that personalised care is key to high quality care. This is care where people have choice and control, choosing the goals that are most important to them. Currently there is too much focus on personal care – while help with basic tasks of daily living is vital, alone it will not help people live with meaning, purpose and connection. We also found that, as the pandemic revealed, relationships with loved ones are key to health and wellbeing, and must be considered centrally in care. Ensuring care staff have the necessary skills and knowledge in dementia and personalised care is crucial. It is also vital that staff are supported with working conditions that value them and foster good practices.

We provide examples of good practice and make recommendations on priorities for a new vision for social care built to enable people to draw on care that is personalised.

QOP1-15. Learning from family carers during COVID-19: An international perspective of residential aged care experiences

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Background: This study aimed to 1) investigate residential aged care (RAC) restrictions and changes (visiting policy, governmental & health authorities' advice, and service delivery) implemented during the COVID-19 pandemic in the UK, Italy and Australia; 2) explore their impact on people with dementia in those facilities and their families and 3) provide recommendations addressing the key aspects impacting people in RAC and their families.

Methods: Fifty-six family carers of people with dementia residing in RAC from the UK (n=26), Italy (n=25) and Australia (n=6) took part in semi-structured interviews between July 2020 and March 2021. The interviews were recorded, transcribed verbatim and analysed by the researchers in each country using thematic analysis, then compared across the countries.

Results: The cross-country thematic analysis identified the following themes: 1) adaptations were implemented in RAC facilities in response to the COVID-19 pandemic; 2) communication options between RAC facility personnel, people with dementia living in RAC and family members; 3) impact of the adaptations and restrictions on people with dementia in RAC facilities and 4) impact of the implemented adaptations and restrictions on families of people with dementia in RAC facilities during the pandemic. The adaptations and changes within the residential care system impacted families' well-being in terms of increased concerns about safety, care quality and difficulties contacting people with dementia living in RAC. Families noted the physical, cognitive and emotional changes in their relatives after a few months without visits/contact. Despite communication via phone and video-communication, families faced several challenges in keeping in touch with residents and RAC personnel.

Conclusions: Our study findings demonstrate the urgent need for safe adaptations in RAC facilities allowing more frequent in-person visits between residents and families and supporting more efficient ways of communication between families and personnel.

QOP1-16. Online interventions: their effect on mental and emotional health in Greek older adults with Mild Cognitive Impairment (MCI) during the second quarantine period.

Marianna Tsatali

Alzheimer Hellas

Objective: The current study was conducted in order to explore the possible effect of online interventions implemented during the second quarantine period due to the Covid 19 pandemic on mental and emotional health in a group of older adults with Mild Cognitive Impairment (MCI).

Method: Three hundred and thirty four participants, who had visited the Day Centers of the Greek Association of Alzheimer Disease and Related Disorders (GAARD) in September 2020, in order to do their initial dementia screening or their follow up assessment, took part in the current study. After finishing the evaluation process, they attended online psychological training session from October to May 2021. Afterwards, they were asked to complete a questionnaire in order to self-report any possible benefits due to the tele- interventions, as well as state emotions before and after attending the weekly sessions.

Results: Descriptive analyses showed that MCI group had reduced levels of anxiety, depression, and loneliness, whereas they reported increased communicative skills, new knowledge as well as general cognitive function. Greater benefit to almost all the aforementioned variables was observed in those who were attending these programs onsite over the last three years period. Pearson Chi-Square analysis showed that those who reported lower levels of anxiety, depression and feelings of loneliness, had elevated levels of happiness before the program's onset, as well as sense of gratitude after the program's completion compared to those who didn't mention differences in their mood and sense of loneliness.

Conclusion: During the second wave of quarantine and lock down measures imposed, our online cognitive training interventions were found to boost older adults' with MCI mental health and psychological status, according to their self-reports. Our future endeavor should focus on shedding light on their possible relationship with objective measures, that is neuropsychological tests as well as psychological scales.

QOP1-17. Cognitive and behavioral effects of the first Quarantine imposed in Spring 2020 due to the Coronavirus 19 in people living Dementia: a longitudinal study

Marianna Tsatali

Alzheimer Hellas

Objective: The aim of the current study was to evaluate the cognitive as well as psychological effect of the quarantine in Greek older adults with Alzheimer's Disease Dementia (ADD) in mild and moderate stages. **Method:** 111 older adults with ADD, who had initially visited the Day Centers of the Greek Association of Alzheimer Disease and Related Disorders (GAARDR) in 2018, took part in the current study. Tests measuring mood, as well as everyday functioning and cognitive measures were performed at baseline (at the time of the first evaluation in GAARDR) during the time period of May to July in 2018, as well as at the two consecutive follow-up assessments, at the same three months period, in 2019 and 2020. Those participants were attending non-pharmacological interventions during this 3-year period, which were digitally implemented during the lockdown measures imposed. **Results:** Mixed measures analysis of variance showed that participants' deterioration rate by means of their performance in neuropsychological as well as psychometric tools administered between 2018-2019 (Deterioration rate D1) and 2019-2020 (Deterioration rate D2) did not change. The only exception was found for RAVLT and phonemic fluency test, as well as FUCAS test whose D2 deterioration rate was greater. Additionally, three path models, which were conducted afterwards, showed that participants' worsened performance in 2019 and 2020 assessment was strongly affected by NPI performance, in sharp contrast to the assessment in 2018. **Conclusion:** During the first quarantine period we found that verbal memory, verbal fluency and also daily functionality, as measured by the FUCAS test, were strongly impaired in ADD, however no other changes were observed. Path analysis showed that behavioral disturbances affected the aforementioned impairment equally in 2019 as well as 2020. This fact could possibly shed light on the real effect of the quarantine on people with ADD.

QOP1-18. WITHDRAWN

QOP1-19. WITHDRAWN

QOP1-20. COVID DEMENTIA EDUCATION IN CARE HOMES [CODECH]

Leah Macaden¹, Michelle Beattie¹, Ruth Mantle², Ann Pascoe³, Lindsay Dingwall⁴, Andrew Gibson¹, Alison Raeburn²

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Most care home residents are older people with nearly 50% having a diagnosis of dementia and complex care needs. The COVID-19 pandemic has heightened some of these complexities affecting staff who care for them in these settings. There is evidence to support that an appropriately trained workforce enhances confidence and competence promoting positive care experiences and interactions both for staff and residents in care homes. In addition, the reallocation of roles, a reduction in the workforce and a need for ongoing learning to meet the changing demands of the pandemic have highlighted the imminent need for a tailored approach to COVID -19 Dementia Education.

The care home sector relies on a workforce that have low level qualifications, a deficit requiring urgent attention in order to support dementia care in care homes to meet demands for new learning at an unprecedented pace in the constantly evolving, shifting and changing COVID 19 landscape. The aim of CODECH was to work collaboratively with colleagues from the care home sector to co create a dementia education resource for blended learning, aligned to the Skilled Level of Scotland's Promoting Excellence Framework for dementia training. An expert group was set up involving multiple stakeholders with subject, pedagogy, clinical, instructional design and technology expertise to inform CODECH.

CODECH was successfully developed and delivered to a group of 24 staff working in care homes using a blended approach for the first time over six weeks with 4 hours of online training each week and 24 hours of reflective / self-directed learning using peer support. This component was supported with three online workbooks [Dementia Care: Essentials / Priorities & Enablers] developed for the first time to support staff development in care homes towards Dementia Care Excellence.

CODECH was funded by the Winston Churchill Memorial Trust's COVID 19 Action Fund.

QOP1-21. How Meeting Centres have continued to support people affected by dementia and flourish in the UK despite the pandemic

Shirley Evans

Association for Dementia Studies

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 (UK MCSP) was established in 2018 and led by the Association for Dementia Studies, 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 (COLP), 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 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. It is expected that there will be over 30 MCs in the UK by the end of 2021. The COLP has grown, with a National Reference Group of 46 and a regular fortnightly group meeting online. There have been three cohorts taking the recently developed online MC training module, including a Singapore cohort.

Moreover, the four demonstrator sites have continued to collect attendance, health and well-being and satisfaction data. We will report on this data collection, which took place during the pandemic, and consider the implications for support as well as presenting progress with MCs in the UK.

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QOP1-22. Can a one-button screen improve the quality of life among people with dementia? Highlights from a research&innovation project, using social tech in elderly care in Norway

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Loneliness among the elderly is a societal problem and increasingly a policy priority, not least during the COVID-19 pandemic. Ageing at home is a political priority in Norway; the average age of nursing home dwellers is 85, among which ca. 80% are diagnosed with dementia.

In our talk we present preliminary results from "Safe and simple point of contact with relatives", a research and innovation project centred on reducing loneliness through the use of social technology in elderly care in Oslo, Norway. Starting in august 2020 until december 2021, the project attempts to adapt the consumer technology "KOMP" for use in public nursing homes. KOMP is a one-button screen with a retro design (reminiscent of an old TV or radio), developed by the Norwegian tech company No Isolation for elderly users with limited digital competence.

We study the experiences of the elderly users, their family, and nursing home staff, for evidence of reduced loneliness, increased quality of life, and other (unanticipated) consequences of using a one-button social technology in a nursing home context.

An important research goal is to determine whether (and how) dementia is a barrier to the successful use of social technologies such as KOMP. A total of 340 KOMP units will be implemented across all 19 public nursing homes in Oslo within Q1 2021.

The project is a collaboration between developers No Isolation, the Nursing Home agency - City of Oslo (SYE), and Oslo Metropolitan University (OsloMet), and is funded by the Norwegian Research Council. OsloMet will study the innovation process and the effects of use, using a mixed methods approach that combines a 6-month longitudinal and triangulating survey with qualitative interviews with staff and family and user traffic data.

QOP1-23. Staff's resilience: COVID-19 outbreak in a Canadian Long-Term Care home

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Although there have been considerable public concerns about the impact of COVID-19 on residents living in long-term care homes, much less attention has focused on lessons learned from staff experiences about caring for people with dementia during outbreaks. The outbreaks added significant additional stress to the nursing workforce, which has historically experienced high turnover, chronic staffing shortages, and increased burnout in long-term care settings. We conducted focus groups (n=20) and individual interviews (n=10) to investigate critical challenges, experiences, and support needed for frontline staff in a long-term care home in British Columbia, Canada. A total of 30 staff in multiple disciplines participated in the study. They included Registered Nurses, Licenced Practical Nurses, care staff, recreational staff, and unit clerks. We applied qualitative thematic analysis and identified four themes: (a) I am proud, (b) we become stronger, (c) I am nervous (d) the vaccine helps. The frontline staff's voices provided a detailed description of their emotional experiences, creative coping strategies and positive stories about caring for the most vulnerable population in extraordinary situations. In our poster, lessons learned and implications for future research and practice will be explored and discussed.

QOP1-24. Family caregivers' perspectives on their interaction and relationship with people living with dementia in a nursing home

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Background: Social interactions are important for people living with dementia in a nursing home. However, not much is known about interactions and relationships between residents and family caregivers, and pertaining experiences of family caregivers. We aim to advance the knowledge on how family caregivers interact with people living with dementia in a nursing home, and how they construct a meaningful connection.

Methods: Qualitative research using interviews with family caregivers to explore perspectives on their interaction and relationship with the person living with dementia. Interviews were performed during the reopening of nursing homes after the first COVID-19 lockdown in the Netherlands, which provided a unique opportunity for family caregivers to reflect on their interaction and relationship with their loved one, as guidelines forced other ways of interaction. Inductive thematic analysis was performed to analyze the data.

Results: From the perspectives of 31 family caregivers, we were able to identify three preliminary key themes: (1) changes in the interaction and relationship, (2) strategies to promote connection, and (3) appreciation of the interaction and relationship.

Conclusion: For both residents living with dementia and family caregivers, the interaction and relationship is important, and family caregivers apply different strategies for constructing a meaningful connection. Nevertheless, some family caregivers seem to experience difficulties with establishing such a connection with the resident. Our results provide a basis for supporting family caregivers in perceiving and establishing mutuality and reciprocity, so that they can experience togetherness.

QOP1-25. Are visits allowed? The impact of the COVID-19 pandemic on care home visitation and care delivery in the UK

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¹University of Liverpool & NIHR ARC NWC, ²University of Liverpool, ³Lewy Body Society, ⁴NIHR ARC NWC, ⁵Sefton Advocacy, ⁶Lancashire & South Cumbria NHS Trust

Background: COVID-19 has caused the sudden closure of care homes to the outside world, to stem the virus from infecting some of the most vulnerable groups of people – older adults residing in care homes. With very little knowledge to date, we aimed to explore the impact of COVID-19 on care provision and visits in care homes from staff and family members' perspectives.

Methods: Care home staff and family carers of people living with dementia across the UK participated via telephone or Zoom. Participants took part in a semi-structured remote interview. Baseline data were collected between October and November 2020, and follow-up interviews were collected throughout March 2021. Anonymised transcripts were analysed separately by two research team members using thematic analysis, with codes discussed and themes generated jointly, supported by research team input.

Results 42 participants (26 family carers and 16 care home staff) took part in the baseline interviews, and 20 purposefully sampled participants (11 family carers and 9 care home staff) were followed up. Prior to vaccination roll out in the UK, at baseline, family carers expressed concern about a lack of clear guidance throughout the pandemic, with care homes delivering care differently and disparities noted in the levels and types of visiting allowed for family members. With the advent of vaccination and increased testing rollout, many family carers still experienced difficulties in visiting their relative at the care home. The fact that some care home staff were not vaccinated, or a lack of knowledge about their vaccination status, caused a great deal of anger in family carers.

Conclusions This is the first empirical evidence to show how care home visits have been affected during the pandemic, despite vaccination and increased testing. Vaccination should be made mandatory for social care staff working with vulnerable older adults.

QOP1-26. Lessons learnt from undertaking dementia nursing home research remotely & online during a global pandemic: Tales from two advance care planning implementation studies

Andrew Harding¹, Emily Cousins², Julie Doherty³, Adrienne McCann³, Sandra Varey¹, Nancy Preston¹, Karen Harrison Denning², Kay De Vries², Kevin Brazil³, Mysupport Group⁴, Necessary Discussions Group⁴

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Nursing and care homes (henceforth referred to as 'homes') in the UK have been and are clusters in their communities for the worst clinical manifestations of COVID-19. However, researchers have had opportunities to support homes during the pandemic by undertaking relevant research. Now approaching 18 months into the pandemic, it is important to reflect on the process of undertaking research in homes during this time in order to identify lessons for future research practice.

This presentation will draw on the experiences of UK researchers (part of an international consortium) who attained funding (before and during the pandemic) to undertake two advance care planning implementation projects in homes. Both projects were undertaken remotely with researchers having minimal or no in-person contact with sites – one adapted to this approach, while the other was designed remotely. We draw on research reflections, field notes and interviews with home staff to identify lessons learnt for future research practice in order to ensure maximum benefit to homes.

Three broad themes are discussed. In terms of engagement (1) we will highlight different approaches to achieving buy-in from homes, engaging with participants and building relationships remotely. In respect of data collection (2) we will illustrate the importance of being responsive to fluid circumstances for study ethics, adapting consent / recruitment processes and discuss the deeply contextual nature of undertaking telephone and video interviews with staff in a deeply challenging environment with no precedent. Finally, we outline how we added value and enriched participation (3), including by reducing burden on homes, delivering free training and providing tablets.

It's possible to conduct research in homes during a pandemic. Being responsive to fluid circumstances, managing expectations and the implementation of various strategies/approaches could facilitate beneficial and meaningful participation for homes and elicit impactful findings.

QOP1-27. How to respond in better ways? Moral judgments and advises from residents, family members and volunteers in nursing homes concerning restrictive COVID-19 measures

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Background: Restrictive COVID-19 measures such as the prohibition of in-person visits in nursing homes (NHs) had a major impact on the daily lives of residents, family members and volunteers. Despite the fact that the measures

affected them severely, they were not involved in these policies. Within a multicenter qualitative study into the impact on loneliness and social needs and what lessons could be learned, we specifically focused on their perspectives. As part of this study we asked residents, family members and volunteers, in retrospect, how they judged these policies, what they considered as most important and what they would do differently with the knowledge we have now, in case of similar challenges.

Methods: For this part of the study we conducted three online Socratic dialogue meetings with NH residents, family members and volunteers. Participants were affiliated with psychogeriatric and somatic wards in Flanders (BE) and in two regions in the Netherlands. The meetings were transcribed verbatim and analyzed through an open, inductive method.

Results: Various (conflicting) values and norms were recognized and weighted by participants, including values like quality of life, social contact and tailored care. Most of them recognized safety as highly valuable, but varied in how to operationalize this into regulations. For example, if family members or volunteers had limited social contacts, they were considered to be less of a risk than care professionals, who often have their own families, and therefore reckoned it morally justified to stay involved in the care for residents.

Lessons learned: Participants considered the NHs as the justified authority to construct tailored restrictions if needed, but should include the wishes and specific needs of residents, family members and volunteers. In addition, NHs should invest in providing clear information for residents, family members and volunteers and facilitate an on-going dialogue with them.

QOP1-28. Digitizing dementia care during COVID-19: Lessons from the scaling-up of Partner in Balance

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Maastricht University

Background: The COVID-2019 pandemic has had a serious impact on the mental and physical health of people with dementia and their carers, as the pandemic has drastically reduced access to dementia support services. However, this pandemic has also changed attitudes towards online support and forced healthcare systems to reinvent themselves in a new, digital direction.

Methods: Recently, Partner in Balance was part of a rapid scaling-up project, funded by ZonMw, to increase support options for people with dementia and their carers during the COVID-19 crisis. Partner in Balance is an eHealth intervention to support caregivers of people with dementia. The eight-week intervention includes video's, tips from caregivers, and feedback from an online coach. Qualitative feedback from coaches was collected during training workshops, intervention meetings, and evaluations.

Results: As a result of this scaling-up, Partner in Balance gained hundreds of new users between September and December 2020. A first lesson from the qualitative feedback is the need to increase the self-efficacy of healthcare professionals, who now need to integrate these new, digital methods into their daily clinical practice. A second lesson is that the scaling-up showed that there was a large variation in the background and needs of the different coaches. More attention is needed on coach diversity, in addition to carer diversity.

Conclusions: This accelerated implementation illustrates the potential of the healthcare sector to increase digitization, which has long lagged behind other sectors. To avoid losing the momentum created by the demand for digital support during the COVID-19 pandemic, digital dementia care providers and healthcare organizations need to facilitate tailored support and training for healthcare professionals, and focus on increasing self-efficacy. This will be crucial for the adoption of evidence-based digital tools in dementia after the current crisis.

QOP1-29. Unexpected increase in physical exercise during the first lockdown of COVID-19 in England in people with dementia: What are the implications for future community care?

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Introduction: Restrictions introduced in response to the COVID-19 pandemic may have led to reduced physical exercise levels in people with dementia, but empirical data in this area are limited.

Aims: To investigate physical exercise levels of participants in the Promoting Activity, Independence and Stability in Early Dementia (PrAISED) Randomised Controlled Trial (RCT) who received remote support during the COVID-19 pandemic first wave lockdown.

Methods: A cross-sectional repeated measure study using self-reported minutes of physical exercise compiled by participants in the intervention group of the PrAISED RCT on monthly calendars for February, May, and August 2020. Wilcoxon signed-rank tests investigated statistically significant differences ($p < .05$) in exercise levels across months.

Results: Thirty participants were selected, with a mean age of 78 years ($SD = 6$; Range 66-88). Male and female participants were equally represented ($n = 15$; 50%). Most participants were white ($n = 29$; 97%) and lived with their primary caregiver ($n = 22$; 73%). Return rate was 76%. Participants reported a statistically significant increase in activity levels between February and May ($Z = -2.013$, $p = 0.044$) and a statistically significant decrease between May and August ($Z = -2.726$, $p = 0.004$).

Discussion: Despite concerns that the restrictions associated with the COVID-19 pandemic might lead to reductions in physical exercise, participants in receipt of the PrAISED intervention increased their amount of physical exercise during lockdown. Findings support the potential for future community care to provide remote support for people with dementia to maintain physical exercise levels independently.

QOP1-30. Management of long-term care in Luxembourg during the COVID-19 pandemic

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The COVID-19 pandemic has exposed vulnerabilities of people living in care homes, with higher risk of infection, severe disease, and death from/with COVID-19 compared to the general population. We present an overview of the impact of COVID-19 on care homes in Luxembourg, and discuss areas of improvement of pandemic management.

Different actors are involved in the pandemic management of care homes in Luxembourg: The health ministry is in charge of handling the COVID-19 sanitary crisis. The family ministry is responsible for the mission of older persons, including the care homes. The association of care home providers COPAS issues advice for SARS-CoV-2 infection prevention and management in collaboration with the ministries. The national ethics commission regularly issues advice. Experts specialized in infectious disease monitoring and prevention (virology, epidemiology) were not systematically involved. Strong pandemic control (confinement) measures were put place in spring 2020. After this phase, no detailed official guidelines for SARS-CoV-2 infection prevention and management in care homes were issued.

Recent figures for Luxembourg suggest that care home residents were disproportionately negatively impacted by the pandemic: Almost one third of all care home residents (29.49%) were tested positive for SARS-CoV-2, compared to 11.51% of the general population. While only 1.05% of Luxembourg residents live in a care home, over 40% of all COVID-19 deaths affected care home residents. A commissioned report ("second Waringo report") is underway to more systematically assess and understand the spread of SARS-CoV-2 in Luxembourgish care homes.

The lessons learned from the COVID-19 pandemic should be used to increase resilience and pandemic preparedness in future crises. Specifically, we should more systematically involve ethics commissions in difficult end-of-life decisions and experts to optimize pandemic management in care homes, while at the same time balancing the mental and physical health impact of the pandemic control measures for residents.

QOP1-31. COVID-19 and the role of technology in dementia: an international study

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Background: Social distancing rules and the closure of services due to COVID-19 have affected the health of older adults, many of whom have dementia. Digital technologies (DT) can effectively support people with dementia and carers during pandemic times. Specifically, they can minimize the effects of social distancing and isolation. Moreover, they can provide a continuity of care and social connectedness, while decreasing exposure to risk and the pressure on health and care systems. Barriers to the use of DT such as digital literacy and lower income households can coexist. The aim of this international study was to explore and compare how DT have been used by people with dementia from different care settings, and their informal carers across four countries (Italy, UK, Australia, and Poland).

Methods: People with dementia and informal carers took part in semi-structured interviews. Transcripts were analysed by researchers in each country using inductive thematic analysis.

Results: 141 participants (47 in Italy; 50 in the UK; 18 in Australia; 26 in Poland) were interviewed. The analysis identified three overarching themes: 1) uses of technology; 2) benefits of technology; 3) limitations of technology. Results show that calls, video calls, and group-chats were effectively used across countries to guarantee the continuity of relationships with professionals, families, and small groups of peers. Telemedicine was used with varying levels of satisfaction. Furthermore, carers experienced more benefits than people with dementia. Similar barriers were reported across countries, and were associated with dementia deficits, low level digital literacy, and the need for carer's supervision.

Conclusions: These international findings highlight the importance of ensuring systems for delivering technology according to people with dementia's impairment and care context to maximise potential benefits and usability. Moreover, it should be complementary to in-person care which should be provided, at least to some extent, even during pandemic times.

QOP1-32. Making a virtue of necessity: how the COVID-19 pandemic promotes dementia care

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Living well with dementia requires high levels of activity and participation, ample social contacts and skillful control of symptoms including the use of non-pharmacological interventions as a complement to drug treatment. During the COVID-19 pandemic, particularly in times of lockdown, supplying these key components of quality of life has become difficult if not impossible, due to contact restrictions and safeguarding procedures. As a consequence, many people with dementia have been exposed to harder access to detection, diagnosis and treatment, social deprivation, accelerated cognitive and functional decline and worsening of behavioural problems. The INDEED Project (Improvement for Dementia in the Danube Region) is co-funded by the European INTERREG-Danube Transnational Programme. The project has created an educational intervention for multiple professions involved in the care of people with dementia. The intervention is delivered in a blended-learning format including an online course and face-to-face workshops available in five languages. In pilot actions it has been evaluated with exceptionally favourable results. As an additional part of this intervention we tried to identify best-practice examples from South-East Europe showing how effective dementia care can be provided despite COVID-19 constraints. Possible solutions included electronic information panels and reminders for people with dementia; assistive technology to support communication, activity,

entertainment, exercise and training; online guidance for staff; behavioural management through telephone helplines; interprofessional teleconferencing, and virtual caregiver support groups. From the best-practice examples important conclusions can be drawn on sustainable improvements of dementia care that are induced by the COVID-19 pandemic.

QOP1-33. Learning despite the pandemic

Lorène Gilly, Volodia Tourtchine

France Alzheimer

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.

Bringing help to health care professionals

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.

Training the volunteers

France Alzheimer's local branches were and still are very impacted by this crisis (with the several lockdown in particular) because they couldn't organise actions for caregivers and people with dementia. Moreover, it has been very difficult to integrate new volunteers.

France Alzheimer's Institute decided to 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!

In order to support our trainers to succeed in their mission, we also organised trainings on how to conduct a training session with videoconferencing.

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

QOP1-34. Day care service provision for people with dementia: A qualitative study with family carers in Ireland

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¹HSE, ²ucc, ³UCC

Background: Approximately 60,000 family carers in Ireland are looking after a person with dementia. One form of carer support that has shown to be of some benefit to carers and a person with dementia is the use of day care services which have been closed in Ireland since the start of the Pandemic. The aim of this study is to explore the influence of day care services on carers of a person with dementia.

Methods: Ten semi-structured interviews were conducted with purposively sampled family carers of a person with dementia attending day care in the south of the Republic of Ireland pre-pandemic. Interviews were audio taped, with each participant's informed consent, to facilitate transcription and qualitative data analysis.

Results: Three key themes were identified: 1) "Service access and initiation" identified deficient service information and inadequate support for the carer with day care placement; 2) "Service acceptability" pinpointed how variations in carers' circumstances can differentiate their support needs. All carers experienced day care as an effective means of professional support, reassurance, and education relevant to the caring role. This study identified the wellbeing of the Person with dementia, care quality and a safe environment as pivotal to the carer's experience; 3) "Experienced outcomes" refers to the respite (i.e., a physical and mental break) that carers received from day care service use and the implications of same, e.g. delay in long-term care placement.

Conclusion: Day care services are an acceptable and effective support and respite service for carers of person with dementia; decision-makers need to recognize this as services resume. Increased resources are needed to expand service provision, improve access and promote service development, so services can be flexible and responsive enough to meet each dyad's individual care and support needs, and premature long-term care placement can be avoided.

QOP1-35. Clinical validation of automatically derived digital features from the Verbal Learning Test (VLT) in early diagnostics of cognitive impairment and dementia

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Background: Previous research has shown that verbal declarative memory is an accurate measure for cognitive decline in early phases of Alzheimer's disease dementia (ADD). Automatically derived features from the verbal learning task (VLT) can potentially be used to differentiate between people with and without cognitive impairment. We

have investigated the value of automatically derived VLT features in clinical practice and their usefulness in early diagnostics of cognitive impairment and dementia.

Method: In the DeepSpA project, patients with (N=70) and without cognitive impairment (N=70) were recruited from the memory clinic of the MUMC+ (Maastricht, the Netherlands). All participants underwent a cognitive assessment including the 15-Word-VLT, which was processed using the Delta application (ki:elements). The relation between VLT features, such as primacy effects (4 first words of the VLT list) and recency effects (4 last words of the VLT list), subjective clustering, serial clusters, slopes (regression-based and learning trial 1-3), forgetting rate (correct count in delayed recall minus highest correct count in learning trials), and syndrome diagnosis, were investigated using stepwise regression analyses, corrected for age, education level and gender.

Results: Preliminary results indicate that, compared to patients without cognitive impairment, patients with cognitive impairment had lower performances on specific automatically derived VLT features as presented by an odds ratio (OR) and a 95% confidence interval (CI): total primacy effect (OR 0.814, 95% CI=0.728–0.909), total recency effect (OR 0.877, 95% CI=0.788–0.977), mean subjective clustering (OR 0.529, 95% CI=0.302–0.925), total serial clusters (OR 0.849, 95% CI=0.765–0.944), regression based slope (OR 0.143, 95% CI=0.057–0.361), learning slope trial 1-3 (OR 0.696, 95% CI=0.554–0.874) and forgetting rate (OR 0.711, 95% CI=0.573–0.882).

Conclusion: First results suggest that specific automatically derived features are useful in the early diagnostics of cognitive impairment and dementia.

QOP1-36. Strategies used by care home staff to manage responsive behaviours of residents with dementia during the COVID-19 pandemic

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Background: Many care home residents exhibit responsive behaviours including aggression and agitation. Psychotropic drugs are often prescribed to manage responsive behaviours but increase the rate of strokes and death in people with dementia. Therefore, it is highly important to identify the barriers and facilitators to implementing non-pharmacological strategies to manage behaviour.

Aim: To understand how care home staff manage responsive behaviours of residents with dementia during the COVID-19 pandemic in order to identify the barriers and facilitators to implementing non-pharmacological approaches.

Methods: The research involved conducting 25 interviews with care home staff from 21 care homes across Ireland. All participants provided written informed consent. Reflexive thematic analysis was used to identify the barriers and facilitators to taking a non-pharmacological approach to behaviour management. Ethical approval was obtained from Lancaster University Faculty of Health and Medicine Research Ethics Committee (Ref. FHMREC20091).

Findings: Care home staff reported using psychotropic drugs in circumstances where the residents' behaviour posed a risk to themselves or others. Non-pharmacological approaches to behaviour management required insight into the residents' personal history to identify the triggers for responsive behaviours. Inadequate staff training in person-centred care posed a barrier to implementing non-pharmacological approaches to manage responsive behaviours. Also, teamwork and communication between nurses and healthcare assistants were often found to be suboptimal. Facilitators to taking a non-pharmacological approach included effective leadership, family involvement and multidisciplinary collaboration.

Key recommendations: To address these barriers, training for care home staff in dementia care should include relevant work experience. Moreover, opportunities should be provided for care assistants to progress in their career and contribute more to multidisciplinary collaboration and equitable decision-making. These recommendations will assist development of dementia guidelines, including national dementia strategies, to implement non-pharmacological strategies to manage responsive behaviours of care home residents with dementia.

QOP1-37. Living with dementia at home: Getting and adapting to specialised day-care support

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Introduction: Caring for a relative with dementia at home is a reality of families worldwide. Numerous studies describe how these families are confronted with diverse difficulties and lack of formal support. Specialised day-care has been shown to be of an important support but with multiple challenges also. It is important to create a deeper understanding of how and if families do adapt to such support, to be able to strengthen its contribution to ease the life of families living with dementia.

Materials and method: Using a longitudinal ethnographic case study approach we followed eight families living with dementia, for two years, from a waiting list to an offer of a specialized dementia day-care. Data collection October 2017 – December 2019. Traditional ethnographic method was used in analyzing the data; field notes, phone calls and semi-structured interviews. We portrayed multiple scenarios capturing the complex situation of adapting to day-care in each family.

Results: The families' situations were all different. Some went smoothly through the face of adaptation, while others were in a chronic struggle. Family caregivers called for an enhanced guidance from professionals. When things seemed to be working well, new challenges emerged calling for a different response. Protecting persons and circumvent uncomfortable situations were examples of ways that family members used to avoid disruption and imbalance in life but could lead to more complications.

Conclusion: In developing feasible competences of specialized dementia day-care to better support families of people living with dementia at home, it is important for professionals to know and understand the different ways families deal

with the impact of dementia. Time and space must be provided to establish trust and create family-centered support in more proactive way.

QOP1-38. Enhancing Dementia Care during the Corona Pandemic: Zooming from Home

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COVID-19 pandemic and subsequent lockdowns created a global public health crisis generating mental health problems including social isolation, stress, and anxiety especially for persons with dementia and their carers. This study utilized digital technology to maintain social connectivity via a virtual group session that focused on the topic of 'what is home.' Participants included 16 day center clients representing an immigrant community identified with mild to moderate cognitive impairment. A trained psychodrama therapist conducted the virtual group meeting based on five key techniques: spectrogram, role reversal, doubling, mirroring, and soliloquy. NVivo software was used for the qualitative analysis of the manually transcribed video recording to identify key themes based on grounded theory methodology.

Zooming from home, clients engaged in significant social interaction. Results of the NVivo analysis identified the following themes of 'what is home': Emotions and home, Home is family, Home is community, and Reminiscence (with objects and traditions). Results suggest that digital interactive technologies, like Zoom, enhance social connectivity thus mitigating the negative impact of social isolation especially during pandemic lockdowns. Our pilot results based on virtual group meetings from home demonstrate that participants can express significant emotive capacity and enhanced connectivity with one another.

While larger studies are needed to confirm these findings, we suggest that this methodology may be used to support persons with dementia as an addition to other community and home care services. From a societal perspective, making available technology to persons with dementia to socially connect and engage through a medium that is not part of their generation has far-reaching implications not only for future research but also for policy considerations, mitigating social isolation and caregiver burden. Changes in reimbursement policies to include these innovative home services may be helpful in building more resilient communities for the more highly vulnerable populations.

QOP1-39. Psychotherapy via Telehealth to Reduce Anxiety in Persons Living with Cognitive Impairment

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Anxiety is a prevalent presenting problem in people living with dementia. Untreated anxiety contributes to a decreased quality of life of people living with dementia and their support persons. Anxiety has been elevated during the COVID-19 pandemic and further exacerbated during lockdowns, imposing social isolation and limited access to support services. Therefore, it has become crucial to adapt psychotherapeutic interventions to the telehealth modality to address anxiety in people living with dementia.

Methods: This is a mixed method study to test a psychotherapy program to address anxiety in people living with dementia or mild cognitive impairment. The program consists of 6 sessions delivered weekly via telehealth videoconferencing. The sessions focus on psychoeducation, anxiety monitoring and relaxation exercises. Each session includes a presentation of short videos to facilitate the content delivery and to support the participants' between-session practice. Eligible participants and their support persons complete a clinical interview and a set of online questionnaires pre- and post-intervention to detect change in individuals' scores using reliable change index analysis (RCI). The qualitative arm aims to evaluate participants' experiences of the program using semi-structured interviews to inform further optimisation.

Results: The study is currently open for data collection (N < 5). The preliminary results show a decrease of anxiety, with individual results showing decrease below the cut-off for anxiety on RAID and/or a statistically significant clinical change (RCI = -2.17). The qualitative data show an overall satisfaction with the program. Participants flexibly adapted the prescribed relaxation techniques to their daily routine and reflected on the benefits of the between-session practice.

Discussion/Conclusion: This small study tests the proof-of-concept of a telehealth-delivered psychotherapy for people living with cognitive impairment. The outcomes will support further modifications of the program to test its efficacy in a pilot RCT.

QOP1-40. Reasons for refusal in MCI research

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Intro: Major recruitment challenges in dementia studies lead to concerns about the representativeness of study samples. While patient motivations for engaging in dementia research are well evidenced, refusal reasons are rarely reported. Our study addresses the dearth of knowledge in why eligible participants decline dementia research.

Aim: To understand the reasons for refusal of potential participants in mild cognitive impairment (MCI) and Alzheimer's disease research.

Method: Firstly, we undertook a literature review, assessing reasons for refusal in MCI research and Alzheimer's disease. Secondly, we analysed empirical data from an ongoing study assessing the impact risk disclosure in patients from South East Scotland who had been referred to a memory assessment service with a clinical suspicion of MCI. We documented reasons eligible participants gave for declining to partake in the research.

Results: Our literature overview revealed that evidence on reasons for refusal in MCI and Alzheimer's disease research often relies on hypothetical scenarios/the perspectives of carers. These include logistical (time/travel) barriers, disruption to normality, and lack of incentive. In our study, 36% (n = 65) of all the eligible participants approached (n=180) declined to take part. The most frequently cited reasons for refusal were "[Taking part in research is] not the sort of thing they would want to do" (n = 15, 24%), "Lack of interest in the study" (n = 14, 22%), "Not considering themselves to have memory problems" (n = 8, 13%), the research being "Not suitable for their life right now" (n = 4, 6%), and "anxiety about memory" (n = 3, 5%).

Discussion: Understanding the reasons why individuals who are eligible for dementia research decline to take part should be taken into account when engaging the MCI and Alzheimer's disease population and could help inform recruitment techniques in the future, leading to more representative study samples.

QOP1-41. Feasibility of using a personal assistant for dementia (PAD) in individuals with early-stage dementia

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Dementia is a progressive, largely irreversible, clinical condition, characterised by global deterioration in intellectual function, behaviour and personality¹. It affects almost one million people in the United Kingdom² and by 2050, 152 million global cases are expected. Dementia is devastating and costly, with current UK healthcare costs of £26 billion annually³ and expected global costs of \$2 trillion by 2030⁴. 66% of these are individual care costs³. This study evaluates the feasibility of using a phone, iPad, or home screen Personal Assistant for Dementia (PAD) in people with early-stage dementia. It explores, specifically the use of orientation screens, daily reminders, medication prompts, healthy eating aids, active living exercises, wellbeing activities, brain training exercises, lost language aids, map functions, memory screens, key contacts, home safety and emergency access functions. Results suggest potential positive effects on wellbeing, confidence, and independence in individuals with early-stage dementia. All study participants provided positive PAD feedback, with 80% reporting increased confidence and independence. Screen preferences, study limitations and potential PAD improvements were evaluated.

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QOP1-42. The associations between stressful life events, Alzheimer's disease biomarkers and cognition in the EPAD Longitudinal Cohort Study.

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Stress may be an important risk factor to understand in the development of Alzheimer's disease (AD). Perceived early life adversity has been associated with smaller cerebral and ventral striatum volumes in the UK Biobank cohort (Gheorghe et al, 2020). Ability to cope with stress in older life has been associated with tau deposition in the Mayo Clinic Study of Aging (Arenaza-Urquijo et al, 2020). Midlife is now accepted as a critical period for AD risk factor development and attention should be paid to the impact of stressful life events experienced during this period of life.

We used the EPAD LCS vIMI baseline dataset (n=1924, excluding participants with missing data). We selected number of life events and age of experiencing these as exposures. Outcome variables selected were CSF pTau and A β 1-42, RBANS total index score and RBANS delayed memory index. Covariates were age, sex, years of education, family history and APOE status. Our statistical analysis approach was linear regression.

In uncorrected models the total number of life events were associated with CSF pTau (β =0.23, p=0.009) and RBANS delayed memory index score (β =0.30, p=0.03). Only the association with the delayed memory index score remains significant in the fully adjusted model (β =0.48, p<0.001). Average age of life experiences across all life events was associated with CSF pTau (β =0.12, p<0.001), RBANS total score (β =-0.08, p=0.03) and RBANS delayed memory index score (β =-0.10, p=0.02), however none of these remained significant in fully adjusted models.

The total number of life events a participant reported was significantly associated with performance on delayed memory tasks in the EPAD LCS vIMI dataset. Future work should focus on understanding the mechanism that may be underpinning these findings. While we cannot stop these events happening, we may be able to develop better interventions to support adverse reactions to the events.

QOP2. (Quick Oral Presentation) Care and support

QOP2-01. A qualitative evidence synthesis of the experiences of people living with young onset dementia and their families.

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Background: The age profile of individuals living with dementia is, more often than not, over sixty-five years (> 65). However, some individuals are living with dementia at a significantly younger age (< 65). While it is less common, it is typically referred to as young (or early) onset dementia. In order to determine the lived experience of this cohort (post diagnosis), a thematic qualitative synthesis of current literature was conducted involving key stakeholders, including people living with young onset dementia, their family members and healthcare professionals.

Methods: A search of electronic databases including PubMed/Medline, Embase, CINAHL, PsychInfo, Scopus, Web of Science databases (1999 – 2019) was conducted with fixed search terms (e.g., “lived experiences” AND “young onset dementia” OR “early onset dementia”) following PRISMA guidelines. Thomas and Harden’s (2008) approach to thematic synthesis was employed.

Results: Data from 25 journal articles from 8 countries, and 9 items of grey literature (including position papers and reports) were reviewed. Synthesised data from the narratives of 860 participants included people living with young onset dementia (n = 598), spouses/partners/relatives (n = 181), children (n = 71) and service providers (n = 10).

Conclusion: There appears to be broad agreement among people with young onset dementia and family members on the impact of a diagnosis and the psychosocial issues it presents. Combined, these factors result in poor quality of life outcomes, and a lack of dignity or selfhood for people with young onset dementia and their families. Therefore, the “traditional” view of dementia as an older person’s disease needs to be challenged in order to improve the quality of life and wellbeing for younger people who are living with the condition.

QOP2-02. Marginalised voices: A mixed-methods study of the needs, experiences and quality of life of people living with younger onset dementia

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Background: Experiences of younger-and late onset dementia must be treated differently, however, the majority of the literature in dementia focuses on people with late onset dementia (LOD), and thus community health care protocols often overlook those diagnosed with young onset dementia (YOD). As a result, people with young onset dementia (PwYOD) remain relatively marginalised when compared to LOD. Given this important gap, this research aims to explore the experiences and (un)met needs of people impacted by YOD. The goal is to understand the challenges in relation to seeking and getting a timely diagnosis, adjusting to the diagnosis and the impact a diagnosis has on the PwYOD and their families. Furthermore, issues such as post diagnosis supports, coping strategies and the availability, appropriateness and usage of health and social care supports and services will be examined.

Methods: Focus group data with PwYOD (and their families) will be analysed using inductive thematic analysis. Specifically, focus group interviews will be used to explore PwYOD, and those close to them, perceptions, opinions, and beliefs, in relation to the above aims. The sample will include people with a formal diagnosis of YOD (with various subtypes) living in the community, and their family (including children) and health care professionals.

Participatory workshops with members of the Alzheimer Society of Ireland’s (ASI) Dementia Research Advisory Team (DRAT) were held to develop the topics of interest and specific questions for the focus group interviews.

Focus groups with PwYOD, between 12-16 participants (4 focus groups x 3-4 participants).

Focus groups with family dyads will consist of between 20-32 participants (4 focus groups x 5-8 participants).

One-to-one interviews with healthcare professionals.

Results: Study is currently ongoing.

Conclusion: It is hoped to translate this knowledge into best-practice strategies and protocols to support people to live well with young onset dementia.

QOP2-03. “I know his needs better than my own”

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Introduction: Caring for a person with dementia predisposes informal carers (carers) to mental and physical disabilities. Carers tend to focus on the needs of the person with dementia and have difficulties expressing their own needs for support. Carers are often overlooked in the rehabilitation process in dementia care even though they have a central role in supporting the person with dementia in daily life.

A systematic approach using an instrument would help facilitate identification of carers’ needs for supportive services. No such instrument has yet been developed to assess carers’ support needs within a person-centered approach.

Aim: The aim of this study is to clarify the main categories of carers’ support needs to inform future development of an instrument to assess carers’ support needs.

Methods: A qualitative approach combining focus group interviews with carers and professionals and individual interviews was used. Participants were recruited in two municipalities in Denmark. Three focus groups with carers (n=18) and two focus groups with professionals (n=13) were conducted followed by five individual interviews with carers. Inductive content analysis was used to clarify carers' support needs.

Results: Carers' support needs were categorised into four areas:

(1) daily life when caring for a person with dementia, (2) focus on themselves, (3) maintain own well-being, and (4) communicate and interact with surroundings.

Overall, carers expressed support needs in common regardless of the relation to the person with dementia. Also, carers tend to focus on the needs of the person with dementia, thus not knowing their own needs.

Conclusion: In future dementia care, new approaches in how to support carers and the person cared for are needed. The four main categories clarified in this study may inform the foundation of developing an instrument to facilitate dialogue between carers and professionals with the purpose of identifying carers' support needs.

QOP2-04. Development and Field-testing of the Dementia Carer Assessment of Support Needs Tool (DeCANT)

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Introduction: Informal carers (carers) have an important role in supporting the health and well-being of people with dementia. However, caring for a person with dementia is associated with poor mental, physical and social health, which makes it important to consider the support needs of carers themselves. At present, a robust questionnaire to identify carers' support needs does not exist. Developing such a questionnaire could facilitate the dialogue with carers and enable supportive interventions for the benefit of both carers and the person cared for.

Aim: The aim of this study is to develop a self-reported questionnaire to assess the support needs of carers of people with dementia and to test its face, content and structural validity.

Methods: A psychometric study design was used. Participants were recruited in primary and secondary health care in Denmark. Items were generated based on interviews and literature review. A person-centred approach using WHO's International Classification of Functioning, Disability and Health (ICF) was used as a conceptual framework to identify carers' support needs. Three rounds of pilot-testing were conducted among carers and experts. A large scale field-test using a survey design was conducted to investigate structural validity.

Results: Initially, DeCANT was developed based on an item pool of 63 items. Iterative pilot-testing ensured face- and content validity, and reduced the item pool to 42 items. A total of 19 carers and 8 experts participated in the pilot-testing. Subsequent field-testing among 301 carers resulted in a 25-item version of DeCANT, and Confirmatory Factor Analysis demonstrated a moderate fit to a four-factor model based on the ICF. This confirmed satisfactory structural validity of DeCANT.

Conclusion: DeCANT is a 25-item carer-reported questionnaire that can be used to help identify carers' support needs when caring for a person with dementia to facilitate dialogue with carers in the rehabilitation process.

QOP2-05. Adapting a guided low-intensity behavioural activation intervention for people with dementia and depression in the Swedish healthcare context (INVOLVERA)

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Global health and social care policy highlights the need to support people to 'live well' with dementia. This is of particular importance given the high burden placed on individuals with dementia, informal caregivers, and society. Depression is highly prevalent in people with dementia, stressing the importance of developing interventions to support people with both dementia and depression. Despite evidence-based psychological interventions (e.g., cognitive behavioral therapy (CBT)) being effective, access is limited. To overcome this psychological 'treatment gap', there have been global efforts made via the provision of low-intensity CBT (LI-CBT). Behavioural activation (BA), an example of a LI-CBT approach shown to be as effective as CBT in the treatment of depression.

Research informed by the Medical Research Council complex interventions framework has been conducted in the United Kingdom to develop and test a guided low-intensity BA intervention adapted for people with dementia. An innovative aspect of the intervention is support to the person with dementia is provided by an informal caregiver, in turn the informal caregiver receives guidance from a healthcare professional. Initial results indicated the intervention was acceptable and feasible, and may therefore represent a solution for the Swedish context. However, before implementing in Sweden, there is a need for contextual adaptation.

Using a mixed-methods study design, informed by principles from participatory action research, this study involved people with dementia, informal caregivers, healthcare professionals and community organisations to co-design and adapt the guided low-intensity BA intervention for the Swedish context. Through a series of iterative phases, we conduct interviews and focus groups with participants to gain feedback on the BA intervention to inform adaptations to improve the acceptability, relevancy, and feasibility of the intervention. After each phase we amend the intervention according to feedback.

During the presentation the preliminary results and research progress will be presented.

QOP2-06. Testing the delivery of post-diagnostic support from primary care - learning from an improvement programme

Julie Miller

Healthcare Improvement Scotland

Description: From April 2018 to March 2021, Focus on Dementia (FoD), a national dementia improvement programme, worked with three GP cluster sites to explore whether relocation of dementia expertise into primary care would make dementia support more accessible and “normalised” to individuals and families. And, whether this would encourage people to come forward sooner for a dementia diagnosis and be more likely to take up support if it is offered via their GP surgery.

Three clusters were selected to become innovation sites with whom we held a series of educational workshops on dementia and quality improvement methodology. Progress at each site was monitored monthly and an external evaluation was commissioned by Scottish Government.

Aims/objectives - to test if:

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.

Results/Outcomes: At March 2021 the three sites had supported over 300 people collectively through a combination of support pre-diagnosis, during diagnosis and for PDS. Due to COVID-19 the final evaluation report will not publish until late July 2021 to be able give definitive findings at this stage however interim data from surveys and case studies includes:

East Edinburgh – improved key information summary (KIS) completion. 50% of PDS referrals had either a KIS created or information added. Earlier take up of assessment for diagnosis.

Nithsdale – wait time for psychiatry diagnosis reduced from 9 months to 6 weeks since implementation of nurse/OT led diagnosis in primary care clinics.

Shetland - 40% increase in uptake of PDS.

QOP2-07. How do people with dementia, care partners and healthcare professionals experience support after a dementia diagnosis: qualitative results from the COGNISANCE study

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Background: To promote the concept of living well with dementia, we need to focus on improving quality of life (QoL) (Martyr et al., 2018). Post-diagnostic dementia support is aimed at maintaining or increasing QoL and provides opportunities for people with dementia (PwD), care partners (CP), and healthcare professionals (HCP) to work together in an early stage of the disease and set realizable goals for care and support (O'Shea, Keogh, & Heneghan, 2018). Despite the wide range of support options available, they are not all frequently used by PwD and CP (Wolfs, de Vugt, Verkaaik, Verkade, & Verhey, 2010). Identifying barriers and facilitators of post-diagnostic support use is the first step to improve post-diagnostic support utilization and satisfaction, and ultimately QoL. The aim of the current study is to provide a detailed and in-depth description of current experiences, barriers, and facilitators of post-diagnostic dementia support that PwD, CP, and HCP encounter.

Study Design: As part of the COGNISANCE project, we conducted online interviews and focus groups with recently diagnosed PwD, CP and HCP. Data collection took place across four countries (Australia, Canada, the Netherlands, and Poland) between March 2020 and September 2020. Projective techniques were used for PwD and CP and focused on the experiences in the first year following a dementia diagnosis. For HCP, the focus groups and interviews examined the diagnostic process, needs after a diagnosis, and post diagnostic support.

Results: We conducted 26 PwD interviews (53% female, +-74 y/o), 10 CP focus groups and 34 CP interviews (53 participants total, 81% female, +-57,5 y/o) and, 11 HCP focus groups and 12 HCP interviews (55 participants total, 80% female, +-47,4 y/o). Each country analysed its own country-specific data. A cross-country analysis is currently being carried out and full results will be available in early Autumn 2021.

QOP2-08. Guidance for family about comfort care in dementia: a comparison of an educational booklet adopted in European countries over 15 years

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To support family caregivers of people with dementia in end-of-life decision making, a family booklet on comfort care was developed in Canada in 2005. The aim of the booklet is to prepare family caregivers for their relative's end of life and reassure them about choices around comfort care. Between 2005 until 2021, this booklet has been adapted and adopted by Japan and a number of European countries-Italy, the Netherlands, Czech Republic, United Kingdom and Ireland, and updated in Canada. Although retaining its core, local adaptations in style and content were needed. We

used qualitative content analysis to create a typology of changes to the original booklet for comparison. Interviews with the editors contributed to methodological triangulation. Using an established framework from the European Association for Palliative Care, we assessed whether the contents of the booklets addressed all domains relevant to optimal palliative care for people with dementia. Results show that the booklets differed in the types of treatment addressed, in particular tube feeding, euthanasia, and spiritual care. There was also variability in the extent to which medical details were provided, an emphasis on previously expressed wishes in medical decision making, addressing of treatment dilemmas at the end of life, the tone of the messages (euphemistic or explicit) and the discussion of prognosis (as more or less positive), and the involvement of various healthcare professionals and family caregivers in care. All booklets addressed all domains of palliative dementia care, although spiritual care and advance care planning received limited attention in the first issued booklets. The local adaptations and updates accounted for socio-cultural, clinical, and legal differences which may also change over time. These results can inform development of educational and advance care planning materials for different contexts.

QOP2-09. The feasibility and acceptability of a pilot Comprehensive Resilience-building psychosocial Intervention (CREST) for people with memory problems/dementia in the community

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Background: Globally, over 50 million people experience memory problems or dementia. The availability of psychosocial support can enable people with dementia to continue leading meaningful lives and participating in society. We explored the feasibility and acceptability of a comprehensive resilience-building psychosocial intervention (CREST) for people with memory problems/dementia, their informal caregivers, GPs, and the community.

Methods: Nine dyads (person with memory problems/dementia plus caregiver) were recruited through local GP practices and dementia support organisations. The people with memory problems/dementia attended cognitive stimulation therapy (CST; 7 weeks), and physical exercise, partnered with older adults from the community (8 weeks). Caregivers attended dementia education sessions (6 weeks). Individual dementia education sessions were delivered to GPs and the community. Intervention processes (e.g., recruitment, content, delivery, data collection methods) were evaluated through qualitative (verbal feedback, interviews) and quantitative methods (ratings, questionnaires).

Results: Dyad recruitment through GP practices fell below target; outreach through local organisations was successful. High attendance (95%) and adherence to programme content (80-90%) were maintained throughout the intervention; secondary exercise elements were not feasible due to low adherence (home diaries: 35%; Fitbit: 67%). The people with memory problems/dementia found the CST activities and physical exercise acceptable, and particularly enjoyed the social aspects (e.g., group "banter", exercising with partners). Caregivers found the education useful and enjoyed sharing their experiences with each other. Attendees at the dementia education sessions found the content acceptable. Programme facilitators confirmed the intervention content was feasible (e.g., content delivered, feedback collected, and measures completed as planned). Minor intervention changes were recommended; where possible, these were implemented immediately for the benefit of the current participants.

Conclusion: The CREST intervention was feasible and acceptable to participants. However, significant difficulties with recruitment impacted the viability of delivering the intervention, and these must be overcome before a full-scale or RCT can be conducted.

QOP2-10. Care needs and wishes of patients with vascular cognitive impairment and their informal caregivers: a qualitative study

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Amsterdam UMC - location VUmc

Background: Post-diagnostic care for cognitively impaired individuals is often tailored towards patients with Alzheimer's disease (AD). However, patients with vascular cognitive impairment (VCI) exhibit different, distinct symptoms, like reduced cognitive speed and mood symptoms. These symptoms require other care directions and potentially increase caregiver burden, especially when unmet.

Objective: This study aimed to identify care needs and wishes of patients with VCI and their informal caregivers.

Methods: We employed a qualitative approach to the research question. We included patients who received a VCI diagnoses at the outpatient geriatric memory clinic of the Amsterdam UMC. With purposeful sampling, we gathered information on thirteen unique patients: age range 63-91, five females and seven patients with dementia. Eighteen interviews (patients n=9, caregivers n=9) were audiotaped and transcribed verbatim. We analyzed the data using inductive thematic analysis. In this abstract, we present the first results after initial analyses.

Results: We identified overarching and separate themes for patients and informal caregivers. Overarching themes were 1) awareness and utilization of care facilities, 2) need of information on VCI diagnosis and prognosis, 3) importance of informal care infrastructure and 4) hands-on attitude of health care professionals. Patient specific themes were 1) relative absence of care needs, 2) wait-and-see attitude and 3) need to feel valuable. Caregiver specific themes were 1) importance of appropriately timed interventions, 2) caregiver burden and ability to host care and 3) mediating role of behavioral changes in the patient.

Conclusions: Patients with VCI and their informal caregivers are often unaware of available treatment options and struggle to construct an image of the VCI diagnosis. Providing more and continued information on the VCI diagnosis, appropriate timing of care, taking the non-linear progression of VCI into account, and hands-on attitude of professional caregivers could ensure more utilization of care by VCI patients and their caregivers.

QOP2-11. A mixed-methods process evaluation of an advance care planning intervention in nursing homes

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Background: ACP+ is a theory-based 8-month multicomponent intervention to implement advance care planning (ACP) in nursing homes. In a cluster RCT, ACP+ showed to increase staff's self-efficacy in performing ACP albeit to a smaller extent than expected; ACP+ did not increase staff's ACP knowledge.

Aim: To evaluate implementation, mechanisms of impact and contextual factors affecting implementation and outcomes of ACP+.

Methods: Mixed-methods process evaluation alongside the RCT in 7 intervention nursing homes, out of 14 participating homes in Belgium (ClinicalTrials.gov NCT03521206).

Management, staff and trainers participated. We evaluated weekly trainer diaries, post-training surveys and attendance lists during implementation, and facility-level data and interviews post-intervention (n=32).

Results: Regarding implementation, 33% of staff was trained on average (range 6%-69%, low to moderate reach); at least 13 of 17 intervention components were implemented as intended in each home (fidelity); 13 types of adaptations were made, mostly related to the training sessions (adapted) and audit (removed). Micro- (e.g. motivation) and meso-level (e.g. coordination) mechanisms impacted implementation. Participants perceived ACP+ to increase staff engagement in ACP and awareness about its importance, and to lead to more structured ACP procedures. However, on-the-job learning experiences were too few. Most important contextual factors were lack of time and resources, staff turn-over and management buy-in.

Discussion: ACP+ was well received and participants highlighted positive effects (e.g. increased ACP awareness) which were not reflected in the RCT results. The lack of large effects on ACP self-efficacy or knowledge may be explained by staff's low to moderate reach in trainings, too few on-the-job learning opportunities, and contextual difficulties. Based on these results, we propose to adapt ACP+ and its theoretical framework to optimize the intervention and its further evaluation.

QOP2-12. "At first, I thought it makes no sense. But then I began to like him" – Results from a scoping review on acceptance of social robots in nursing homes

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Background: Social robots are increasingly used in care provision for older adults, and in particular for people with dementia. Research on the acceptance of social robots is highly relevant in this evolving research field. The Almere model of acceptance is developed specifically to capture the acceptance of social robots, which differ from other technologies, as they are embodied social actors socially interacting with humans. This scoping review synthesizes the literature on acceptance of residents and staff in nursing homes.

Methods: We have conducted a scoping review systematically searching PubMed, PsycInfo and CINAHL in August 2020, updated in June 2021. The Almere model of acceptance and its constructs has defined our search strategy, search string, data extraction and guided the narrative synthesis of the results.

Results: The 16 papers included in the review provided results on all constructs of the Almere Model. The majority of the papers (12) focus on residents with dementia. Especially attitude, perceived usefulness, perceived ease of use and perceived enjoyment were frequently studied, whereas perceived adaptivity and trust were rarely studied. We will focus the presentation on the results with regard to how residents and staff perceived the usefulness and sociability of the robots. Perceived usefulness is discussed in a majority of the papers both from the perspective of staff and of residents. Perceived sociability is interesting, as it is a concept specifically developed to understand the acceptance of social robots.

Conclusion: The Almere model of acceptance is useful to understand the acceptance of social robots in nursing homes. There are many different forms of perceived usefulness facilitating the acceptance of social robots, such as reducing loneliness and stimulating communication and activities. Regarding perceived sociability, the literature reports residents having fun with the robot, the robot providing friendship and the robot opening up for communication.

QOP2-13. Olfactory stimulation in dementia care: a rapid review

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Background: There is a growing interest in using olfactory (smell) stimulation in dementia care. This is due to the well-documented unique relationship between olfaction, memory, and emotional processes at the level of brain anatomy. Although the increase in popularity in clinical practice, limited studies evaluate the effectiveness of olfactory interventions.

Aims: This study aims to extend current knowledge by synthesising the evidence on the efficacy of interventions using olfactory stimulation for people with dementia, and to assess the effects of different types of odours and administration methods using a mixed methods approach.

Methods: The rapid review was conducted based on searches in six electronic databases. Eligible studies were assessed for methodological quality and synthesised using a narrative approach.

Results: A total of 20 studies were included in the review, exploring the effects of olfactory stimulations in relation to three main domains: responsive behaviour, cognitive functions, and physical functioning, including sleep, appetite,

and balance. High heterogeneity was found on odours and methods of application used, with the majority of studies administering lavender oil using a diffuser. Mixed results were reported on the benefits of olfactory stimulation on responsive behaviours and cognitive function. Although the evidence available is limited, encouraging results were found regarding olfactory stimulation and increased sleep duration, food intake and balance.

Conclusion: Although high heterogeneity in this review limited clear conclusions, the results of the included studies are consistently in favour of the use of olfactory stimulation as a non-pharmacological intervention for people with dementia. Future research should systematically investigate the conflicting outcomes reported, by clarifying why and how olfactory stimulation works. Qualitative investigations are warranted to provide further insight into the experience of olfactory stimulation and any factors associated with positive outcomes.

QOP2-14. Facilitators and Barriers of the Implementation of a Personalised Integrated Stepped Care Approach to prevent or treat Neuropsychiatric Symptoms (the STIP-Method)

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Introduction: Most people with dementia in nursing homes show one or more neuropsychiatric symptoms of dementia (NPS). Two consecutive Dutch Health inspectorates in nursing homes showed a late, inadequate or incorrect response to NPS. Three proven effective approaches have joined forces to develop one combined intervention, the STIP-Method: the personalised integrated stepped care approach to prevent or treat NPS. We implemented the STIP-Method, supported with a web application in two nursing homes (N=240) with the aim to investigate facilitators and barriers for implementation.

Methods: The implementation of the STIP-Method is done by means of sounding board groups including informal caregivers, care professionals and managers. Qualitative data on facilitators and barriers were extracted from 61 transcripts. Quantitative data about the extent of implementation were extracted from patient records (n=240). Results: Qualitative analysis points towards the following facilitators: external incentive; acknowledgement of difficulties in managing NPS; acknowledgement for the need of a more integrated approach; leadership; ownership and collaboration. Barriers include a lack of notion about the costs and benefits of the STIP-Method; insufficient support from managers and a less-methodological workflow. Quantitative analysis shows multiple deficits in clinical reasoning e.g. the absence of an integral interdisciplinary goal attainment plan.

Key conclusions: Both qualitative and quantitative demonstrate difficulties in the implementation of the STIP-Method. First of all, nursing homes need an external nudge to start working differently and more effectively to prevent or treat NPS. Secondly, insight in barriers and facilitators for working more effectively is a prerequisite for nursing homes to pinpoint the bottlenecks and subsequently counteract them. For a successful implementation of the STIP-Method, (1) a truly integral approach, (2) a consistently methodological way of working, and (3) clear management (including the CEO) to steer the former two, are shown to be both crucial and lacking in the nursing homes.

QOP2-15. My Future Wishes

Bindi Dhesi

Alzheimer's Society

Alzheimer's Society was commissioned to engage with people affected by dementia on how to best initiate conversations relating to planning for the future, often known as Advance Care Planning (ACP). Currently people affected by dementia are not effectively supported with such conversations. When a person becomes unwell or is admitted into hospital or care establishment, decisions relating to that person's care and treatment are made under pressure by carers who have little or no knowledge of what is available or the decisions are taken by health and social care professionals.

We created an online survey attracting national responses from people affected by dementia, sharing their views and experiences around difficulties of having conversations about their future.

We held four workshops across West Yorkshire and Harrogate consulting on; where in the journey they would like to have conversations relating to ACP, who would they want to involve in those conversations and what exactly they want to talk about. With this information we looked at the available samples of resources that provided information on ACP and captured workshop attendees views. We produced a prototype of the resource and captured suggestions on what was missing and what should be included. All workshop attendees were consulted on what to name the resource, knowing 'ACP' is not easily understood.

Our biggest outcome was the resource, 'My Future Wishes Conversation Starter Pack' piloted by Alzheimer's Society Staff and external stakeholders within three Local Authority boroughs providing a spread of urban, rural and demographic diversity. Covid-19 and national lockdown affected piloting timescales. The resource is available electronically, enabling complete online access. The resource is promoted by stakeholders highlighting the importance of discussions around future planning now more than ever due to the pandemic. It supported the need to ensure conversations are had and handled with upmost sensitivity.

QOP2-16. The Dementia Pathway

Kielan Arblaster

Alzheimer's Society

At Alzheimer's Society, we campaign for better care, support and system reform, knowing from people affected by dementia the number of issues they face in their fight against the disease. This includes hurdles at various points of the dementia pathway. From diagnosis to death, people are navigating a disjointed system that fundamentally doesn't

work as well for them as it does for people with other conditions. People with dementia and their families are therefore left to fight for the care to which they are entitled, whether it meets their needs or not.

While research continues to strive for a cure in the future, and treatments and models of care to support people in the shorter term, this does not negate the need to take action and focus on what should be done now – stopping people falling through gaps in the current system and improving quality of life.

Our report, 'From diagnosis to end of life: the lived experiences of dementia care and support', forms the first output of a long-term project we are undertaking on the dementia pathway. It analyses the gaps between what care and support current guidance and legislation affords people living with dementia and what they are receiving. A recurring theme throughout people's experiences is a sense of disjointed, fragmented care. The report sets out a roadmap of how we can achieve change. The recommendations to national and local health and social care actors will address the current care and support needs of people living with dementia.

Our next output will focus on diagnosis, exploring the reasons behind why people with dementia face inequalities in accessing a diagnosis. We will set out recommendations for how to increase diagnosis rates for people within Black, Asian and Minority Ethnic communities, address regional variation, and increase diagnoses within care homes.

QOP2-17. Psychosocial interventions for people with dementia: a guide to improve knowledge, understanding and implementation

Jean-Bernard Mabire

Fondation Médéric Alzheimer

Introduction: Psychosocial interventions are essential for people with dementia. In practice, implementation difficulties may be present, and interventions are not always adapted to the needs and difficulties of people with dementia. The Fondation Médéric Alzheimer proposes a guide to improve knowledge, understanding and implementation of psychosocial interventions.

Methods: This guide was developed in four steps. 1. A survey of French professionals to determine whether this guide meet a real need. 2. Selection of interventions. 3. Writing of the chapters presenting the interventions. 4. Chapters' adaptation to people living with dementia and family caregivers.

Results: 1. The survey confirmed the need for such a guide to better understanding psychosocial interventions to better targeting them according to people with dementia needs. 2. The interventions presented were selected based on scientific evidence of their positive effects: Adapted physical activity; Animal assisted interventions; Art therapy; Cognitive rehabilitation; Cognitive stimulation therapy; Dance-based interventions; Horticultural therapy; Multisensory stimulation; Music therapy; Reminiscence therapy. 3. For each intervention, an expert wrote a chapter according to a model: presentation, theoretical backgrounds, scientific evaluation, implementation and practical advice. Chapters have been reviewed by another expert and by professionals and academics not experts of the interventions. The guide also provides tables based on different functions for which interventions have been scientifically shown to have positive effects. 4. The chapters of the guide have been adapted into factsheets with the contribution from people with dementia and family caregivers to provide them suitable information for a better knowledge and understanding of the interventions available to them.

Conclusion: This guide is the result of collaborative and participatory work between professionals, academics, people with dementia and family caregivers. It is not a substitute for the training required to carry out these interventions, but rather provides theoretical and practical knowledge to better implement them.

QOP2-18. Disclosing a diagnosis of young onset dementia: a best practice model

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It has long been recognised in research literature that people aged under 65 years with suspected dementia experience significant difficulties acquiring appropriate assessment and a timely diagnosis.

The disclosure of a diagnosis of a dementia to a person with a young onset dementia is often complex as they are more likely to have a rarer subtype of dementia, symptoms can often be non-memory related and there is a higher likelihood that the dementia is linked to a genetic or metabolic disease. How a person experiences disclosure can have a long-term impact on their experience of dementia. Immediate post-diagnostic advice and support options can differ. Younger people may have dependent children, be in employment and be financially supporting the family. There can often be increased carer stress and relationship difficulties to address.

It requires considerable skill and expertise to deliver a diagnosis of dementia in a way that is both honest and respectful, using accessible language that the person and their supporter/carer can understand. Delivering a diagnosis of young onset dementia in this manner requires advanced preparation including: sourcing appropriate written information; securing an appropriate environment for the disclosure and; protected time with a doctor and health and social care professional.

During the disclosure itself close attention needs to be paid to: how the diagnosis is communicated to the person; how to manage the emotional response to the diagnosis; giving realistic hope for the future and; providing pertinent post-diagnostic information and advice. It is hoped that by adopting this style of approach we can improve the experience of diagnosis for people and equip them with the appropriate information and supports to enable them to manage their lives going forward.

The information presented forms part of the Irish Dementia Model of Care (National Dementia Office, forthcoming).

QOP2-19. 'Some Dance to Remember': The psychosocial effects arising from the introduction of an adaptive Irish Céilí dance programme for people with dementia and their carers

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This presentation summarises the psychosocial effects arising from the introduction of a pilot adaptive Irish céilí dance programme for people with dementia and their carers. This two-year interdisciplinary arts-based Masters by Research project was led by a social care professional with a limited background in Irish dance. The céilí dance programme took place in a dementia day care/respite centre based in the mid-west region of Ireland between November 2019 and February 2020. Dances were adapted through a process of collaboration to reflect participants' levels of mobility, agility, cognitive skills and confidence. Semi-structured interviews with people with dementia and professional care staff were conducted before, during and after the dance programme. All interviews were transcribed and viewed through the lens of thematic analysis to facilitate an in-depth examination of emerging themes arising from the lived experiences of the participants. As the research programme has now reached a conclusion, it is appropriate to reflect on both the research process and outcomes, and answer such questions as:

What were the key psychosocial effects arising from the dance activity for people with dementia and their carers?

How can the pilot adaptive céilí dance programme be rolled out on a more formal basis throughout the mid-west region of Ireland and further afield?

What opportunities for future research in the area of adaptive Irish céilí dance for people with dementia and their carers remain to be explored?

QOP2-20. An observational study of personal care interactions with people with advanced dementia in family and care-home settings

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Background: People in the later stages of dementia often require assistance with their personal care. Due to factors such as difficulties understanding and communicating, some personal care interactions can be difficult for carers and people with dementia.

Aim: To examine personal care interactions with people with advanced dementia in family and care-home settings to enable learning from each setting to inform educational resources.

Methods: One-off video-recorded observations of personal care interactions with a person with advanced dementia (when the person was covered, such as teeth cleaning) in family and care-home settings. Five family carer/relative dyads (12 interactions) and nine care-home staff/resident dyads (14 interactions) were observed (total observation time 03:01:52; family 01:20:37, care-home 01:41:15). Analysis used the resistance-to-care scale (RTC-DAT) and the Menoh Park Engagement Scale (MPES). Two researchers independently rated observations. Observations and transcripts were also thematically analysed.

Findings: Resistance-to-care was present in 42% family observations and 21% care-home, with pushing away and saying no most common. In 58% family and 79% care-home observations people with dementia participated in the target care activity for over half the observation. People with dementia expressed pleasure in 58% family and 50% care-home observations and discomfort in 42% family and 29% care-home observations. Both care-home staff and family carers demonstrated understanding of the person's care needs and used a range of techniques to make care acceptable and to engage the person in their care such as endorsing the person's actions, partnership working, and using humour.

Conclusion: Although, discomfort and resistance can occur in personal care interactions in advanced dementia, there is also scope for pleasure and engagement. The findings provide much needed insight into ways to improve care experiences for people with dementia. Appropriate training/guidance for care-home staff and family carers could support more engaged and pleasurable care experiences for people with dementia.

QOP2-21. Enhancing dyadic interaction of persons with behavioral variant frontotemporal dementia and their carers. A qualitative change evaluation of video feedback at home

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Background: Due to progressive loss of social cognitive abilities, persons with behavioral variant frontotemporal dementia (bvFTD) and their carers have a high reported need for psychosocial support in everyday life, especially in creating mutual understanding. In a previous mixed-methods feasibility study, we focused on supporting dyadic interaction and applied video feedback according to Marte Meo® in five participating dyads at home.

Objectives: In the qualitative strand, we aimed to explore a) intuitive patterns of dyadic interaction, b) similarities/differences to the interaction elements of the applied intervention, c) visible changes in dyadic interaction before and after the intervention.

Design and Methods: The embedded qualitative change evaluation was part of the pilot effect study of the mixed method approach. We used videography based on focused ethnography for data collection. A video was taken of each dyad at a shared meal before (t0, t1) and after the intervention (t2) using a fixed camera. The intervention, delivered by a trained therapist, took place five times in a weekly session. Video data were annotated using the Eudico Linguistic Annotator (ELAN) and analysed using video interaction analysis.

Results: We identified enabling, habitual and restrictive strategies of the carers who mostly took the lead to create mutual and shared actions during mealtime, while the persons with bvFTD initiated actions through explicit body language. As video feedback according to Marte Meo® focuses predominantly on succeeding interaction, we found similarities but also differences in the modes of interaction. Dyads that started at a less common level of interaction improved the most.

Conclusion: Mutual attunement and sensitive interaction skills are prerequisites for achieving interaction in dyadic care situations. Video feedback is a promising tool to improve mutual understanding and should be evaluated in a confirmatory study, transferred to different settings in dementia care and strengthened by an international network.

QOP2-22. Music Mirrors: investigating an adaptive intervention supporting the activities of daily life for people living with dementia

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¹University of Zurich, Center for Gerontology, ²Come Singing & Music Mirrors

Introduction: For each one of us the deeply embedded sound track to our early years - scraps of sound, music or words long forgotten - can trigger feelings and memories and bring the past to life.

Method: In 2017 Zurich University together with the URPP 'Dynamics of Healthy Ageing' began a four-year investigation of Music Mirrors, (Musikspiegel) a simple idea to capture and store positive memories and associations by linking them to sounds or music. The project examined the feasibility of making and implementing Music Mirrors in residential dementia care, hospitals and domestic settings in Switzerland, and assessed their effectiveness in easing the activities of daily life eg mobilisation, hydration, social integration, and their impact on caregivers.

Results: Findings concluded that Music Mirrors could form a useful practical addition to care plans for people living with dementia and a means of building bridges of understanding between carers and cared-for.

Oral Presentation with filmed vignettes: This oral presentation presents and illustrates those findings with filmed vignettes of Music Mirrors in use in Switzerland.

QOP2-23. Movement for Change – Sport England and Alzheimer's Society Partnership

Steve McFadyen, Jenna Peel

Alzheimer's Society

One in four people in England are living with a long-term health condition. For these individuals, being physically active can help manage their conditions and symptoms, as well as reduce the risk of other comorbidities. Despite this, individuals with a long-term condition are twice as likely to be inactive compared to the general population. This figure is higher for people living with dementia specifically, with research suggesting that over 80% are inactive.

Since 2018, Alzheimer's Society has partnered with Sport England to ensure people with dementia are supported to continue doing the physical activities they enjoy and reduce levels of inactivity. In February 2019, we launched the Dementia-friendly Sport and Physical Activity Guide to encourage organisations to become dementia-friendly. This guide provides clear recommendations and case studies that highlight best practice examples in this area and enable people to lead healthier, active lives. Implementation of the guidance has shown an increase in; people talking about dementia to reduce the stigma around it (60%), people accessing physical activity services (43%) but also an increase in the motivations of people affected by dementia to lead more active lives (48%).

The next partnership phase launched in June 2021 and begins with a comprehensive evidence review to provide the foundations for an evidence based physical activity strategy for dementia and to identify gaps in the research. Further insight gathering on the barriers and motivators to physical activity for people with dementia will be used to work with Alzheimer's Society's award-winning Innovation team to drive ground-breaking thinking and develop creative solutions to these challenges. Solutions will focus on helping people affected by dementia to become and stay active through adding more movement into their daily routines in a way that works for them.

QOP2-24. Creating a website for people with dementia

Andrea Oostijen, Yvonne Koster

Alzheimer Nederland

Goal: Alzheimer Nederland aims to help people with dementia (pwd) online by contributing to their self-esteem, self-efficacy and by increasing their independence for as long as possible. Consequently dementie.nl created a website that pwd can use independently, meeting the needs of people with dementia in a user-friendly environment.

Method: Firstly, we studied the needs of pwd regarding information websites and we investigated their ability to use digital services:

We tested the online activity and ability of 5 pwd in an early stage. All 5 still used the internet, preferably on a tablet.

Based on different research reports we found the best ways of digital communication for pwd in an early stage. The research also enhanced the most relevant topics that pwd need in order to stay independent.

With the outcome of these investigations, we started a Design thinking process to make a prototype for the website. The prototype was tested with individual face-to-face interviews with 11 pwd.

The test results were integrated in the final design, topics and content forms.

Results:

- A post-diagnostic website with a calm design, easy navigation, for pwd to use independently

- Comprehensible content in different forms: oral and text
- A website integrated in dementie.nl (1 million visitors per year)
- A clear and simple onboarding

Conclusion: We created a user-friendly website for and with people with dementia to help them keeping their independence for as long as possible, to strengthen their self-esteem and their self-efficacy.

The website is live since April 2021 and has had more than 8.000 visitors in the first 3 months.

Curious? Please visit www.dementie.nl/ikhebdelementie

QOP2-25. Improving dementia care through self-experiences: a scoping review

Anja Bieber, Juliane Stubner, Manuela Grünzig, Fabiola Böhm, Fabian Wilde, Gabriele Meyer

Martin Luther University Halle-Wittenberg, Institute of Health and Nursing Sciences

Every professional involved in dementia care should gain a sound understanding of the impact of dementia to anticipate the care that is required. One way to improve the understanding is to try to experience for yourself what it is like to live with dementia and to see the world from the perspective of the person with dementia. For this purpose, innovative technologies such as virtual reality interventions (VR) and virtual dementia tours (VDT) are becoming increasingly important. An investigation that gives an overview of the current self-experience practices in the literature seems to be worthwhile.

We conducted a scoping review as a part of the Improving dementia care Through Self-Experience (INTenSE) project. INTenSE is a European project (DE, IE, IT, NL), funded by the ERASMUS+ program, aimed at supporting professionals and informal caregivers by means of innovative learning approaches and the use of ICT tools that explore the lived experience of people with dementia.

The scoping review aimed at providing an overview of self-experience practices in dementia care. The search covered the databases PubMed, CINAHL, Web of Science and Cochrane. Publications in the English language between 2010 to 2020 were included. We analysed the investigated self-experience practices and summarised the findings narratively.

A total of 31 studies were included, of which 15 studies had quantitative designs, n=10 had qualitative designs and six had a mixed methods design. The studies covered several self-experience practices, i.e. VR interventions, movies, games, complex interventions, non-virtual simulation exercises, theatre interventions, role-playing, and VDT interventions. The investigated self-experience practices varied in terms of dementia-related knowledge or empathy towards people with dementia. No simulation will ever fully allow participants to understand the lived experience of dementia. The self-experience practices or simulation exercises should complement rather than replace other strategies of improving the understanding of people with dementia.

QOP2-26. A co-ordinated approach to post diagnostic support: The Critical Success Factors

Lynn Flannigan¹, Jill Carson²

¹Healthcare Improvement Scotland, ²Alzheimer Scotland

Based on data suggesting people referred for diagnosis frequently present at a more advanced stage of dementia, 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). The impact of COVID has exacerbated this, with a 25% drop in the number of people receiving a dementia diagnosis in Scotland in 2020/21 compared to 2019/20. Individuals referred for PDS with more advanced illness are likely to have co-morbid conditions. This, added to the social factors that have been impacted by the pandemic, means that co-ordination of care is critical to avoid negative outcomes such as early admission to long-term care and crisis hospital admissions.

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. Our approach 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. 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 organisation. 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.

QOP2-27. Keeping the balance: What makes a good dementia telephone helpline?

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Caring for a person with dementia imposes a huge cognitive, psychological, physical and economical burden on family carers. Among other forms of support, dementia counselling telephone helplines have been developed as a low-threshold response to the carers' very diverse needs. Previous research has shown that the major tasks of counselling helplines include information about dementia, navigation through the complex health and social care systems, psychological support, individual problem solutions, suggestions for behavioural management and targeted referral

to local sources. In the present study we tried to determine how well counsellors manage to provide these deliverables. To that end we designed a qualitative study that followed a participatory two-step approach. In a first step, we conducted two focus group interviews with family carers of people with dementia as potential users and asked them to discuss quality criteria for a dementia counselling helpline. From their answers we concluded that the art of helpline counselling is to master several balancing acts – such as keeping the delicate balance between providing too much and too little information, exaggerating or simplifying the problem presented and acting too professional or too personal. In a second step, we applied their answers as yardstick to the records and transcripts of 63 counselling sessions provided by the “Alzheimer Telefon” of German Alzheimer Association. The thematic analysis of the counselling sessions showed that helpline counsellors possess various techniques to master the balancing acts – such as untangling of unclear or overcomplicated questions of a caller. We identified off-balance-instances in which, for example, the counsellors overwhelmed the caller by providing too much information. However, for the most part, we found counsellors to choose their techniques according to the individual needs of the caller and the type of request.

QOP2-28. Development of the Fotoscope App: A tool for creating meaningful connections between nursing home residents with dementia and their carers

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Aim: The study aimed to develop the web-app, ‘Fotoscope’- a tool to deliver a Fotoactivity-intervention, facilitating meaningful social interactions between (in)formal carers and nursing home residents with dementia through conversations centered around generic artistic photographs, related to the residents’ personal interests. This study is funded by the EU and conducted within H2020-MSCA-ITN-2019 (DISTINCT; grant number 813196).

Method: The researchers worked with the visual artist who composed the photo-database for the Fotoactivity (Theijssmeijer et al., 2018), (in)formal carers of people with dementia, people with dementia themselves, ICT professionals, and experts in the field of psychosocial-care in dementia. Since May 2020, online (due to Covid-19) project group meetings and three user-feedback groups were held to decide on the categorization of the photographs in the Fotoscope, user requirements and app functionalities, app name, and overall design.

Results: In December 2020, the feasibility of delivering the Fotoactivity in the nursing homes using the Fotoscope was examined through user-tests. An online protocol was implemented due to the pandemic. 2 formal carers, 1 informal carer and 4 residents with dementia were recruited. Students and researchers observed the interaction between residents and carers via online video-calls. (In)formal carers evaluated their experience of using the Fotoscope via the System Usability Scale (SUS). SUS results showed that carers agreed it would be easy for most people to understand how the Fotoscope works, they felt confident using it, found it easy to use, and would like to use it often. Carers also reported that residents reacted more actively and positively to the activity than expected and appreciated the photos.

Conclusion: As the online protocol proved feasible and user-tests positive, the study is currently continued by an explorative randomized evaluation trial on a larger scale with two care organizations in the Netherlands, with completed data collection expected by June 2022.

QOP2-29. Conducting Site Evaluations to Inform a new Community Model of Palliative Care for People with Dementia

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Background: Palliative care is suitable for anyone with a life-limiting illness, including people with dementia. It addresses physical, psychological, social, and spiritual needs, and is suitable from diagnosis until the end-of-life. Ideally, palliative care will be delivered in a community-based model, as most people with dementia wish to remain at home. A pragmatic mixed-methods project is informing the development of a new service-delivery model for dementia palliative care for the Irish healthcare system. The aim of the current sub-study is to robustly evaluate existing services to inform this new model.

Methods: A survey targeted at dementia and palliative care experts in Ireland and the United Kingdom identified exemplar services. Using purposive sampling, with a maximum variation strategy, four “model” services were selected for evaluation. Data collection included interviews, focus-groups, and questionnaires with service providers and service-users, and routinely collected data. Each service was described with a logic model. Services were then compared using the RE-AIM framework.

Results: The four services were organised very differently: some were led by Specialist Palliative Care, others by Psychiatry of Old Age; some prioritised “early” referrals, others focused on the last year of life. There were however common elements to the success of a service, including: a “key worker” to link the person with dementia and their families with all relevant services; frequent holistic needs assessments; Advance Care Planning; specific psychological and social support for families; education for all multidisciplinary team members on palliative care; equipment to support care at home for those with advanced dementia.

Conclusion: This in-depth evaluation revealed core components, and the critical activities, of a community model of palliative care for people with dementia. A new service model will need to be flexible, as its success depends on local resources and champions, rather than a focus on a prescriptive organisational structure.

QOP2-30. Advance care planning for people with dementia

Susanne van den Buuse

Family caregivers who feel prepared for future changes, experience a lower care burden. In this preparation for the future, also known as advance care planning, the dementia case manager (a professional trained as a nurse or social worker, and specialized in dementia care) plays a key role. Also, when care professionals provide enough information about care and support in the last phase of life and discuss this with family caregivers, the latter experience this last phase more positively. I will share these and other important findings from our new factsheet "Advance care planning with dementia" in this presentation.

Advance care planning is understood to be an essential part of good care. This is especially the case for dementia, because this is a progressive disease, characterized by the loss of the ability to utter wishes and needs. This is why the recently revised Care Standard for Dementia (Zorgstandaard Dementie) urges care professionals to start advance care planning immediately after the diagnosis. In practice this entails discussing topics with the person with dementia and their family caregivers like future behavioral changes, moving to a nursing home, who gets power of attorney, and their thoughts about the end of life and euthanasia.

Although the importance of advance care planning is evident, the Dementia Monitor 2020 shows that it is not yet common practice. Together with Nivel, the Dutch research institute for care research, Alzheimer Nederland developed a factsheet based on the findings of the monitor to underline the importance of advance care planning with dementia to care insurance companies and care providers. More advance care planning will enable more people with dementia and family caregivers to cope with their life with dementia in a better way.

QOP2-31. Delivering High Quality Post Diagnostic Support During the Covid-19 Pandemic - Alzheimer Scotland

Julia Mackenzie, Janice Stewart

Alzheimer Scotland

The Scottish Government has a commitment that everyone diagnosed with dementia will receive a minimum of 12 months Post Diagnostic Support (PDS). Alzheimer Scotland Link Workers work with Health & Social Care Partnerships to deliver this service using the Alzheimer Scotland 5 pillar model.

Prior to the pandemic, PDS was delivered in the person's home. It also incorporated face to face groupwork.

The challenge was how to continue to deliver high-quality personalised PDS when we could no longer visit in person.

Within days of the first lockdown, 70+ Link Workers received training in how to use different digital platforms. Regular contact was maintained with those receiving PDS, using digital platforms where appropriate, and telephone calls where not.

PDS information support groups and peer support groups were delivered online. This was a new way of working for everyone: those delivering the groups and those attending. The people we supported were understanding, and very grateful for the service offered during such very difficult times for them.

Link Workers helped source digital devices for many people, enabling them to learn new skills, and access support previously unavailable to them.

Key Findings: PDS can be delivered in different ways using a blended approach of digital and personal contact where appropriate. Delivering digitally can increase accessibility for some people, particularly in rural areas, or for those with mobility issues. A blended approach will be offered in the future increasing access for all.

In conclusion Alzheimer Scotland Link Workers have continued to deliver high quality PDS to those they were already supporting, and to people newly diagnosed during the pandemic.

A blended approach of face to face contact where appropriate, combined with digital support and telephone support, will be how PDS is offered in the future.

QOP2-32. Evaluating the Dutch RHAPSODY program: a web-based educational and skill-building program for caregivers of persons with young-onset dementia

Maud Daemen¹, Jeroen Bruinsma¹, Christian Bakker², Rob Groot Zwaafink³, Raymond Koopmans², Andrea Oostijns³, Frans Verhey¹, Marjolein de Vugt¹, Kirsten Peetoom¹

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Caregivers of persons with young-onset dementia (YOD), defined as symptom-onset before 65 years, express an explicit need for tailored support and information about YOD. Therefore, the European RHAPSODY project developed a web-based educational and skill-building program for these caregivers. The program provides information on managing behavioral changes due to dementia, dealing with role change, and available support. A pilot RCT conducted in England, France, and Germany showed good acceptability and feasibility of the program. This study aimed to tailor the program to the Dutch context and evaluate the free-access Dutch version of the RHAPSODY program in terms of user acceptability and satisfaction.

A cross-sectional mixed methods study was conducted. Web metrics explored user behavior. A short pop-up survey, an extensive survey and semi-structured interviews assessed user acceptability (range 1-7) and satisfaction (range 1-5) among caregivers and healthcare professionals. Quantitative data were analyzed with SPSS statistics and qualitative data were evaluated using Atlas-Ti.

In total, 10.830 page views were registered. Preliminary results showed that user acceptability scored a 6.0, and opinions regarding satisfaction with the program, including its relevance (4.5), understandability (4.3), applicability in daily life (4.1), and likelihood of recommending to others (4.3) were very positive. Interviews underlined these findings, emphasizing the necessity and desirability of the program where educational and practical information about YOD are

bundled in one place. Web metrics showed the program remained in use three months post-evaluation, as evidenced by the 6903 page views.

The Dutch RHAPSODY program provides the opportunity to inform caregivers and healthcare professionals on YOD, as results indicate good acceptability and feasibility. Creating awareness among YOD caregivers and healthcare professionals is important because the program proves to be of added value to existing available support, as it meets the need for tailored support and information regarding YOD.

QOP2-33. The potential utility of Acceptance and Commitment Therapy for informal caregivers: a systematic review

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Acceptance and commitment therapy (ACT) is a transdiagnostic and evidence-based approach that shows promise in improving mental health and overall wellbeing. Therapeutic goal of ACT is increasing psychological flexibility rather than symptom reduction. Among various caregiver populations, informal caregivers of people with dementia (PwD) experience the highest rates of depression (43%). Therefore, increasing acceptance through ACT-based interventions may support informal caregivers of PwD with coping skills and reduce their perceived burden. Despite of rapid rate of growth in ACT studies, a comprehensive overview of ACT interventions for informal caregivers of adult patients is still missing.

This systematic review examines the feasibility, clinical effectiveness, quality of evidence, and mechanisms of change in ACT interventions for various informal caregivers' populations. A systematic search of 5 databases (PsychInfo, PubMed, CINAHL, Cochrane, Embase) resulted in 3468 hits. A total of 16 intervention studies met inclusion and were analysed in full text. Six studies used ACT in informal caregivers of PwD and 11 studies included informal caregivers of patients with other conditions (e.g., cancer). The Psychotherapy Outcome Study Methodology Rating Form (POMRF) was used to evaluate methodological quality of studies.

Generally, ACT appeared to be feasible and acceptable. Interventions' efficacy varied and negative psychological symptoms (e.g., depression) were most often assessed. Different types of study designs, intervention elements, and populations highlighted the applicability of ACT in context of caregiving and also areas for future research to grow the evidence base. Further ACT studies that include positive psychological outcomes of ACT (e.g., quality of life), especially for informal caregivers of people with chronic conditions, are desirable.

QOP2-34. A co-ordinated and strategic allied health professions approach to rehabilitation in dementia to improve outcomes

Elaine Hunter, Alison McKean

Alzheimer Scotland

Introduction: Connecting People, Connecting Support is the first allied health professional (AHP) evidence informed dementia policy document within the UK with 4 ambitions to transform the AHP contribution to rehabilitation (Alzheimer Scotland 2017, 2020). Research evidence, clinical expertise and the voice of the person with dementia was integrated into the rehabilitation approach in dementia in Scotland.

Objectives: This presentation will debate the emerging evidence base in rehabilitation in dementia and will outline the key elements of implementing a national AHP approach to rehabilitation for the benefit of people with dementia and their families in local services.

Approach: The AHP rehabilitation approach in dementia in Scotland will be shared, outlining

A strategic AHP biopsychosocial model to rehabilitation that integrates research, clinical practice and people's narratives.

A co-ordinated approach to co-design self-management resources available digitally

How AHPs worked collaboratively to provide tailored consultations, advice and or education

The delivery of new emerging evidence based AHP-led interventions, providing personalised and tailored rehabilitation when the need is identified

An improvement approach to evaluate the impact and benefits of the AHP rehabilitation offered to people with dementia

Practice Implications: Lessons learnt when implementing the emerging evidence base in rehabilitation in dementia will be considered, sharing lessons learnt and what this can mean for an international audience.

Conclusion: Rehabilitation in dementia is emerging as a "right" for people with dementia and their families. However, the recognition of the benefits of rehabilitation in dementia is still evolving with many barriers to access timely rehabilitation. We need to work in partnership to ensure rehabilitation is integral to dementia care and available on diagnosis, with the overall aim to increase a person's quality of life and independence while also support a person's hopes, aspirations and dreams.

QOP2-35. Virtual reality for older adults living with dementia: A multi-stakeholder perspective

Aisling Flynn, David Healy, Catherine Houghton, Dympna Casey

NUI Galway

Virtual reality (VR) use in the dementia care landscape is an emerging area which shows promise (Kim et al., 2019). There are a lack of systematic reviews which explore the experiential aspects of VR use across the spectrum of

immersion. The QES aims to address this gap by exploring key stakeholders' experiences and perceptions of VR for older adults living with dementia.

Methods: Qualitative evidence synthesis (QES) was chosen to explore the experiential elements concerning the research aims. QES analyses studies as one unit as opposed to separate studies which strengthens the research findings (Houghton et al., 2016). Thematic synthesis as per Thomas and Harden (2008) was used to analyse the included studies. Several electronic databases, forward and backward citation searching, and hand searching were conducted to identify additional articles. Methodological quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) tool.

Results: 15 reports of 14 studies were included for analysis. Such studies spanned across the spectrum of immersion, clinical settings, countries and stakeholder groups. Analytic themes capture the VR journey for older adults living with dementia. The themes explore: stepping into, immersion in and stepping out of virtuality. The 'Confidence in the Evidence from Reviews of Qualitative research' (GRADE-CERQual) was used to assess the researcher's confidence in the findings (Lewin et al., 2018).

Conclusion: There is a need to design VR spaces which are suited to the dynamic needs of older adults living with dementia. The implementation of VR also plays an important role in one's experience and perception of the technology. There is a need for adequate introduction, facilitation, and reflection on VR use in order to inform future research and implementation.

QOP2-36. WITHDRAWN

QOP2-37. Scaling up a community-based intervention for people affected by dementia: what is the value?

Nathan Stephens¹, Shirley Evans²

¹Nathan Stephens, ²University of Worcester

The Meeting Centres Support Programme [MCSP] provides community-based social, emotional and practical support for people affected by dementia to adjust to the changes dementia brings. Since development in the Netherlands the MCSP has been successfully adapted and implemented in the UK led by the Association for Dementia Studies, University of Worcester. In January 2020, Worcestershire County Council announced £540,000 to scale up the provision of MCSPs across the county: Worcestershire Meeting Centres Community Support Programme [WMCCSP].

The novel county-wide approach will build real capacity, increasing the amount of people accessing post-diagnostic support, integrating services, reducing inequalities, and improving health and wellbeing; fundamental to the COVID-19 recovery plan. This raises questions about the type of the 'value' interventions such as the WMCCSP should seek to achieve, including how it is captured and measured (Redding, 2016). This becomes more relevant when recognising only a portion of outcomes will be related to health, but much of it is likely to support individual and community wellbeing and development. In this context, understanding and measuring 'value' is timely.

A Concept Analysis of value in the context of community-based interventions for people affected by dementia informed a robust and systematic definition to assess the value created and/or destroyed by the WMCCSP. The research will develop strong definitions of value from the perspective of key stakeholders including people affected by dementia.

Social Return on Investment principles will be employed to understand outcomes created and/or destroyed by the WMCCSP for stakeholders and measure them within an endogenous framework that encapsulates what is, per say, valuable. Progress on the process, challenges, and breakthroughs of this innovative and developmental approach will be presented at the conference.

Redding, D. (2016). New approaches to value in health and care.

Worcestershire County Council. (2020). Worcestershire's dementia centres lead the way in supporting sufferers.

QOP2-38. Improving relationship quality between persons with dementia and their informal caregivers with a psycho-educative intervention

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Introduction: Current relationship quality between the person with dementia and their informal caregivers is an important determinant of both persons' well-being and of the caregivers' ability to continue caregiving. Dementia caregiving dyads are likely to experience negative changes in their relationship due to dementia, such as declines in reciprocity, affection, communication or opportunities for shared activities. As reciprocity is difficult to maintain due to the increasing needs of the person with dementia, caregivers need new skills to maintain it and sustain the relationship with their loved one with dementia.

Method: Qualitative semi-structured interviews with 13 informal caregivers were performed before, during and after their participation in a psycho-educative intervention, to collect data on changes regarding the relationship to the person with dementia and intervention components facilitating or preventing these changes.

Results: Having specific knowledge about the disease and its consequences on the abilities of the affected person helps caregivers better understand the behavior of the person with dementia as well as better adapt their expectations and their own behavior to the needs of this person. Adapted interactions allow persons with dementia to respond positively, for example by showing less distress and giving compliments. Other strategies such as sharing experiences with people in similar situations, reframing unhelpful thoughts and distinguishing between changeable and unchangeable aspects of the situation help informal caregivers to "let go" or to act when adapted. Caregivers who do this perceive more calmness which allow them to enjoy the time shared with the person with dementia and to maintain reciprocity.

Conclusion: Helping informal caregivers maintain reciprocity and positivity in their relationship with their loved one living with dementia is essential for both persons' well-being, and we have first evidence that it can be achieved with a psycho-educative intervention.

QOP2-39. Cognitive Stimulation Therapy (CST): An inpatient Speech and Language Therapy (SLT) intervention study

Emma Finch

n/a

Background: Cognitive Stimulation Therapy (CST) is an evidence-based non-pharmacological intervention for people with dementia, typically consisting of 14 structured sessions. CST has a robust evidence base proving its positive effects on a person with dementia's cognitive function and quality of life.

Some studies have shown positive trends towards improved communication skills; however, this has never been the sole focus of studies to date. The intervention is not typically studied by Speech and Language Therapists (SLTs) and has not been widely studied in an acute hospital setting.

Aim: This study aims to investigate whether a modified version of CST, run by an SLT, would result in an improvement in the communicative functioning of participants with a diagnosis of dementia.

Methods & Procedures: A total of 23 inpatients on a specialist geriatric ward with a diagnosis of dementia were included. A single group, pre-/post-test design was utilised. Each participant's communicative functioning was rated using the Holden Communication Scale (HCS) after the first (T0) and last (T1) intervention attended.

Outcomes & Results: A paired samples t-test was completed to evaluate the impact of CST intervention on the participant's HCS scores. There was a statistically significant decrease in HCS scores from T0 (M= 25.5, SD= 10.1) to T1 (M= 16.0, SD= 7.7), $t(22) = 8.4$, $p < .0005$ (two tailed), indicating an improvement in communication. The mean decrease in scores was 9.4 (SD= 5.4), with a 95% confidence interval ranging from 7.1 to 11.8.

Conclusions & Implications: Preliminary evidence was found to support the use of CST in acute hospital settings, with the possibility of utilising the expertise of SLTs to maximise the effects of CST on a person's communicative functioning. Implications for future research and for clinical practice for SLTs in dementia care are discussed.

QOP2-40. Measuring momentary cognition in a memory clinic sample with mild cognitive impairment using the experience sampling method: an exploratory validation study

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Objective: This study is a post-hoc analysis of the 'Monitor-Mi' study aiming to explore the validity of using the Experience Sampling Method (ESM), a structured diary approach, when obtaining momentary data on cognitive functioning in everyday life.

Methods: A sample of memory clinic patients living with Mild Cognitive Impairment (MCI) (n=22) were instructed to complete 8 daily assessments using the ESM for 6 consecutive days, including questions on momentary memory, language, and concentration problems. To assess the validity, the momentary cognition scores were correlated with each other and three clinical assessment tools: the Mini Mental State Examination (neuropsychological screening tool), Deterioration Cognitive Observee (proxy-tool), and Cognitive Failure Questionnaire (retrospective self-report). Additionally, the data will also be explored to identify sub-groups.

Preliminary results: On a group-level, the momentary cognition scores did not significantly correlate with the clinical tools; however, momentary memory, concentration, and language problems correlated positively with each other on a medium to strong level. On an individual level, cognitive fluctuations showed great variation between and within patients. Sub-group analysis will be completed shortly.

Conclusions: Clinical tools and ESM items seem to measure complementary aspects of cognition. The ESM can be of added value to the traditional approach as individual patterns can be explored and allow a fine-grained insight into daily experiences. However, more research is needed for the ESM to be used to its full potential when assessing cognition in memory clinic settings.

Keywords: experience sampling method; mild cognitive impairment; cognition; assessment tools; memory clinic.

QOP2-41. Improving primary care based post-diagnostic support for people living with dementia and their families

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Background: There are widespread concerns over the adequacy of post-diagnostic support and care for people living with dementia and their families. Despite a growing focus internationally on enabling people to live as well as possible with dementia, it is unclear how this can best be achieved within current health and social care systems.

Methods: We conducted literature reviews and extensive qualitative work to inform a new complex intervention based in primary care. This was developed through three phases using the Theory of Change. In Phase 1 a series of scoping workshops reviewed evidence to agree the most promising options to improve post-diagnostic support; Phase 2 focused on how selected options could be delivered and by whom; Phase 3 involved a wider range of stakeholders to check the coherence of the overall Theory of Change and proposed activities and pathways.

Results: Over 100 stakeholders, including the multidisciplinary project team, people living with dementia and their carers, service managers, frontline staff and commissioners took place in face-to-face or virtual meetings. The final intervention comprises three complimentary strands of work focusing on: developing systems, delivering tailored care and support and building capacity and capability. While we anticipate that the emphasis on these strands will vary according to the local context, we believe that attention to all three is needed to achieve sustainable change. A clinical dementia expert will lead the intervention across approximately ten general practices, providing impetus, expertise and support.

Conclusion: The intervention draws on reviews of, and newly generated, research, with a focus on building on existing good practice. The process of intervention development was challenging, and more protracted than anticipated, due to restrictions caused by the COVID-19 pandemic. We are now conducting a pilot study to explore whether the intervention can be successfully implemented.

QOP2-42. Psychosocial interventions in 5 cognitive-behaviour units: results to a European audience

Laëtitia Ngatcha-Ribert¹, Jean-Manuel Morvillers²

¹Fondation Médéric Alzheimer, ²University Sorbonne Paris Nord

In 2019, Fondation Médéric Alzheimer and Gêrond'if (Paris) have surveyed 5 UCC ("Unités cognitivo-comportementales" in French), that is cognitive-behaviour units. These hospital units are specialized in the care and support of people with cognitive disorders, who present productive behaviour disorders. The objective was to gather a better knowledge of the practices of the specialized professionals, the satisfaction of persons with dementia and their families, issues and challenges faced.

Methods: Data were collected through an ethnographic survey, in 5 UCCs in Ile-de-France, based on field observations between June and November 2019 as well as 124 semi-structured interviews with professionals, family caregivers and patients themselves. Our presentation will focus on the cultural shift that has occurred with the introduction of psychosocial interventions (PSI) in hospitals.

Results: Relational care, provided during occupational activities and PSI workshops (games, cooking, gym, Snoezelen, art-therapy, music-therapy, etc.), is expected, and sometimes even required, by the heads of the care teams (nursing assistants, nurses) who traditionally provide technical care. In this physically and psychologically exhausting environment, the solidarity and sometimes the decompartmentalization of roles could be observed, the multidisciplinary team being composed also of professionals of the rehabilitation and of the social field (social assistants).

Nevertheless, "drifts" have been noted: admission criteria not respected, patients with long average lengths of stay, infrequent and non-diversified PSI, etc. Many caregivers complain about patients who do not meet the criteria and therefore cannot participate in psychosocial activities, but whether or not a patient is admitted depends on extra-medical parameters.

Conclusion: This survey, unique in France in terms of extent and scope, shows that issues surrounding PSI are at the heart of these units, which deserve to be rethought. After more than 10 years of existence, the UCCs seem to be at a turning point and need to recover the necessary dynamism.

QOP2-43. Predictors of discomfort with diagnostic disclosure by people with dementia: A cross-country comparison between the UK and the Netherlands

Jem Bhatt¹, Gianna Kohl¹, Rose-Marie Dröes², Majon Muller², Katrina Scior¹, Georgina Charlesworth¹

¹University College London, ²Amsterdam University Medical Centres

Background: Dementia is considered a heavily stigmatised condition leading many people to socially withdraw and not disclose their diagnosis to others. This can result in less access to valuable post-diagnostic support and resources. Although cultural differences in stigma exist, little is known about factors involved in discomfort with disclosing the diagnosis in people with different cultural backgrounds. This study aims to determine predictors of discomfort with disclosing the diagnosis to family and friends in people with dementia across the UK and the Netherlands.

Method: A cross-sectional design was applied. Data were collected through an online survey or face-to-face interviews among community-dwelling people with dementia in the UK (n=40), and as part of an INTERDEM fellowship in the Netherlands (n=40). Data regarding participants' background characteristics, discomfort with disclosure, self-stigma, stigma-related harm and coping resources, concealment of diagnosis and secrecy, and self-esteem were collected. Firstly, Spearman rank correlations were calculated to assess the correlation between measures, while ANCOVA was used to assess differences in the stigma outcomes measures between the UK and Dutch participants. Secondly, to investigate predictors of discomfort with disclosure, data will be analysed by regression analyses, controlling for country differences in background characteristics.

Results: The UK and Dutch sample differed on age and time since diagnosis. UK participants experienced more self-stigma than participants from the Netherlands ($F(1,80) = 4.14$ $p < .05$). Significant positive correlations were found between discomfort with disclosure, secrecy and internalised shame. Next, regression analyses will be conducted and results will be presented at the conference.

Conclusion: Research on diagnosis disclosure and self-stigma in people with dementia is still scarce. This study improves the understanding of disclosure, self-stigma, and related clinical outcomes in a multinational context, thereby informing the development of post-diagnostic interventions to address fear of disclosure and self-stigma in people with dementia.

QOP2-44. Personalised Activation and Motivation for Multidomain Training with the Socially Assistive Robot AMIGO Using a Coach-Companion Framework

Lucas Paletta¹, Sandra Schüssler², Julia Zuschneegg², Gerald Lodron¹, Thomas Orgel¹, Michael Schneeberger¹, Silvia Russegger¹, Dimitrios Prodromou³, Sebastian Brunsch³, Lara Lammer⁴, Sandra Pansy-Resch⁵, Josef Steiner⁶

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There is already a body of work suggesting that Socially Assistive Robots (SARs) - combining user support and social interaction - can effectively improve the lives of people with dementia (PwD). However, most research has been conducted using animal robots, particularly, the evidence of SARs for PwD living at home is not sufficiently evident.

'AMIGO' using the Pepper robot and Tablet-based training combines continuous daily activation as 'Companion' with a 'Coach' component that engages during multidomain training with cognitive and sensorimotor exercises. The Companion entertains with music, dancing and biographic pictures, reminds of dates, and involves into dialogues. The Coach rewards and comforts PwD during exercises. The engagement of the PwD is evaluated with AMIGO's camera based analytics of psychomotor dynamics.

A mixed-method study with randomized controlled trial and complementary interviews using content analysis was performed with an intervention group (16 PwD; IG) using AMIGO and a control group (16 PwD; CG) with exclusively Tablet-based training for three weeks. Data were collected using standardized questionnaires (MMSE, DEMQOL, TUI) and interviews.

The intervention was applied to PwD with 68.8% Alzheimer's dementia with age M=81.9 years (CG: 83.6), MMSE M=19.9 (20.7) and 68.8 % females (81.3%). The comparison of quality of life (DEMQOL) between the groups showed a significantly greater increase using the robot (IG: 5.48, CG: -0.31, p = 0.023). Main qualitative results: Attitude/feelings - PwD reacted mainly positively to Pepper. The PwD found Pepper pleasant and funny. Social behaviour - AMIGO was well received as family member and promoted communication in PwD. Meaningful activities-Music and dance activities stimulated PwD particularly positively.

AMIGO significantly increased the quality of life of the PwD in the robot group. As the additional qualitative results demonstrate, this increase can be attributed in particular to the promotion of communication and social contacts by Pepper.

QOP2-45. Design of a co-developed online resource for people living with dementia, carers and healthcare professionals in the first twelve months post diagnosis (COGNISANCE)

Jane Wilcock¹, Marie Poole², Henry Brodaty³, Louise Robinson², Greta Rait¹, COGNISANCE Team³, Spencer du Bois⁴

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Background: COGNISANCE is a research programme (Australia, UK, Canada, Netherlands, and Poland) in partnership with people living with dementia, informal care partners, healthcare professionals and key national and international dementia organisations and researchers.

We have co-developed a resource to support people living with dementia, carers and healthcare professionals for the first 12 months following diagnosis. This time after diagnosis is when many people feel overwhelmed and under-supported.

Methods: Each country held local workshops with representatives from each stakeholder group. The workshops focussed on the key messages, motivators for information seeking, experiences of dementia diagnosis and post diagnostic support, that were important to the user groups as well as the design.

Results: A generic English language website that can be culturally adapted and tailored to different geographical locations and languages was produced. The workshops determined that the resource should be available online, current, practical, and relevant at a regional and individual level. Personalisation was important for all three key audiences and they can select specific but complimentary topic areas. Individuals can create their own journey and select content that is currently relevant to them at the time. Language, tone, and accessibility for the online resource were essential as was access without individual logins or passwords.

Conclusion: The need for a practical, empathetic and individually tailored resource was identified. The resource is a website that has an individual planning toolkit for the first twelve months following a diagnosis. We will present the content and functionality focussing on how each element reflects the co-developers views on a useful and usable resource to help plan for a life with dementia.

QOP2-46. Feasibility of the SOCAV-in-Primary-Care psychosocial intervention - Lessons learned

Phebe Das, Gerbrich Douma, Hanneke Donkers, Lieve Roets-Merken, Maud Graff

Radboudumc, IQ Healthcare

Background: An increasing amount of studies show that coaching-based methods and practice facilitators play an important role in the implementation of nursing interventions. The psychosocial intervention "SOCAV-in-primary-care" (SOCAV-PC), is a programme based on the Community Occupational Therapy in Dementia programme (i.e. the COTiD (in English)/ EDOMAH programme (in Dutch)) and on the Kalorama-Self-management Training and Coaching programme for nurses. It involves training and coaching for nurses and nurse-assistants to enable them to support persons with dementia (PwD) and their caregivers to maintain or improve their self-reliance, daily functioning in meaningful activities and quality of life. SOCAV was successfully tested in nursing homes and its feasibility is currently

tested in primary care. This study will present the facilitators, barriers and lessons learned during the feasibility study of SOCAV-PC.

Methods: The feasibility of implementing the SOCAV-PC programme was evaluated using the framework of Bowen. Two-weekly meetings between the PwD, informal caregiver and the nurse aimed to create a person-centered approach around the PwD in their daily living environment. The approach requires a collaboration between the informal caregivers and the nurses. Spread over nine months, the informal caregivers and nurses were coached in this person-centred approach by a trained SOCAV-coach. Data was derived from (1) intervention and coaching diaries from the nurses, (2) coaching diaries of the SOCAV coaches, (3) focus groups among nurses, and (4) individual interviews with PwD and their informal caregivers.

Results: We will present and discuss our findings using the concepts of Bowen regarding acceptability, demand, implementation, practicality and limited-efficacy at the conference. Most of all we will address the facilitators, barriers and lessons learned for implementation during this study.

Conclusion: This study will provide insights in the way nurses and informal caregivers can work together in a person-centred way in complex and vulnerable situations.

QOP2-47. Design of a co-developed online resource for people living with dementia, carers and healthcare professionals in the first twelve months post diagnosis (COGNISANCE)

Jane Wilcock¹, Marie Poole², Lee-Fay Low³, Meredith Gresham⁴, Henry Brodaty⁵, Louise Robinson², Greta Rait¹, COGNISANCE Team⁶

¹University College London, ²Newcastle University, ³University of Sydney, ⁴University of New South Wales, ⁵University of New South Wales, ⁶University New South Wales

Background: COGNISANCE is a research programme (Australia, UK, Canada, Netherlands, and Poland) in partnership with people living with dementia, informal care partners, healthcare professionals and key national and international dementia organisations and researchers.

We have co-developed a resource to support people living with dementia, carers and healthcare professionals for the first 12 months following diagnosis. This time after diagnosis is when many people feel overwhelmed and under-supported.

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Results: A generic English language website that can be culturally adapted and tailored to different geographical locations and languages was produced. The workshops determined that the resource should be available online, current, practical, and relevant at a regional and individual level. Personalisation was important for all three key audiences and they can select specific but complimentary topic areas. Individuals can create their own journey and select content that is currently relevant to them at the time. Language, tone, and accessibility for the online resource were essential as was access without individual logins or passwords.

Conclusion: The need for a practical, empathetic and individually tailored resource was identified. The resource is a website that has an individual planning toolkit for the first twelve months following a diagnosis. We will present the content and functionality focussing on how each element reflects the co-developers views on a useful and usable resource to help plan for a life with dementia.

QOP3. (Quick Oral Presentation) Policy and societal aspects

QOP3-01. Dementia-friendly research: Findings from co-research with people living with dementia

Katie Davis

Glasgow Caledonian University

It is estimated that worldwide, there is a new diagnosis of dementia every four seconds. Research into the lived experience of dementia is gaining prominence notably important and with that, a call for people with dementia to have their voice heard. Within the current literature, it is noted that although participatory approaches to enquiry are being adopted to study the experiences of people with dementia, the voice of people with dementia is often lost. Therefore, it is important to consider methodologies that put people living with dementia at the centre of not just participation, but of the design, data collection and analysis of the research as well.

Co-operative inquiry (Heron and Reason, 2006) is a methodology, whereby the traditional research roles of researcher and participant are replaced by a partnership that fosters a creative, practical collaboration. Co-operative inquiry is an approach to participatory research that involves cycles of action and reflection and aims to address the concerns of the population being researched. It is a methodology that has been limited in its application within the dementia research field but supports the need for people living with dementia to be involved in research beyond that of a participant.

This recorded presentation will explore how co-operative inquiry can enhance the participation of people living with dementia in research. The presentation draws upon the findings from a co-operative inquiry carried out with a group of people living with dementia in the North West of England. The benefits and challenges of co-researching with people living with dementia will be explored and suggestions for future work in this area presented.

QOP3-02. Understanding perceptions of Motor Cognitive and Movement Programs in African American women with Mild Cognitive Impairment

David Lazris

Background: 10% to 20% of Americans aged 65 or older have mild cognitive impairment (MCI) with 10% progressing to Alzheimer's Disease (AD) each year. Underserved groups, including African Americans (AAs), are among the most vulnerable to MCI and AD. Motor-cognitive function, the ability to think while moving, is understudied in AD, although evidence continues to amass about the benefits of exercise and movement for AD.

Objectives: Understanding the attitudes, perceptions and beliefs about motor-cognitive integration, and examining physical activity of diverse community members will allow refinement of multimodal interventions designed to improve motor-cognitive and cognitive function.

Methods: We conducted focus groups of older adults who reported subjective MCI (n=15; Black: n= 12, 2 White, mean age 71.7+ 5.8).

Results: Findings from thematic analysis showed most participants knew of benefits of exercise, e.g., reducing medication, improving the ability to focus, fewer mental health issues, and increased community building. However, most participants were not getting adequate exercise due to factors including pain, increased responsibilities, and safety fears. There was enthusiasm for multimodal interventions designed to target body and brain health and provided suggestions to enhance the proposed interventions.

Conclusion: Results provide useful insights regarding improving participation among hard-to-reach and historically under-represented groups in clinical movement-based research. Participant's discussion focused primarily on the way motor cognitive integration prevents falls, maintaining memory and independence. The reported perceived benefits and limitations to exercise as this population understands it can help researchers and physicians better engage the community for lifestyle changes that will support greater motor-cognitive health.

QOP3-03Challenging behaviour in migrants with dementia at home: experiences of their nurses and informal caregivers

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Background: Challenging behaviour is a common issue in community-dwelling people with dementia which can reduce quality of life and increase caregiver stress. Home care professionals and informal caregivers have difficulties managing the challenging behaviour in migrants with dementia living at home.

Aim: To describe the experiences of nurses and informal caregivers with challenging behaviour of community-dwelling people with dementia of migrant background. This study is part of a larger study that aims to develop a method for community nurses and case managers to support informal caregivers and people with dementia of migrant background in managing challenging behaviour.

Methods: Qualitative study, including 15 semi-structured interviews, with member-checks during two focus group sessions. Participants included home care professionals and informal caregivers. Data were analysed using thematic analysis.

Results: We elicited six themes regarding the experiences of nurses and informal caregivers with challenging behaviour of migrant clients with dementia: 1) Building trusting relationships is hindered by language barriers and the late involvement of professionals; 2) Taboo and shame hinder openly discussing dementia and challenging behaviour; 3) Mutual expectations of care may vary and need to be explored; 4) Information about dementia or challenging behaviour may not come across; 5) Standard options of care do not fit the specific characteristics and preferences of families of migrant background; and, 6) Nurses of non-migrant background can learn from informal caregivers as well as their colleagues of migrant background.

Discussion and conclusion: Managing challenging behaviour of people with dementia of non-Western background is complex for both nurses and informal caregivers. Based on their experiences a method for managing challenging behaviour should address conversations about trust, mutual expectations regarding care, and the dementia process.

QOP3-04. "The Mosaic Approach" to Music & Movement for PLWD and carers. This unique approach fosters connection and togetherness, with physical, social and emotional benefits

Paula Hain

Mosaic Dance

"The Mosaic Approach to Music and Movement" was developed after delivering sessions for PLWD with amazing results. This unique approach celebrates individuals whilst nurturing a sense of togetherness, resulting in increased physical, social and emotional wellbeing, boosting mood and improving feelings of connection.

First, is always to focus on what participants CAN do, rather than what they can't. This raises self-esteem, confidence and control. Reframing limitations in terms of what IS possible consistently leads to greater ranges of movement and improves mood. Secondly, value small movements and reactions. For example, finger-tapping on a table together can result in valuable and pleasurable interaction. Thirdly "meet people where they are". Releasing expectations of consistent moods or reactions and accepting the person in front of you and their reality without judgement. Fourthly, the Mosaic Approach creates a positive atmosphere. This is achieved through open body language, physical and eye contact, communicating intentions clearly, explaining to PLWD that movement and dancing is entirely optional - they need do nothing more and their very presence is appreciated and valued. Dance and movement is naturally both active and interactive and watching others dance increases emotional and social wellbeing too. The fifth part of the

Mosaic Approach is offering group and individual appreciation and gratitude at every session; this clearly uplifts and increases the self-esteem of participants.

In summary, the Mosaic Approach recognises individuals and simultaneously creates a sense of togetherness, on a one to one or in a group scenario. It achieves this by always focusing on what we CAN do, recognising small reactions as highly valuable, meeting people where they are, creating a positive atmosphere and offering genuine appreciation and gratitude for the moments created. I look forward to providing further detail and examples of its implementation and results for PLWD and for carers too.

QOP3-05. Characteristics of dementia-friendly hospitals: An integrative review

Christina Manietta¹, Daniel Purwins², Christiane Knecht³, Martina Roes²

¹University of Witten/Herdecke, ²German Center for Neurodegenerative Diseases Site Witten, ³FH Münster University of Applied Sciences

Background: There are many different international efforts to improve the care of people with dementia in hospitals. In this context, the term "dementia-friendly hospital" has become more and more common in international publications, but the understanding of dementia-friendliness remains unclear.

Objectives: (a) To systematically identify current discourses on dementia-friendly hospitals and (b) to analyze and describe the characteristics of dementia-friendly hospitals within these discourses.

Method: An integrative review according to Whitemore and Knafl (2005) was conducted. The databases MEDLINE, CINAHL, PsycInfo and Cochrane Library were searched systematically (03/21). Additional resources such as search engines, grey literature databases, subject databases and targeted websites were searched to identify different types of literature. Two reviewers independently screened the records for inclusion and extracted general information. The included records were analyzed using an inductive content analysis in an iterative process using MAXQDA.

Results: We identified 3863 records and included 32 records. Most records were grey literature (e.g. practice articles) and based on best practice, only two scientific articles were included. The included records were mostly described from a hospital perspective and only two referred to the perspective of people with dementia. The analysis revealed six characteristics of dementia-friendly hospitals. Characteristics related to the patient and their care are "person-centeredness", "continuity", "environment" and the "consideration of dementia and other phenomena" in the context of dementia. Additional characteristics are "valuing relatives" and "knowledge and expertise" within the organization of dementia and multiprofessional expertise.

Discussion: These results show that the discourses on dementia-friendly hospitals are held mostly without the presence of people with dementia. This represents a major research gap especially in relation to current developments to emphasize the participation of people with dementia in research. However, the term "dementia-friendly hospital" is used very heterogeneously.

QOP3-06. Prevention of dementia using mobile phone applications (PRODEMOS)

Marieke Hoevenaar-Blom¹, Eric P Moll van Charante², Melanie Hafdi², Esmé Eggink², Patrick Witvliet², Manshu Song², Youxin Wang², Wei Wang², Willem A van Gool², Carol Brayne², Edo Richard²

¹Amsterdam Medical Research BV, ²

Background and aims: The rising prevalence of dementia will largely occur in low- and middle-income countries. Mobile Health (mHealth) can improve accessibility to prevention and facilitate self-management. We aim to investigate whether optimization of dementia risk factors using an interactive mHealth intervention leads to reduction of dementia risk and to evaluate implementation of the intervention.

Methods: Participants are randomized to a coach supported, interactive mHealth platform facilitating self-management of dementia risk factors (including hypertension, diabetes, dyslipidemia, physical inactivity, smoking, poor diet, depression) or to a control platform with static health information. People are eligible if they are 55-75 years, of low socio-economic status (UK) or from the general population (China), have ≥ 2 dementia risk factors, and are in possession of a smartphone. The intervention and follow-up will be 12-18 months.

Results: The study logistics and mHealth platform have been tested in a 6-week pilot study (n=21 in UK, n=56 in China), demonstrating the feasibility of the intervention. The prospective open-label blinded endpoint (PROBE) RCT is intending to enrol 2400 participants in the United Kingdom (UK, n=1200) and in China (n=1200). Recruitment has started in both countries, but the COVID related restrictions have been severely disruptive. The primary effectiveness outcome is dementia risk as measured by the CAIDE risk score. Main secondary outcomes are improvement of individual risk factors and cost-effectiveness. Implementation outcomes include acceptability, adoption, feasibility, fidelity and sustainability of the intervention.

Conclusion: The PRODEMOS trial, targeting populations with a high dementia risk and poor access to preventive care, will provide proof-of-principle for the implementation potential and effectiveness of a coach-supported mHealth intervention to reduce the risk of dementia. The final results are expected in the second half of 2023.

Trial website www.prodemos-project.eu

Trial registration number ISRCTN15986016

Subsidizing party Horizon 2020 (779238) and the National Key R&D Programme of China (2017YFE0118800)

QOP3-07. Alzheimer's Disease International World Alzheimer Report 2021 – Journey to a Diagnosis of Dementia

Karen Watchman, Chris Lynch

Alzheimer's Disease International

The World Alzheimer Reports are a comprehensive source of information on dementia. Each year the report covers a different topic and is launched during September, World Alzheimer's Month, as part of a global awareness raising campaign. The 2021 World Alzheimer Report examines the crucial topic of dementia diagnosis and Alzheimer's Disease International (ADI) commissioned McGill University Research Centre in Studies in Aging and the McGill Faculty of Medicine and Health Sciences, Montreal, Quebec to oversee the report development.

Three online surveys distributed in April and May 2021 gathered information from clinicians involved in the diagnosis of dementia (n=1,111 from over 100 countries), people living with dementia and family caregivers (n=2,311), and ADI member Alzheimer and dementia associations (n=106). This is supplemented in the World Alzheimer Report by a series of brief essays from clinicians and academics, and personal contributions about individual experiences of diagnosis from people living with dementia and family members.

The accompanying ADI awareness raising campaign during World Alzheimer Month 2021 focused on warning signs of dementia, routes to diagnosis, and risk reduction activities. Key findings from the surveys and report recommendations will be presented, including the impact of COVID-19 disruption and interruption to the diagnosis pathway.

QOP3-08. "You have Alzheimer's, but no dementia (yet)": considerations regarding a diagnosis of AD based on biomarkers

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Background: The NIA-AA research framework proposes a purely biological definition of Alzheimer's Disease (AD). This implies that AD can be diagnosed based on biomarker abnormalities, regardless of clinical symptoms and signs. While this brings opportunities, it also raises challenges. We aimed to provide an overview of considerations regarding the disclosure of AD pathology before the onset of dementia.

Methods: We conducted a systematic literature review according to PRISMA guidelines by searching PubMed (on 10 December 2020) for publications on conveying AD biomarker results to individuals without dementia. Our query combined variations on the terms Alzheimer's Disease, disclosure or diagnosis, preclinical or prodromal, and biomarkers. Two reviewers independently screened the resulting 3185 titles and abstracts for eligibility and examined 129 full text records for relevance. We included theoretical articles in English, on communicating amyloid and/or tau results to individuals with mild cognitive impairment, subjective cognitive decline or normal cognition. MAXQDA-software was used for inductive data analysis.

Results: We included 25 publications. From these we extracted 26 unique considerations, which we grouped according to their primary relevance to a clinical, personal, or societal context. Clinical considerations included (lack of) validity, utility, and disclosure protocols. Personal considerations covered psychological and behavioral implications, as well as the right to (not) know. Finally, societal considerations comprised the risk of misconception, stigmatization, and discrimination. Overall, views were heterogeneous, often contradictory and tended to focus on adverse effects.

Conclusion: Perspectives on a diagnosis of AD before dementia vary widely. Empirical research is urgently required, especially on harms and benefits for individuals and society, taking perspectives of medical professionals, patients and the public into account. Our findings provide a starting point for clinicians to communicate about a biomarker-based diagnosis with patients, which becomes increasingly important in light of the conditional approval of a first disease-modifying drug for AD.

QOP3-09. Increasing knowledge on dementia risk reduction in the general population: results of a public awareness campaign

Stephanie Van Asbroeck¹, Martin P. J. van Boxel¹, Jan Steyaert², Sebastian Köhler¹, Irene Heger¹, Marjolein de Vugt¹, Frans Verhey¹, Kay Deckers¹

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Strategies to reduce dementia risk are needed to minimize the burden of this growing public health concern. Most individuals are not aware that dementia risk reduction is possible, let alone how this could be achieved. Health education, such as public awareness campaigns on the topic of dementia risk reduction, can meet this need. A public health campaign (including social media and offering an online individual risk assessment tool) was carried out over a 7-month period in Flanders, Belgium. Impact was assessed in two independent online surveys, before (n = 1,003) and after the campaign (n = 1,008), in representative samples of adults aged 40-75 years. Questions regarding personal needs, wishes and barriers were also included. After the campaign, more individuals (10.3%) were aware that dementia risk reduction is possible than before the campaign, and more individuals correctly identified 10 out of 12 surveyed modifiable dementia risk and protective factors. However, no differences were observed in low-educated individuals. Further, specific differences in potential needs, wishes and barriers for future campaigns or interventions were observed between demographic strata. The majority of the respondents (89%) indicated that they would welcome more information on improving their brain-health. More than half (54%) also believed that they lacked the necessary knowledge to make brain-healthy behavior changes. In conclusion, effective public awareness campaigns on the topic of dementia risk reduction

are feasible and timely, given the state of the evidence. Special efforts need to be made to develop effective campaigns, tailored towards low-educated individuals.

QOP3-10. Culture change for dementia - A coalition led response to raising awareness of dementia and inspiring stakeholders to create dementia inclusive communities

Fiona Foley¹, Emer Begley²

¹Health Service Executive, ²National Dementia Office

Dementia: Understand Together in Communities is inspiring individuals, organisations and community groups to take action and create communities where people living with dementia and their families are respected, supported and connected.

The initial phase of the campaign included TV and radio advertisements (2016-2018) to raise awareness and increase understanding of dementia. The second phase is an innovative framework of a grassroots social movement to bring about a culture change around dementia at a community level. Supported by a coalition of partners from public, private & voluntary sectors, the core message is inclusion, engagement and making community resources enabling to ensure that a diagnosis does not exclude a person because of stigma or a socially or physically disabling environment. Services & supports are amended/developed and made accessible in partnership with those living with dementia.

350+ community champions and 40+ national partners are leading this movement of change in communities and inspiring others to get involved.

Others engage in media (2020)

Over 36.800 Facebook followers

Over 205.500 website visits

Biennial national representative survey examining the impact of the campaign shows (2018):

59% of people who recall the campaign took some action

12% increase in those who believe people with dementia can participate in a variety of activities from 2016

Third survey results available August 2021

A process evaluation of the framework showed (2019):

National partners / champions feel they raised awareness and understanding of dementia within their own organisation (83%) / their own networks (81%).

Examples actions: focus groups/workshops with people with dementia, awareness training, walkability audits, inclusive cultural and sporting activities, shared learning events.

Conclusion

The social movement model, collaborative partnership approach, transferability of campaign's key messages and the call for action across communities is proving successful in changing the dementia landscape in Ireland in a sustainable and scalable way.

QOP3-11. Fiestas, Statues and Spirituality: Collective Rituals as Community Dementia Care in Andalusia

Chloe Place

20 Graham Road

This presentation explores how spirituality and community rituals form a meaningful part of dementia care in Andalusia, Spain. Findings were drawn from fourteen-months of ethnographic fieldwork in 2019 investigating people's lived experiences of dementia care in a rural Andalusian town. Devotional practices towards the community's patron Virgin Mary statues, and the fiestas that celebrate them were found to have therapeutic effects on people with dementia living in the town. Devotional interactions with the Virgin Mary statues were experienced as comforting, and offered spiritual kin-like companionship to people with dementia. The statues were animated during the town's fiesta processions which stimulated social cohesion and intergenerational solidarity. Both family caregivers and healthcare practitioners incorporated these rituals into their care practices by supporting people with dementia to participate in the processions. The celebratory multisensorial nature of the processions could reawaken profoundly embodied memories in people with dementia, despite their increasing forgetfulness, which they experienced as therapeutic. In the town's care home, people with dementia engaged in specific craft activities to prepare for the fiestas. The seasonal, repetitive nature of fiestas orientated people with dementia to the present, whilst linking them to their community's shared past. Participation in these collective rituals for people with dementia strengthened their sense of belonging and reaffirmed them as important community members. I argue that these local religious rituals thus generate a spiritually empowering and therapeutic role in community dementia care in Andalusia. This study demonstrates how cultural activities can be harnessed to create dementia-friendly communities where people with dementia feel valued and able to participate in civic life. Understanding the benefits of collective ritual participation for people with dementia is particularly relevant as we negotiate new forms of socially-distanced dementia care under the Covid-19 pandemic.

QOP3-12. Using literature and narrative medicine to promote management of ethical dilemmas in life with dementia

Sigurd Lauridsen, Frederik Schou-Juul, Marie-Elisabeth Holm, Anna Folker, Peter Simonsen, Sofie Skov

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Background: Dementia's effect on people with dementia's autonomy and capability to make decisions creates several ethical issues. The issues range from when to quit driving, insecurity regarding having sex with a spouse with dementia, and transition to nursing homes, and many more. People with dementia, family and professional carers report distress, as they increasingly are faced with and need to manage these ethical issues.

Research aim: To develop an intervention to improve people with dementia and carers' knowledge of ethical dilemmas in dementia care as well as their involvement and confidence (self-efficacy) in managing them.

Design and methods: The CARE-intervention has been developed in a participatory action research design with people with dementia, family and professional carers and key stakeholders.

Results: Presentation of the CARE-intervention. CARE employs elements of narrative medicine and uses fiction to gain a better understanding of the ethical issues. It targets three distinct groups: People with dementia, relatively early in the disease; family carers of people with dementia and professional carers at nursing facilities.

It is organized as workshops where a moderator facilitates an inclusive and respectful meeting among the respective target groups, where participants freely can discuss difficult ethical issues as they appear in select fictional or autobiographical texts on life with dementia. The dialogue will be facilitated by an experienced moderator, providing a series of open and close-ended questions about the texts. By interacting with fictional texts and participating in an open peer-dialogue about the issues, it is our hypothesis that people with dementia and their carers will gain confidence in, and consequently become better at, managing ethical issues.

QOP3-13. Awareness raising campaign in Finland: "The power of touch"

Anne Leinonen

Muistiliitto

Even if you don't remember everything, you can always feel touch and presence of your family and friends. The awareness raising campaign by Alzheimer Society of Finland called "The power of touch" focused on these things.

With the campaign we wanted to awaken positive feelings. We gave out information about memory related diseases and encouraged people who are worried about their memory to seek help. We also wanted to make the work of our local associations more visible and to reduce the stigma related to dementia.

The campaign gave a voice to the people with dementia. With the help of our local associations, we asked people with dementia to tell us what family, friends and presence of others means to them. The marketing agency creating the campaign turned these stories into three different radio spots.

The national radio campaign ran for two weeks in the spring 2021. We reached 2,9 million Finns over 18, and they heard our spots 4,7 times on average.

The radio spots were also made as videos for social media. With those and photos we ran two week long campaign on Facebook, Twitter, Instagram and LinkedIn. We reached over 165 000 people and the campaign raised a lot of likes and comments, most of them positive. People shared their experiences and told us that the issues the campaign raised were important. Even when Covid-19 was limiting the interactions, the message of the campaign was received well.

QOP3-14. Museums as places for cultural participation of people with dementia

Claudia Kaiser

Ostfalia - University of Applied Sciences

Cognitive disabilities as well as functional limitations in everyday life often lead to a withdrawal of older people from social and cultural life and thus potentially to social isolation. Nevertheless, it is well known that participation in social and cultural life contributes to the preservation of everyday resources, normality, well-being and quality of life of any older person as well as their family members.

Museums are important places for cultural education and participation of people of all age groups. In line with the requirements set by the UN Convention on the Rights of Persons with Disabilities many museums have reduced barriers for (older) people with disabilities or cognitive restrictions in order to facilitate their access to cultural participation. Moreover, some have set up specific activities for people with dementia and their relatives.

The presentation will report findings from an online survey of museums in North Rhine-Westfalia (Germany) and give an overview of the museums' activities of facilitating inclusion, their programmatic and educational concepts, internal or external co-operations and the sustainability of their activities regarding the target group of (older) people with cognitive restrictions. It will also present hands-on experiences gained in two museums implementing an arts-based and biography-based cultural program for people with dementia.

QOP3-15. Development of a patient decision-aid to improve shared decision-making regarding a timely dementia diagnosis: the exploration phase

Iris Linden¹, Claire Wolfs², Marieke Perry³, Job Metsemakers³, Trudy van der Weijden³, Marjolein de Vugt³, Frans Verhey³, Ron Handels³, Marcel Olde Rikkert³, Carmen Dirksen³, Rudolf Ponds³

¹Maastricht University, ²Maastricht University/Alzheimer Centre Limburg, ³

Background: The importance of an early dementia diagnosis in a mild stage of the disease is often stressed. However, whether an early diagnosis is beneficial in terms of patients' health and well-being is still debated. As a consequence, the debate is shifting towards a timely diagnosis, which implies that a diagnostic process is initiated at the right time

for the person with memory complaints and their significant other(s) so as to meet their preferences, needs and expectations.

Objectives: We aim to develop a patient-decision aid (PtDA) that will improve shared-decision making in deciding on starting a timely diagnostic trajectory. The PtDA will be developed in three phases: (1) exploration phase, (2) development phase, (3) evaluation phase. People with dementia, caregivers and general practitioners (GPs) are closely involved in the development process of the PtDA. This study summarizes the findings of the exploration phase and explains how these findings are used to develop a PtDA.

Methods: GPs, people referred to a memory clinic and their caregivers were interviewed about their experiences with the decision-making process for starting a diagnostic trajectory and their needs and thoughts on the use of a PtDA in this process. These interviews were thematically analyzed. Furthermore, a systematic review on patient and caregivers' preferences regarding a timely diagnosis was conducted and used as deductive framework for thematic analysis.

Conclusions: GPs expected a PtDA to cover the pros and cons of starting a diagnostic trajectory and to manage expectations regarding treatment possibilities and of referral to memory clinics. The needs of people referred to a memory clinic and their caregivers' needs were more directed towards information on treatment possibilities and the hope to find the cause of their memory complaints. These findings were translated to a factsheet on what to consider in the development phase of the PtDA.

QOP3-16. Ethical issues in dementia guidelines for people with dementia and informal caregivers: A qualitative review of dementia guidelines

Frederik Schou-Juul, Frederik Schou-Juul, Sigurd Mørk Rønbøl Lauridsen

Statens Institut for Folkesundhed

In this presentation, methods and findings from a qualitative review on which ethical issues are represented in Danish dementia-specific guidelines, will be presented. The presentation will adhere to the outline of the following abstract:

Background: Growing evidence shows that ethical dilemmas represent a central challenge with extensive implications for people with dementia and their relatives. Hence, caring for people with dementia in an informal setting requires awareness of relevant ethical issues.

Aims: To map and synthesize the ethical themes, represented in public Danish dementia-specific guidelines targeting people with dementia and informal caregiver, as well as to produce an analysis of the guiding recommendations.

Methods: The data collection was conducted, using public search engines and outreach to relevant organizations, in which 653 references were retrieved. After screening for formal criteria such as publication year, target group, public availability and finally controlled for content of ethical issues and recommendations, 15 were identified. The qualitative analysis was organized using NVivo.

Results: We found that the guidelines contained a complexity of ethical issues, which we were able to categorize under four distinct ethical themes: Full disclosure of private or sensitive matters; Accepting dependence on others and receiving help; Changes in what is perceived as dignified socializing and communication with people with dementia and lastly Decision-making, informed consent and autonomy.

Conclusions: The ethical issues represented in the four overarching themes suggest that Danish dementia-specific guidelines targeted at people with dementia and their relatives do in fact represent a broad spectrum of ethical issues. However only a small fraction of the guidelines contains substantial focus on ethical issues and provide recommendations thereto, which may indicate that, the need for guidance on ethical issues is not being met, and that further research is required to specify additional ethical guidance to benefit these target groups.

QOP3-17. Agitation and End-of-Life: Towards an Advance Directive that Prepare for Agitation and Behavioral Symptoms in Alzheimer's Disease

Mary Michael

Otsuka America Pharmaceutical, Inc. & Global Council on Alzheimer's Disease

Advance Directives provide legal documentation of a person's wishes regarding medical treatment and care, allowing people and their families to decide in advance how care and treatment should be provided at end-of-life. For people living with advanced stages of Alzheimer's, Advance Directives give specific instructions to ensure a person's will is being met. Yet Advance Directives that anticipate for the eventualities of Alzheimer's Disease often fail to prepare for the care and treatment decisions prompted by agitation and other behavioral symptoms.

This presentation proposes a framework for how Advance Directives can anticipate decisions that arise as a person experiences agitation and other behavioral symptoms of Alzheimer's.

The framework draws from the development of Psychiatric Advance Directives (PADs) led in part by the American Psychiatric Association. Specifically, PADs allow individuals to specify in advance which treatments may be administered in response to acute episodes of psychiatric illness at a time when someone is unable or unwilling to provide consent. Our project contends that the mechanisms underlying PADs be modeled but modified to help people prepare for agitation and the behavioral aspects of Alzheimer's.

We propose a four-part framework for Advance Directives to prepare for agitation and other behavioral aspects of Alzheimer's:

Psychiatric medications. What treatments may – or may not – be used to manage agitation or other behavioral disturbances?

Agitation prevention and de-escalation. What strategies can caregivers employ to mollify agitated behaviors?

Lifestyle preferences and values. What values – religious or otherwise – should guide care and treatment?

Information sharing and access. When and how should caregivers, medical professionals, and family members be notified about behavioral disturbances?

It is well-established in academic literature that agitation and behavioral aspects of Alzheimer's cause difficulty for families as the disease progresses. Advance Directives that prepare for agitation can help to create a plan and ease these challenges.

QOP3-18. Mapping the Lived Experiences: The Dyad Journey of People with Agitation in Alzheimer's and Their Care Partners

Mary Michael

Otsuka America Pharmaceutical, Inc. & Global Council on Alzheimer's Disease

Much analysis has been dedicated to understanding the individual journeys of the "patient" and the "caregiver" in Alzheimer's disease. This work has provided valuable insights, but priorities remain unaddressed:

- how is the journey in Alzheimer's shaped by the complexities of agitation and other behavioral aspects of the disease;
- how can insights from "social listening" structure our understanding of these journeys;
- how can we understand the dyad journey of the person with Alzheimer's and the care partner, particularly through the lens of agitation?

This project, "Mapping the Lived Experiences" recasts the Alzheimer's journey to better reflect these priorities. We offer a visual interpretation of the journey with the rationale and proof points that underpin it.

"Mapping the Lived Experiences" prioritizes agitation and other behavioral aspects of Alzheimer's as pivotal challenges on the disease journey. We frame the journey into two overarching phases: "the first loss," which accounts for widely recognized symptoms of the disease, such as memory loss and declining cognitive function; and "the second loss," which is characterized by behavioral aspects of the disease.

The "milestones" moment framework reflects an interpretive framework developed through an ongoing "social listening" research project. This social listening research allows analysis of the online conversation as it is happening in social channels and discussion boards. Our research posits that journeys – for both the person with Alzheimer's and the care partner – are not linear, straight-line trajectories, but jagged, fragmented paths marked by "milestone moments" that shape thinking, understanding, and behavior.

"Mapping the Lived Experiences" offers a dyad visualization and articulations, as it fuses the journeys of the person with lived experience and the care partner together in the same visual space. This approach reveals how these journeys relate, inform, and ultimately depart from one another.

QOP3-19. Stimulating age-friendly communities: Results from implementing the Senior Friendly Communities project for age-friendly municipality policies

Mignon Schichel¹, Marja Veenstra², Hannah Christie², Marjolein De Vugt², Frans Verhey²

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Background: The interregional Senior Friendly Communities (SFC) project was implemented to support the process of municipalities becoming more age-friendly, specifically on public health policies supporting people with dementia (PWD), people with late-life depression (PLD), and informal caregivers (IFC). It was implemented in 33 municipalities in the Euregion Meuse-Rhine, including 10 Belgian, 13 Dutch and 10 German municipalities. Its goals were: first, to promote the implementation of activities relevant for PWD, PLD and IFC. Second, to increase the local authorities' awareness of age-friendliness, and of PWD, PLD, and IFC in particular. The third goal was to stimulate municipalities to sustainably include the target groups in their policies.

Methods: We conducted interviews among the participating SFC municipalities to answer the research question to what extent SFC has achieved its goals. At these interviews, policymakers and other relevant stakeholders were present to complement each other, but one answer per municipality was provided.

Results: The results show that awareness was the main gain for participating municipalities. The first and second goals were largely achieved and first steps were taken on the path towards the third goal. The lessons learned are that municipalities need to dedicate time, financial resources and staff to such a project and that more resources may become available when the themes of SFC are the responsibility of municipalities and/or high on the political agenda. In addition, expectations management between the project managers and participants is very important, and one should take into account the complex nature of municipalities, and potential time constraints that come from external funding when implementing similar projects.

Conclusions: The lessons learned from implementing SFC can guide similar projects aimed at facilitating municipality policies to become more age-friendly, specifically for people with dementia, people with late-life depression and informal care.

QOP3-20. Better ways to bank: innovating to support people living with dementia to manage their day-to-day finances

Natasha Morgan

Alzheimer's Society

Innovation at Alzheimer's Society is based on developing and applying new solutions to meet the needs of people affected by dementia where no effective solutions currently exist. Our Innovation Team is led by the priorities of people

affected by dementia, learning from their experiences, involving them in solution-building and ultimately measuring success by the difference we make to their lives. This person-centred approach to innovation helps us break out from our own limited experiences and develop new ways to take on dementia.

This presentation will discuss two projects: a partnership with Santander to develop a dementia banking phoneline, and Sibstar, a debit card and app for people affected by dementia.

We will demonstrate how we used a 'sprint' approach to co-design a new banking service with people affected by dementia in just four months. We involved people from the start by listening to the challenges they face when managing their day-to-day money including impulse purchases, scams, and difficulty accessing bank accounts due to complicated security systems. We then held online creative workshops to co-produce ideas for solutions, resulting in a design for a new banking with dementia phoneline.

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.

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

QOP3-21. Facilitating the involvement of people with and at risk of Alzheimer's dementia in prevention research: The EU-FINGERS example

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EU-FINGERS is a European, JPND-supported project aimed at developing a novel methodology for precision prevention of dementia, based on the successful experience of the multidomain Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER). Within the scope of this project, the consortium deemed crucial to explore and include in the project the perspectives of people affected by or with an interest in Alzheimer's disease (AD) and brain health. To do so, an Advisory Board (AB) composed of people who are at different stages across the AD continuum (e.g., asymptomatic at-risk, Subjective Cognitive Decline, Mild Cognitive Impairment, early-dementia) and carers has been set up. The AB currently consists of 16 members from seven different European countries. The AB meets regularly and provides ongoing feedback and advice to the research team.

A number of challenges have been encountered during the set-up and the beginning of the AB activities, mostly due to the COVID-19 pandemic. The first part of the presentation will report on the discussions and lessons learned on how to organise an international AB involving people at different stages across the AD continuum, as well as how to work in an online remote setting and overcoming the obstacles of the 'digital world' in people across the AD continuum. In the second part of the presentation, the outcomes of the discussions that took place during the first nine months of the AB activities and the value of this work for the project will be summarised.

QOP3-22. Deciding where to live

Kees Blankman

Vrije Universiteit Amsterdam, Law Faculty

One of the most far-reaching decisions in a lifetime is deciding where to live. Where is my home, my residence? For persons with dementia the choice is sometimes between staying at home or moving to an institution such as a home for the elderly or a nursing home.

From a human rights perspective there are four options: the person decides for himself, a supporter helps him deciding, someone else decides on behalf of him, or the court decides. According to art. 19 of the Convention on the Rights of Persons with Disabilities these decisions are to be made by the person himself. If the decision-making capacity of the person with dementia is impaired, support might be needed. In case of supported decision-making special attention must be paid to undue influence, whether the support is given by family members or by professionals in elder care. As a last resort substitute decision-making can be applied in case supported decision-making proves insufficient and all options for support have been tried.

In most jurisdictions involuntary admission into an institution can be ordered by the court. The criterion is not impaired decision-making capacity but danger connected with dementia.

In all situations the participation of the person with dementia in the decision-making process must be maximised and safeguards must be present mostly of all against undue influence or jumping to deciding in the objective best interest of the person.

QOP3-23. Exploring decision-making capacity of Alzheimer's disease patients using fMRI and interviews: a proof of concept

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Introduction: Recognizing or denying decision-making capacity to a person with Alzheimer's disease poses major legal and ethical problems, particularly when confronted with issues such as aging in place or transfer to a nursing home. To date, it is the clinician's assessment, based on a global analysis of his clinical evaluation and neuropsychological tasks, which enables decision-making assessment. Given the difficulty it represents sometimes, the research question concerns the contribution of neuro-imaging technologies as an aid to the evaluation of decision-making capacity.

Method: We included in our proof-of-concept study 4 healthy older patients and 2 older patients with dementia (mild stage) followed in a memory clinic. Each of the participants completed neuropsychological tests with a focus on executive functions, anosognosia and judgemental skills. Next, they performed a decision-making task, the Balloon Assessment Risk Task (BART) in functional MRI, and, finally, they participated in a semi-structured interview completed with interview of their caregiver. For both patients, their referring geriatrician was questioned a priori on his assessment of their decision-making capacity.

Results: The results showed a common activation pattern in functional MRI between the patient considered competent in decision-making and the healthy subjects, unlike the patient who was not clinically competent. The qualitative analysis highlighted major anosognosia in both pathological situations, but decision-making in everyday life situations differed between the 2 patients.

Discussion: This study shows the feasibility, on a sensitive topic, to explore the potential contribution of functional neuroimaging as tools. Semi-structured interviews with the patient, relatives and the referring geriatrician highlighted the complexity of this topic. It also demonstrates the value of conducting mixed research, combining neurosciences and social science to explore complex clinical issues in people with dementia.

QOP3-24. Dementia-sensitive planning of urban environments: interviews with planners focused on perspective-taking

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Background: Whereas research has established various concepts for dementia-sensitive indoor environments, studies have focused less on how urban environments might support wayfinding behavior and positive spatial experiences of people living with dementia. An essential step for planning dementia-sensitive environments (e.g., private indoor care facilities and public outdoor environments) is taking the perspective of people living with dementia. In this study, we explore how environmental planners engage in perspective-taking when planning or re-designing dementia-sensitive, wayfinding-supportive, public urban environments.

Research question: What are planners' assumptions about people living with dementia?

Methods: We will conduct semi-structured expert interviews with architects, urban designers, urban planners, and planning stakeholders. The interview questions revolve around planners' conceptualizations about people living with dementia, in the context of planning dementia-sensitive, wayfinding-supportive, public urban environments. We will explore planners' perspective-taking methods, their resources and best-practice, as well as which knowledge gaps or need for support they identify. In an additional design task, planners are invited to take the perspective of a person with dementia. We will use qualitative content analysis to derive themes relevant for perspective-taking, and categorize the answers based on different use cases. We will then summarize the insights on planners' perspective-taking, and contrast these with the perspective dementia advocates describe, in order to identify how these perspectives differ or correspond.

Preliminary results: We will present our preliminary results at the conference, such as planners' assumptions about people living with dementia. These, among other things, relate to planners' expectations about the physical and cognitive abilities of people living with dementia, their activities (e.g., destinations in an urban environment), and their preferences and needs (e.g., about orientation, social interaction, security, privacy, or sensory stimulation) in public environments.

Conclusions: We will indicate possible ways for supporting planners' perspective-taking, which might contribute to developing future dementia-sensitive, wayfinding-supportive, public urban environments.

QOP3-25. Can engagement in cognitively stimulating and social leisure activities compensate for other dementia risk factors? A prospective cohort study

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Background: With the projected surge in global dementia cases, research is increasingly focusing on lifestyle factors as preventive measures. Social and cognitive leisure activities are promising targets, but it is unclear which types of activities are more beneficial. This study investigated the individual and joint contribution of cognitive and social leisure activities to dementia risk and whether they modify the risks associated with other potentially modifiable and non-modifiable risk factors.

Methods: We used data from the English Longitudinal Study of Ageing (ELSA) from 7,917 participants, followed up from 2008/2009 (Wave 4) until 2018/2019 (Wave 9) for incident dementia. Self-reported baseline cognitive activities, the number of social memberships and social participation were clustered into high and low based on a median split. Subsequently, their individual and joint contribution to dementia risk, as well as their interaction with other dementia risk factors, were assessed with Cox regression models, adjusting for age, sex, level of education, wealth and a composite score of 11 lifestyle-related dementia risk factors.

Results: After a median follow-up period of 9.8 years, the dementia incidence rate was 54.5 cases per 10,000 person-years (95% CI 49.0-60.8). Adjusting for all covariates, higher engagement in cognitive activities (HR=0.58; 95% CI 0.40-0.84), a greater number of social memberships (HR=0.65; 95% CI 0.51-0.84) and a higher degree of social participation (HR=0.71; 95% CI 0.54-0.95) were associated with lower dementia risk. In a joint model, only engagement in cognitive (HR=0.60; 95% CI 0.40-0.91) activities and social memberships (HR=0.75; 95% CI 0.56-0.99) independently explained dementia risk. We did not find any interaction with other risk factors.

Conclusions: Engagement in cognitive and social leisure activities may be beneficial for dementia risk, independent of each other and other risk factors. Engagement in both should thus be recommended when designing dementia prevention measures and health advice initiatives.

QOP3-26. Scottish Dementia Working Group - Members Blogs

Wendy Rankin, SDWG Members Sdwg, Caroline Russell

Alzheimer Scotland

The Scottish Dementia Working Group (SDWG) is a national, member led campaigning and awareness raising group, for people living with a diagnosis of dementia in Scotland. We are funded by Alzheimer Scotland and the Scottish Government and are the independent voice of people with dementia within Scotland.

Before the Covid 19 pandemic, SDWG members would regularly attend conferences, meetings, and events, sharing their lived experiences with health and social care professionals, stakeholders, and other people living with dementia. When the Covid-19 pandemic hit, there were no more face to face meetings with members, or in-person attendance at events. The SDWG had to quickly adapt to a new way of working and campaigning, with support from the SDWG staff team to do this digitally.

The members met to discuss ways that they could continue to engage both locally and nationally, and how they could keep sharing their experiences, to keep campaigning and to continue to raise awareness. The members met digitally to discuss other ways of having their voices heard and highlight the lived experience. They decided to produce monthly blogs. These allowed members to engage with a new digital audience and continue to raise awareness of dementia and the awareness campaigns of the group. The blogs were shared both locally and nationally through social media platforms, newsletters, and links to the Alzheimer Scotland website where they are hosted. The blogs have shared a range of experiences from members including younger onset dementia, receiving a diagnosis while still in full time employment and being hospitalised with Covid 19.

Members have benefited from reflecting on their experiences and being part of the creative writing process. Even through the most difficult of times, they have continued to maintain a powerful voice for people living with dementia.

QOP3-27. Dementia care for an ethnically diverse population: a new conceptual lens

Saloua Berdai-Chaouni

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Europe knows an increasing share of older migrants and ethnic-minorities with dementia. Various attempts are made to provide more 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 indicate that we need to rethink the dominant care approaches for this sub-group. The reasons are threefold. These current dominant care approaches 1) underline that dementia care for older migrants and ethnic minorities is determined by their ethnic-cultural background, 2) do not meet the complex interaction of personal, cultural and religious aspects in defining care needs of this persons with dementia, and 3) 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 dementia care provision for a diverse population. This conceptual lens centralize of the needs of the older person with dementia without being oblivious to needs of informal caregivers and professional caregivers that are present in the care relationship and which consequently influence the care provision. It is also aware that these needs are complex, dynamic, situational and present at the individual level but reflecting gaps and challenges at the institutional and societal level. Accurately detecting, understanding and responding to these visible and invisible needs is required in order to move toward dementia care that is inclusive for marginalized populations. To conclude, this conceptual lens provides an innovative capturing of the dynamic complexity of influences, actors and localities within dementia care provision. It broadens the scope in the search for suitable and inclusive dementia care for a diverse population, suggesting that building blocks for this goal should be searched at the different levels: micro, meso and macro.

QOP3-28. Digital art workshops: encouraging creativity and connections during the pandemic

Cara Rooney, Nicola Lorimer

Alzheimer Scotland

The aim of the 'Creative Christmas Digital Art Workshop' was to provide people with dementia, and their carers, with the chance to experience the therapeutic benefits of creative activities, and encourage the development of a new skill, during the darkness of lockdown. It was also hoped that, by the end of the project, each participant would have a tactile piece of art, truly personal to them and their families, bringing them closer together, and counteracting feelings of isolation.

People with dementia and their carers found out about this inspiring project through their contacts within Alzheimer Scotland. Participants chose a place that was special to them, and an outline of this place in snow was drawn on a canvas, in preparation for hour-long painting sessions.

These were held weekly, for 5 weeks, via Microsoft Teams. The first 10 minutes of the session were used for a presentation of inspiring artwork, illustrating that there is no set way to paint, and emphasising that the aim of the

workshop was about enjoying the experience. The rest of the session was focused on the interaction between participants, and working on the paintings. This project brought light into people's lives during what has been a difficult time for everyone, and participants became friends during the process.

In these workshops, we overcame the challenges of translating a tactile process into a virtual format, and the technical issues of ensuring anyone can take part, regardless of location or abilities.

This presentation will show how engaging digital art workshops can be, and the beneficial outcomes they can offer for people living with dementia and their carers, including counteracting isolation, and reconnecting with family during a lockdown. It will also consider the next steps we are taking to ensure people all over the country can join in too.

QOP3-29. 'Reconnect' Project: A collaboration to create a comfortable virtual environment and counteract social isolation during the pandemic

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¹Alzheimer Scotland, ²The McManus: Dundee's Art Gallery and Museum

The 'Reconnect' project was a collaborative project between The McManus: Dundee's Art Gallery and Museum, and Alzheimer Scotland in Dundee. The aim of the project was to combat isolation during the pandemic through weekly reminiscence sessions, centred on a series of clips from the museum's 'Talking Dundee' oral history archive.

The Museum's Creative Learning Team hoped this meant that, even whilst the museum was closed, people with dementia and their carers could experience the rich content it has to offer, learn more about their city, feel re-connected to cultural provision, and forge new friendships, while shielding in their homes. The project was generously supported by both the Art Fund and THAT (Tayside Healthcare Arts Trust).

All participants received a memory journal containing pages focusing on childhood, working life, social life, hobbies and pastimes, and 'My Dundee'. Each session was based on one of these themes, and oral history clips were played, sparking memories for participants, which they then shared with the group.

Of particular benefit was each individual being able to record their memories of the theme, prior to the session, with notes and photographs. This meant they felt more at ease with speaking and sharing, knowing they had what they wanted to say written down. Participants also enjoyed showing objects they had in their homes, resulting in everyone learning more about each other than they would normally during an online activity.

This presentation will discuss the value and the challenges involved in creating a comfortable and informal virtual social environment, in which, individuals can feel as free to participate in conversation, as they would in person. It will also explore the potential in using tailored learning resources as 'starting points', to spark inspiring conversation about memories, and to create connections in a time when we had to stay apart.

QOP3-30. Assessing the fitness to drive of people with cognitive impairment: a systematic review of the current evidence

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Background: The assessment of driving ability in people with cognitive impairment is a topic of great social relevance due to the high prevalence of dementia. To maintain social participation, it is desirable to enable active and safe participation in road traffic for as long as possible. Therefore, evidence-based methods for assessing the fitness to drive are needed.

Method: A comprehensive systematic literature review was conducted on the research question, "Which evidence-based methods are suitable for assessing the fitness to drive in people with dementia or mild cognitive impairment?" for the period 2015-2020. The search was conducted in the Medline, PsycINFO, LIVIVO, PubPsych, Scopus, Cinahl, and CENTRAL databases.

Results: Thirty studies were included in the qualitative analysis. The identified methods for testing driving ability can be divided into practice-based testing procedures and office-based assessments. Practice-based tests are: On-road driving, simulator, and naturalistic driving. Office-based methods are: neuropsychological testing, driving-specific testing, and self-assessment questionnaires.

Conclusion: Evidence-based methods for the assessment of driving performance were identified in all domains. However, the results are heterogeneous. There are advantages and disadvantages of each method. A combination of different methods is recommended. This should be performed as a standard from a certain age or occurring impairments.

Funding: This research is funded by the Bavarian State Ministry of Health and Care (StMG) as part of the Bavarian Digital Registry – digiDEM Bayern (funding code: G42d-G8300-2017/1606-83).

QOP3-31. Visiting a Virtual V&A Dundee

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Alzheimer Scotland have worked with V&A Dundee to make Scotland's highly acclaimed design museum as accessible as possible for people living with dementia and their carers, including developing tailored activities and delivering dementia friends training for staff.

After the museum opened in September 2018, this included tours of the major exhibitions and object-based workshops in our Day Care sessions.

In response to Covid-19 we explored ways of continuing this high quality support and delivered multiple live virtual tours including the Mary Quant exhibition and the Scottish Design Galleries, allowing many more people to take part, regardless of their physical location or ability to travel to the museum. This also reduced people's isolation and ensured they felt connected, with social opportunities offered throughout these difficult times.

Alzheimer Scotland and V&A Dundee were able to take the joy and inspiration of design to people living with dementia and their carers. Those who participated told us that digital technology enabled rich conversations and stimulated the mind and senses, providing opportunities for them to socialise, share memories, discuss, laugh, and contemplate.

Following the success of the virtual tours we developed a programme of online activities that would bring the Mary Quant exhibition to life. The activities explored all aspects of the exhibition through presentations, a virtual walkthrough, tactile handling of objects and group discussion.

In working with the V&A Dundee we have learnt the positive impact that engaging with a museum can have and it is something we will continue and build upon using a blended approach and developing longer-term opportunities through a collaborative partnership.

The project enabled and enhanced the joy of human connection and shows that location and logistics are not a barrier and people can continue to benefit from these opportunities, staying connected and enriching each other's lives.

QOP3-32. A Web-Based Tool to Support the Diagnostic Process of Memory Clinics: Clinicians, Patients, and Care Partners' Evaluation of ADappt using the Think Out Loud Method

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Background: ADappt is a Web-based tool to support professionals, patients and care partners in the diagnostic process of memory clinics. The prototype, designed in co-creation with end-users, harbours modules for interpreting and communicating diagnostic test results.

Objective: To conduct an end-user evaluation of the ADappt prototype using qualitative methods, to obtain input for further improvement.

Methods: We combined the Think out Loud (ToL) method with semi-structured interviews. Ten clinicians (6 geriatricians, 2 neurologists, 1 internist geriatric medicine, 1 specialized nurse; 11±6 years' experience), 5 patients, and 1 partner (65±8yrs, 50% female) participated. Data collection is ongoing, we aim to include N=8 patients and partners. Participants prepared a fictional patient's first and disclosure consultation while using the modules directed towards them (clinicians: conversation guide to shared decision-making, overview of diagnostic tests, topic list, risk calculation tool, result page; patients and partners: animations, question prompt list, result page). ToLs and interviews were jointly analysed with qualitative content analysis. Comments were divided into the following categories: design & presentation, content & information, and navigation & structure.

Results: Clinicians thought ADappt was an easily accessible tool with appealing visuals, and indicated they would like to use ADappt in practice. They agreed upon the content provided and thought it could serve as a memory aid during consultations and as a reference for junior doctors. Regarding the risk calculation tool, clinicians were confused about a certain button, and some foresaw practical limitations. Patients and partners indicated they would like to use ADappt in practice. They made suggestions on the lay-out of the results page.

Discussion: Participants evaluated ADappt as a useful, easy-to-read tool. Further improvements include adjustments regarding navigation & structure and design & presentation. We use this final improvement round to build a demonstration version of ADappt, ready for feasibility testing in Dutch memory clinics.

QOP3-33. Nutritional status of people with dementia in the domestic environment: the Bavarian Dementia Survey (BayDem)

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Background: People with dementia (pwd) have an increased risk of developing malnutrition. However, there are very few analyses of the nutritional status in the domestic environment.

Research question: The aim of the analysis is to examine the nutritional status and the presence of appetite and eating disorders of pwd in the domestic environment.

Methods: BayDem is a multi-center, longitudinal study that was conducted at three different sites in Bavaria, Germany. Participants were pwd (according to ICD-10) and their informal caregivers. Data were collected by standardized face-to-face interviews in collaboration with local players. The nutritional status was assessed based on the body mass index (BMI). The existence of appetite and eating disorder was evaluated using the corresponding questions in the "Neuropsychiatric Inventory".

Results: At baseline (t0) 12% (n=29), 6 and 12 months later (t6 and t12) 10% (n=19 and 13) of the pwd were classified as malnourished (BMI <20 kg/m²). Women were significantly more frequent affected by malnutrition than men at t0 (17% vs. 5%; p=0.004). According to information from the informal caregivers, 32% (n=72) of the pwd suffered from appetite and eating disorders at t0, 28% (n=47) at t6 and 25% (n=29) at t12.

Discussion: The results of this analysis show that malnutrition is common in pwd in the domestic environment. The investigation on the existence of appetite and eating disorders underlines that pwd in the domestic environment are particularly at risk of malnutrition.

Practical implications: It is of great importance to inform about the problem of malnutrition so that nutritional problems can be identified at an early stage and suitable countermeasures can be induced.

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QOP3-34. Creating dementia-friendly municipalities with the Dementia Scan

Josephine Lambregts

Alzheimer Nederland

Municipalities in the Netherlands have a big responsibility to provide care and support to people with dementia and their family caregivers. To help them improve their dementia policy, we have developed the Dementia Scan. The Dementia Scan is an online tool in the form of a questionnaire with seven themes that are at the basis of a dementia friendly policy. Examples of themes are: "Coordination of care and support", "Training of professionals and volunteers" and "Support of the family caregiver". The results are displayed in a visual graph and can be compared to the national average scores and to the results of neighboring municipalities. In this way, the Dementia Scan allows municipalities to see at a glance where they stand. The scan allows us to open the conversation and work more closely with municipalities to achieve dementia-friendly policies. The Dementia Scan was launched last year and both municipalities and our volunteers who have used the scan are very enthusiastic about it. More than 60 municipalities have had the conversation using the Dementia Scan. This number is expected to double next year. It is already proving to be a valuable tool for Alzheimer's Netherlands to create better care and support at the local level for people with dementia and their family caregivers. In our presentation we will demonstrate the Dementia Scan and share our findings on using the scan in practice. Concrete tools like the Dementia Scan take us further in achieving our goal of dementia friendly policies.

QOP3-35. Future-proof housing for people with dementia

Anne de Boer

Alzheimer Nederland

In the Netherlands housing for people with dementia is not adequate enough. A recent study of Alzheimer Nederland shows that a gap exists between the home and the nursing home. The care or support provided at home, is not sufficient enough to maintain living at home. In addition, the current homes of people with dementia are not future-proof: houses are often too big and not accessible enough (have stairways, doorsteps). Because of the negative image of the nursing home, people with dementia and their family caregivers postpone moving to the nursing home, which often leads to crises behind the front door. To prevent this from happening we need close the gap between the home and the nursing home. In our research we asked people with dementia, their caregivers and healthcare professionals what is needed to do so.

For a home to be dementia future-proof, it needs to meet the following six requirements:

A private apartment, not just a room

Safety and care can be increased if needed

Freedom, no locks or rules

Possibility to live together with your partner

In the same neighborhood where the current house is located

A place to meet others

Alzheimer Nederland uses the results of the study and the six housing requirements to advocate and campaign for adequate housing for people with dementia. In the presentation, we will show the results and the further steps we will take.

QOP3-36. Towards a framework of living well with dementia

Franka Bakker, Yannick Liefting, Simone de Bruin

Windesheim University of Applied Sciences

Background: A general framework of living well for ageing seniors was previously developed, based on gerontological theories on ageing well and multiple interviews with 67 community-dwelling seniors. In this study we aimed to specify the framework for people with dementia, to better understand what constitutes living well with dementia.

Methods: We conducted semi-structured interviews with three persons with dementia, five informal caregivers, and six health and social care professionals who work in the field of dementia care (April-May 2021). Photo-elicitation was used as supporting tool for interviewing the three persons with dementia. Data were thematically analyzed.

Preliminary results: We identified six themes reflecting the aspects that were found important to live well with dementia:

own(ing) life (autonomy, identity);

purposeful living (gratitude and acceptance, having goals and challenges, spirituality/religion, being of meaning to someone else, joy);

living with others (keeping position in family and social network, being involved, intimacy, positive image of dementia);

place to live (familiar and pleasant (e.g. nature) environment, providing structure);
healthy living (nutrition, mental and physical health); and
active life (stimuli from e.g. social engagement, exercise, hobby's).

Additionally, analyses indicated the importance of the role and competences of the informal caregiver in facilitating a good life.

Conclusions: The proposed framework may provide a starting-point for how to create dementia-friendly communities and services from a holistic view on health and quality of life. In order to maintain a good life with dementia support from multiple levels will be needed. The model does not only provide insights for how people with dementia can realize a good life themselves, but also for how people in their environments can support them (i.e. informal carers, care professionals, society as a whole). The framework will be further developed and validated.

QOP3-37. Reducing stigma and the best practices in addressing isolation and stress with people living with dementia during COVID-19

David Krivec, Štefanija Lukič Zlobec, Špela Glišović Krivec

Spominčica - Alzheimer Slovenija

The conception of dementia as a part of normal ageing is causing a lot of harm to the timely diagnosis and is linked to poor care management and increases burden of caregivers. Moreover, the COVID-19 pandemic has reduced the care access and the follow-ups of patients were postponed.

The daily habits and routine were also very affected during the pandemic and we faced increase of stress, burden of caregivers and deterioration of patients' and carers' health. We conducted a survey with people with dementia and their relatives about the needs, problems, and lack of services during the lockdown. The huge impact we have observed was on loneliness and social isolation, patients' deterioration of symptoms of dementia and responsive behaviors. We encouraged people with online meetings where we performed several tailored-training programs, chats among carers, exercises, meetings with professionals and other activities. All of these allowed also people from rural areas or people facing poor logistic connection to stay active, socialize through media.

We also encourage people to socialize and be outdoors at the Library under the tree-tops that provided interesting and diverse workshops on a daily basis. By doing this, we have been transforming the shadows of cities into islands of free reading, places of inspiration and encounter (when allowed). Moreover, we have strengthened the dementia-friendly points network, that include nursing homes, police stations, firefighters, libraries, schools, ministries, municipalities, shops, banks and other. We train the employees about dementia, communication, post diagnostic support and person's rights. Member organizations provide friendly and accessible use of their services and promote the dementia friendly principles in the community.

The online meetings, libraries under the tree-tops and dementia-friendly points are therefore a nice presentation of good practices how to reduce stigma and to tackle the patients' and carers' loneliness and stress.

QOP3-38. Information provided to people with dementia and their carers on advance care planning: a content analysis of dementia associations' websites in Europe

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Background: Advance care planning (ACP) is a process focusing on communication and reflection on preferences for future care and treatment, which can result in documentation of these preferences. Given people with dementia have high chances of cognitive decline, ACP is important. Many people use the internet to find health information. Some of the most commonly accessed sources to look for dementia-specific information are dementia associations' websites. Currently there is no overview of which information about ACP is provided to people with dementia on these websites.

Aim: To gain insight into the information provided to people with dementia and their carers about ACP on dementia associations' websites in Europe.

Methods: We conducted a qualitative content analysis of dementia associations' websites in Europe. We screened websites for ACP information and coded it using a predefined codebook of key ACP themes.

Results:

We included websites from a total of 26 associations; from 20 countries and 1 international association, and covering 12 different languages. We found that 10 websites did not mention ACP. The information on the remaining 16 websites varied in terms of themes addressed and amount of information. Four explicitly provided a definition of ACP. Websites frequently mentioned legal frameworks (n=10, 705 excerpts), choosing legal representatives (n=12, 274 excerpts), and care and treatment preferences (n=14, 89 excerpts); while themes such as communication with family (n=9, 67 excerpts) and professionals (n=9, 49 excerpts) or identifying personal values (n=9, 73 excerpts) were less addressed.

Conclusion: Key ACP themes are under-addressed on dementia associations' websites in Europe. More comprehensive information about the ACP process and how to start could serve as a useful resource for people with dementia and their carers.

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QOP3-39. Study Design of FINGER-NL: a Multidomain Lifestyle Intervention in Dutch Older Adults to Prevent Cognitive Decline

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Previous multidomain lifestyle intervention trials to prevent cognitive decline in non-demented elderly have found conflicting effects, with positive findings including the multidomain FINnish GERiatric intervention (FINGER) study [1], and in specific at-risk subgroups in other trials [2,3]. As part of a world-wide effort to replicate and build on these results, FINGER-NL aims to investigate the effectivity of a 2-year multidomain lifestyle intervention in Dutch older adults to prevent cognitive decline.

Methods: FINGER-NL is a Dutch multi-center, randomized, controlled, multidomain lifestyle intervention trial among 1,206 older adults at risk for cognitive decline with a duration of 24 months. Participants will be randomized in a 1:1 ratio to either of two groups. The high-intensity intervention comprises 8 modules, namely physical exercise, cognitive training, management of metabolic and vascular risk factors, nutritional counseling, Souvenaid®, sleep counseling, stress management, and social activities. The low-intensity group receives online lifestyle-related health education. Primary outcome is 2-year change from baseline on a cognitive composite score covering processing speed, executive function and memory. Secondary outcomes including changes in specific cognitive domains, Amsterdam Instrumental Activity of Daily Living Questionnaire (A-IADL-Q), LIBRA score, and lifestyle component specific outcomes. Participant recruitment will start in June 2021.

Results and conclusion: Results of FINGER-NL will provide further insight in the effectiveness and feasibility of a multidomain lifestyle intervention to prevent cognitive decline in older adults. Given the current lack of curative treatment options and the growing prevalence of cognitive impairment and dementia, lifestyle interventions may play an important role.

[1] Ngandu T, Lehtisalo J, Solomon A, et al. Lancet 2015

[2] Moll van Charante EP, Richard E, Eurelings LS, et al. Lancet 2016

[3] Andrieu S, Guyonnet S, Coley N, et al. Lancet Neurol. 2017

QOP3-40. Living with dementia in supported housing: Findings from a systematic review and thematic synthesis of qualitative research

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Background: Most people with dementia live in the community, with one third of this population living alone. Poor housing conditions contribute to a loss of independence and increased disability for people with dementia, with living alone linked to faster cognitive decline, increased risk of hospitalisation, and social isolation. Literature suggests that supported housing can protect against these risk factors, by integrating housing with additional support or care services. However, the benefits and challenges of living with dementia in supported housing are not fully understood.

Methods: This systematic review and thematic synthesis sought to understand how living in supported housing influences the lives of people with dementia, from the perspectives of people with dementia, their supporters, health, and social care professionals. Seven databases were searched for relevant qualitative research, uncovering 3,163 unique records. Eleven published articles were included in the thematic synthesis.

Results: One core theme was generated, Maintaining Independence and Autonomy, divided into three subthemes – Support and Care, Social Relationships, and the Physical Environment. Factors like person-centred care, social interaction, and good environmental design contributed to the maintenance of independence and autonomy for people with dementia. Barriers like low staff ratios, stigma, and limited access to the wider community led to a loss of independence and autonomy – often leading to people with dementia being referred or managed out of the settings to receive care elsewhere. Although the articles acknowledged the importance of maintaining independence and autonomy for people with dementia, it appeared that supported housing settings often lacked the resources and facilities to make this a reality.

Conclusions: More high-quality research is needed from the perspectives of people with dementia to understand how supported housing can prevent hospitalisations and premature care home admission, promote independence and autonomy, and facilitate the maintenance of social networks and community connections for this population.

QOP3-41. Migrant live-in carers for people with dementia: moral conflicts and ideas of good dementia care. An analysis of social media and online group discussions

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Background: Migrant live-in care for people with dementia is an increasingly popular approach to relieve family caregivers, but leads to several legal and moral conflicts. However, evidence about the family perspective is very limited and systematic ethical analyses are lacking. Social media provide a virtual space in which family carers use

the opportunity to seek exchange and information. Our project examines moral conflicts as regards live-in care, ideas of good dementia care and the impact of the COVID-19 pandemic.

Methods: An exploratory-qualitative approach with 1) a systematic ethical analysis of online forums, and 2) online group discussions with family carers on live-in care in the context of dementia.

Results: Analysis of manifest and latent moral conflicts in the argumentation patterns of family carers yielded three central hypotheses: 1) Live-in care seems to be without alternative, but creates in a field of tension between prioritisation of individual needs while defending against the accusation of contributing to the reproduction of structural inequality (social ethics). 2) Family carers implicitly judge live-in carers based on biomedical ethics principles. Respecting autonomy of the person with dementia in due consideration of the principle non-maleficence is the guiding expectation (professional ethics). 3) Family carers expect certain character traits and virtues (e.g. solicitude, engagement, and trustworthiness). Live-in carers are expected to put the wellbeing of the person with dementia before their own needs (individual ethics).

Discussion: The analysis of argumentation patterns of family carers found in online content proved to be a fruitful approach to learn about their expectations and ideas of good dementia care as regards migrant live-in care and helped us to develop case examples to stimulate the online group discussions in step 2) of the study. The results will help to formulate empirically informed ethical recommendations on live-in care and the specifics of dementia.

QOP3-42. Dementia-friendly environments in social housing areas

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Alzheimerforeningen / The Danish Alzheimer Association

In Denmark, nearly 30 percent of all persons diagnosed with dementia live alone, often in social housing. When a person with dementia lives alone it is often connected to challenges such as neglected self-care, isolation, and default of housing.

With project RUM'ighed, the Danish Alzheimer Association cooperates with nine social housing organizations and eight municipalities to create dementia-friendly environments in social housing areas with a special focus on persons with dementia living alone. The project runs from 2019-2021 and focuses on three initiatives:

The first initiative concerns optimizing the cooperation between the municipality and the social housing organization. The aim is to make it easier for the operating personnel in the social housing areas to acknowledge whom to contact in situations of concern for a resident. By sharing this information, the assumption is that the cooperation between the parties involved contributes to an earlier detection of a resident's dementia. Further, it enables the municipality to better reach out and help the resident with dementia living alone.

The second initiative focuses on disseminating basic knowledge of dementia among operating personnel and other residents in the social housing area to become Dementia Friends. Basic knowledge of dementia dissemination to the operating personnel is the primary focus, as it is often the operating personnel who encounter situations where a resident with dementia needs help.

The third initiative concerns the physical indoor and outdoor accessibility for residents living with dementia. In this project, the Danish Building Research Institute has developed a guide on how to create dementia-friendly environments in social housing areas based on the needs of residents with dementia. The project finishes in 2021 but a model of how to expand the concept to more social housing areas is currently in progress.

QOP3-43. Culture, Alzheimer and the Covid-19 pandemic

Lorène Gilly, Volodia Tourtchine

France Alzheimer

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.

Virtual visits

To bring joy and support to the people in need, since June, 2020, France Alzheimer, in partnership with The Swisslife Foundation, has decided to organise virtual visits of museum for people with dementia and their caregivers. These events are organised 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 of art, 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.

Maintaining the link and encouraging openness

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 around the works of art 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.

QOP3-44. Assessing and Improving Health Equity and Access to Healthcare to African-Americans with Alzheimer's Disease

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Background: African American populations are disproportionately impacted by Alzheimer's disease (AD) relative to their Caucasian counterparts as a result of differences in lived experiences and social determinates of health. Not only are African American populations twice as likely to develop AD, but African American populations are also less likely to receive appropriate care compared to Caucasian Americans.

Objectives: This project aims to explore evidence of racial disparities in AD diagnosis and treatment, examine the social and economic costs of delayed and non-treatment of African American populations, and provide recommendations to advance equity in AD diagnosis and treatment.

Methods: The methodology consisted of two streams of data collection, a literature review and key informant interviews. A targeted literature search was used to identify articles and research reports domestically published through 2021 regarding AD and racial disparities, social and economic burden of disparities, and potential interventions to address disparities. From this, 41 articles were reviewed. Twenty experts were identified and interviewed to assess current perspectives related to barriers and solutions to advance health equity in AD.

Results: The literature review and interview process highlighted persistent, racial disparities in AD diagnosis and treatment, rooted in the long history of systematic racism. Challenges in overcoming racial disparities in AD diagnosis and treatment are grounded in multifactorial challenges at all levels of the socioecological model, including, but not limited to, disparities in access to quality education and information, access to healthcare, economic stability, community support, and pharmaceutical research and development processes. Suggested interventions to advance racial equity in AD diagnosis and treatment range from strategic community engagement models to policies addressing diversity in clinical trials.

Conclusion: To achieve racial equity in AD diagnosis and treatment, solutions moving forward must engage, support, and be implemented at all levels of the socioecological model.

QOP3-45. Dementia prevention through a personalized medicine methodology, based on Artificial Intelligence and Machine Learning: the European LETHE project

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Dementia and Alzheimer's disease (AD) prevention is a global public health priority. Effective disease modifying drugs are not yet widely available, but a multidomain lifestyle intervention (FINGER randomized controlled trial, RCT) has been shown to improve cognition and other related outcomes in older adults from the general population at-risk of developing dementia. FINGER combined healthy balanced nutrition, physical exercise, cognitive training and social activities, and vascular/metabolic risk management, in a large-scale, long-term RCT. Findings from FINGER and other RCTs also emphasized the need for personalized approaches, where preventive interventions are tailored to individuals' risk profile and maximize their prevention potential. Building on FINGER successful experience, the LETHE European Consortium aims to develop algorithms and tools for personalized risk profiling, using Artificial Intelligence and Machine Learning methodology, while leveraging on existing data from observational studies and the FINGER RCT.

LETHE also aims to establish a digitally supported multidomain lifestyle intervention for the prevention of cognitive decline, based on the evolution of the FINGER model. The LETHE model will include individualized risk profiling, personalized recommendations for risk reduction, personalized feedback and support. The LETHE solution will be tested in a feasibility, multinational trial validating the achieved improvements. The overall aim is to develop a personalized prevention model for people at risk of cognitive decline, empowering people in relation to their brain health by a healthy lifestyle and proper vascular care. The scalability of digital solutions tested in LETHE can also inform the development of large-scale and cost-effective programs for dementia risk reduction and prevention.

To ensure that key aspects of the LETHE project are informed by the meaningful contribution of people affected or with an interest in dementia and brain health, Alzheimer Europe organises public involvement (PI) activities.

LETHE is supported by the EU Horizon 2020 funding programme.

QOP3-46. Projections of quality adjusted life years lost due to dementia, 2020-2050: a population-based microsimulation study

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Erasmus MC

Background: The future burden of dementia on patients and caregivers is expected to increase due to population ageing, but no published studies have examined the number of quality adjusted life years (QALYs) lost while accounting for established declines in age-specific dementia incidence.

Methods: We developed a dementia microsimulation model that synthesizes population-based data from the Rotterdam Study with changes in demographics between birth cohorts in the Netherlands from the early 1900s onwards. We assumed disutility values for patients and caregivers specified by dementia severity and setting (home vs. institutional care). We determined the life years lived with dementia and the QALYs lost due to dementia for both

patients and caregivers until 2050 for three different dementia incidence trend scenarios: 1) stable age-specific incidence, 2) linear decline by 13% per decade, 3) nonlinear declines averaging 13% per decade.

Result: Assuming a stable age-specific incidence resulted in 467,000 life years lived with dementia in the year 2050, corresponding to a 156% increase compared to 2020. The number of QALYs lost due to dementia for patients and caregivers for 2050 was 149,000 and 22,000, respectively. In contrast, the linearly declining trend resulted in 299,000 (95%CI: 234,000–375,000) life years lived with dementia in 2050, up 68% (95%CI: 39–102%) from 2020, and a number of QALYs lost for patients and caregivers of 96,000 (95%CI: 75,000–120,000) and 14,000 (95%CI: 11,000–18,000), respectively. Results for various non-linear declines fell between the stable and linear trend.

Conclusion: The future burden of dementia is highly susceptible to secular trends in age-specific incidence, with the number of lost QALYs amendable by one third for patients as well as caregivers if previously reported incidence trends can be maintained until 2050. These projections foster hope for curbing the dementia epidemic in high-income countries and underline the need to similarly fulfil preventive potential worldwide.

QOP3-47. “We want to participate!” – The journey of a public library, museum and information service point towards dementia-friendliness

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The project “A library for everyone - the dementia friendly library Wiener Neustadt” aims to foster social participation of people with dementia and their caregivers as well as to contribute to de-stigmatization and to enhance health-literacy in the public. It consists of three phases: the needs assessment, the intervention phase and the transfer/sustainability phase. The participatory health research (Hockley et al., 2013) project needs assessments included focus groups with caregivers of people of dementia and walking interviews with caregivers and people living with dementia.

Despite the changes necessitated by covid-19, especially the distance rules, we were able to implement the planned measures with adjustments. We attribute this to the high level of commitment of the organisations and individuals involved. Workshops dealing with topics like communication, environmental design issues and health literacy were held with the staff from the regional museum, the public library and the information service point from the city hall. All three organizations started practice projects to work against stigma and ensure participation of people living with dementia in the community. All interventions were developed collaboratively in the steering group with the local self-help group Alzheimer Austria including an activist living with cognitive impairment. We present findings from the first phase of the projects and first results from the practice projects.

Hockley, J. M., Froggatt, K., & Heimerl, K. (2013). Participatory research in palliative care: actions and reflections. Oxford University Press.

QOP3-48. Effects of an educational intervention on quality of life and knowledge about dementia, among family caregivers of people with dementia and with a migrant background

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¹Nivel, ²Alzheimer Nederland, ³

Background: Dementia care and support services are less often used by persons with a migration background than by persons with no migration background. In the Netherlands, this specifically yields for people with a Turkish or Moroccan background. This might in part be related to limited knowledge about dementia and care and support services. Timely access to care and support is not only important for persons with dementia, but also for their family caregivers, since it can contribute to lowering their care burden. In this study we examined the effects of an educational peer group intervention on knowledge about dementia and on health-related quality of life (HRQL) among family caregivers of persons with dementia from Turkish or Moroccan origin.

Methods: A clustered randomized controlled trial was conducted to examine the effects of the intervention on knowledge about dementia and on HRQL (consisting of three components: emotional wellbeing, social wellbeing and general health status). The intervention (two interactive group sessions) entailed providing information about dementia and care options. Multilevel analyses were conducted using data collected before the start of the intervention (baseline), directly after the intervention (one to two weeks after baseline) and three months after the start of the intervention.

Results: Data for 386 participants was analyzed. Improvement in knowledge about dementia over time was significantly greater in the intervention condition than in the control condition. Furthermore, a significant effect on emotional wellbeing was measured directly after the intervention and on perceived general health status three months after the intervention. No effect was found on social wellbeing.

Conclusion: Culturally sensitive peer group education on dementia and on care options, can to some extent enhance knowledge about dementia as well as HRQL in the short term, among family caregivers. Peer group education about dementia could therefore contribute to multicultural dementia care.

QOP3-49. White Matter Network Structure as a Substrate of Cognitive Reserve in Cerebral Small Vessel Disease: The Maastricht Study

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Objective: Visible abnormalities of cerebral Small Vessel Disease (cSVD) are associated with cognitive decline and increased dementia risk. However, there is heterogeneity in effect of cSVD burden on cognitive outcomes, which might be explained by inter-individual differences in cognitive reserve (CR). These differences may partly arise from variations in white matter connectivity networks. We sought to explore the role of connectivity in CR by studying whether connectivity measures modify the association between MRI-derived cSVD burden and cognition scores in a large population-based dataset.

Methods: The Maastricht Study is a population-based cohort study with extensive phenotyping, enriched for type-2 diabetes. Cognitive test scores, structural connectivity data, and 3T MRI were available for n=4798 participants (mean age(±SD)=59.2(±8.7), 50.2% male). Images were assessed by Fazekas score (≤1 or ≥2), presence of microbleeds and lacunar infarcts in terms of dichotomous measures, and combined into a cSVD score (range 0-3). Node degree (ND), a measure of the mean interconnectedness of nodes in the structural connectome, was used as connectivity score. A composite cognition score (CS) was taken as the mean score across three cognitive domains (Memory, Information Processing Speed and Executive Function). Multivariable linear regression analyses were used to investigate the interaction effect between ND and cSVD score on CS, adjusted for age, sex, education, and diabetes status.

Results: Higher cSVD score was associated with lower CS. ND modified the association between cSVD score and CS in the adjusted model (p for interaction p<0.004). Clear cognitive differences were present across cSVD levels with low ND; this association was attenuated in a dose-response fashion with increasing ND.

Conclusions: Structural ND provides evidence of an individual's CR based on white matter organization in the presence of damage from cSVD. Even in participants with the highest cSVD burden, sufficiently high ND was associated with normal CS.

QOP3-50. "Mind Your Words" - Promoting Dementia Inclusive Language and Change of Perception in Dementia Care in Hong Kong

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Jockey Club Centre for Positive Ageing

Stigmatising attitudes towards mental and related disorders have long been a significant factor in mental health policies in Hong Kong. It is commonly used 'the demented', 'demented patients or sufferers', 'wandering', 'burden', etc., to describe people with dementia in the working context in Hong Kong. The particular terms were directly translated into Chinese or Cantonese words with a very negative connotation. With the support of Ms Kate Swaffer and joining Dementia Alliance International, a qualitative research with in-depth interviews among people with dementia and frontline care staff in Hong Kong was done to better understand the Chinese terminology of dementia care. The findings showed that the use of language would affect the self-perception of people with dementia and the perception of care practitioners. With the back translation of the Chinese terms in Hong Kong, people with dementia were being labelled as "madness", "insane", "trouble-maker", "naughty child", etc. Regarding the unmet needs of people with dementia, their responsive behaviour was identified as "over-demanding" and "psychiatric symptoms". By highlighting how the medical perspective on dementia denies the importance of taking the subjective views of people with dementia into account and empathising with their self-perception, this research showed how focusing on their physical care at the expense of their emotional needs can undermine their quality of life.

A paradigm shift needs to occur in the care model and policies for planning dementia care services in Hong Kong in response to that problem. Against those stereotypes and generalisations, public education and training should be organised to focus on the perspectives of people with dementia and their rights to speak out and be heard. Undoubtedly, the government should stop validating negative perceptions of dementia and people with the condition but instead stress the importance of person-centred care and a dementia-friendly approach in dementia care services.

QOP3-51. AI-Mind: artificial intelligence as key for dementia prevention for people affected by Mild Cognitive Impairment

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More than 10 million Europeans show signs of Mild Cognitive Impairment (MCI), a condition defined by minor deficits in cognitive functions, e.g. memory, but not severe enough to significantly impact activities of daily life. Although MCI is associated with cognitive changes significant enough to be noticed by the person affected and by family members, it is not a disease. However, as 50% of the people with MCI have a higher risk of developing dementia later in life, early screening assessment would allow early risk evaluation and facilitate preventive interventions against a high-impact neurocognitive disorder.

AI-Mind, a five-year project funded by the European Commission involving fifteen research organisations, hospitals, and companies from eight European countries, aims to use artificial intelligence (AI) to enable clinicians to screen people with MCI at risk and not at risk of developing dementia. During its lifetime, two new AI-based digital tools will be developed: the AI-Mind Connector will identify dysfunctional brain networks, and the AI-Mind Predictor will assess the dementia risk by using data from the Connector, advanced digitalised cognitive tests, and genetic biomarkers. The integration of these two tools in a cloud diagnostics-support platform will facilitate and accelerate the identification of both functional brain network disturbances and dementia risk, providing personalised patient reports for further guidance and preventive or prolonged disease management recommendations.

A naturalistic observational study will be conducted, to validate the AI-Mind tools in a clinical setting. The multicentre study will take place in Norway, Finland, Italy and Spain, and will involve a total of 1,000 participants with MCI. Besides introducing the background and describing the objectives of the project, the recruitment process of participants and lessons learned will be presented.

Poster presentations

POS1. (Poster presentation) Resilience and COVID-19

POS1-01. Day care COVID-19 & Dementia During the covid we looked for ways to keep in touch with the clients (elderly migrants). Co-creation is very important in this

Sevilay Luiken-Dalli¹, Larry Gardiner²

¹IMEAN Care B.V., ²IMEAN Care

COVID-19 has affected everyone, including the migrant elderly with dementia. IMEAN care is a culture-sensitive daycare for migrant elderly with dementia. We saw what Covid-19 did to the elderly, they became isolated, lonely and fearful. Many of these elderly people went to their country of birth each year for at least 3 months. This was no longer possible because of the lockdown, the homesickness and fear increased among these elderly people. They were afraid that they would no longer be able to return to their native country. Relatives have died that they have not been able to say goodbye to or who travel for the funeral. IMEAN care actively maintained contact with the clients during the lockdown. We have not been idle and have used healthcare technology in co-creation. We noticed that these elderly people are not digitally skilled and have never heard of healthcare technology. We have kept them active through this co-creation. We will tell you how we did this during our presentation. We don't talk about the elderly, we talk with them! We tailor the activities to the target group on the daycare.

POS1-02. Relationship between built environment and dementia during covid-19 pandemic

Silvia Mangili, Alessandro Morganti

Politecnico di Milano

The increase of the elderly population (17.4% of the total population over 65 years old in Europe in 2009, and 20.3% in 2019) is related to the progressive growth of age-related diseases. Patients with cognitive impairment often find themselves leaving their homes to move into nursing homes; in fact, 50% of the residents in these facilities suffer from dementia, and 40% in severe form. Today, it's renown that the built environment has a very strong impact on people with dementia's health, due to the deterioration of the patient's psychophysical functions resulting from the progression of the disease, like problems in orientation. This relationship was stressed during the pandemic, as patients with dementia were forced to social distancing and segregation within facilities where the spread of the virus was exponential.

Patients with dementia who lived in nursing facilities were among the greatest victims of the pandemic because of their frail condition (average 2.5 times more than pre-pandemic period).

The purpose of the study is to investigate the relationship between the built environment and patients with dementia during the covid-19 pandemic, in order to identify the most critical environmental characteristics.

A systematic literature review has been run, combining selected keywords through Boolean operators. 86 articles were found among scientific literature. After full text analysis, 8 articles were selected.

From the analysis, five main factors emerged as crucial for safety and well-being of people with dementia that live in facilities: facility design, ward size, indoor air quality, use of technology, and social aspects.

The design strategies of these categories will be detailed below.

These findings show the importance of rethinking spaces for patients with dementia focusing on resilience, flexibility and security of facilities, ensuring the well-being and engaging patients in physical, social and occupational activities that are necessary to slow down psychophysical decline.

POS1-03. Overcoming the COVID-19 constraints on person-centred dementia care: a narrative inquiry of experiences of residential care staff in Belgium

Anne Martin, Eleni Hatzidimitriadou

Canterbury Christ Church University

Person centredness is a non-negotiable basis for good standards of dementia care. The COVID-19 pandemic however rattled global systems of health and social care to the detriment of person-centred dementia care. This presentation illustrates the experiences of residential care staff of overcoming COVID-19 constraints on person-centred dementia care in Belgium. A narrative inquiry engaged residential care staff to explore their perspectives on how dementia care amidst the COVID-19 pandemic evolved over time. Criterion purposive sampling aimed to include only participants involved in caring for people with dementia in an organisation providing a multitude of other services. The narrative correspondence inquiry elicited three in depth accounts of the transition of overcoming the COVID-19 constraints on person centredness in a residential dementia care context. The transition process as a unit of analysing the content of participants' narratives generated four overarching themes comprising: the chaos in uncertainties; restructuring the service; transition shock; and reorienting the duty to person centred dementia care. The anxiety surrounding the risk of COVID-19 infections, challenges of confining residents to their rooms, unfamiliar infection spread control procedures and task-oriented care processes destabilised the residential care environment. Measures applied with an emphasis on minimising risks of COVID-19 cross infections contravened the core values of person centredness in dementia care. However, co-locating staff from different specialisms on the dementia care unit to contain the ripple effects of COVID-19 engendered new ways of getting to know people with dementia and collaborative passions for

refocusing care processes. The study identifies opportunities to rethink the usual structure of residential dementia care and the need to establish values and priorities that enable continuous person centredness in predicaments such as pandemics.

The study is part of the Community Areas for Sustainable Care and Dementia Excellence (CASCADE) project funded by Interreg 2 Seas Mers Zeeën [2S02038]

POS1-04. Dementia and covid-19 – Scotland's National Action Plan to continue to support recovery for people with dementia and their carers

Jan Beattie, David Berry

Scottish Government

As the pandemic progressed during 2020 we recognised the need to address what we were hearing about – that people living with dementia and their family carers were disproportionately impacted by the pandemic.

In the autumn of 2020 we set up a series of structured conversations with people living with dementia, family carers, community groups and dementia care providers to establish what had helped them get through the pandemic and what still needed to be done in the short and medium term. We ran 14 virtual events that engaged directly with 100+ organisations and individuals. An online questionnaire was completed by 99 organisations or individuals.

The resulting plan is a collaboration between The Scottish Government, COSLA the local government umbrella organisation and health and social care organisations from across Scotland. It explains how the Scottish Government is working, and plans to work, with others to strengthen community resilience, support people with dementia and their families to continue to get the right care and support at the right time as we live with, come through and recover from, the pandemic.

People with a diagnosis, family carers and social care and health professionals as well as those working in a variety of community settings, all welcomed the opportunity to share their experiences of the pandemic and contribute to the plan which they believe is an important tool in re-mobilising services and supports and re-building quality of life and wellbeing.

We want to share both the plan and the inclusive process of developing it.

POS1-05. The role of social health in dementia during the SARS-CoV-2 pandemic

Marta Lenart-Bugla¹, Maria Maćkowiak¹, Adrianna Senczyszyn¹, Dorota Szczesniak¹, Elzbieta Trypka¹, Katarzyna Lion², Joanna Rymaszewska¹, Rabi Chhattat³, Mark Gabbay⁴, Wendy Moyle², Ilaria Chirico³, Clarissa Giebel⁴

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Background: 'Social health' (SH) can be defined as the role of social ability in achieving a dynamic balance between opportunities and limitations. In the context of dementia, the term covers the individual's ability and independence to participate in social activities along with the influences of the surrounding social network. The SARS-CoV-2 pandemic and the related limitations in access to medical and social services contributed to the social isolation of people from high-risk groups. This situation highlighted the role of social factors and their relationship to the mental health of people with dementia.

Methods: Qualitative and quantitative designs were applied to present social health and its determinants of people with dementia aged 65 and over in relation to social care service closures and self-isolation during the SARS-CoV-2 pandemic. The data from the cross-country population-based study and the semi-structured telephone interviews was analyzed and integrated across Poland, UK, Australia and Italy.

Results: We identified the level of SH and its determinants using the original Social Health Index in relation to self-isolation and changes in the use of services before and during the pandemic among the people with dementia. Moreover, the qualitative data showed the indirect consequences of the introduced restrictions in the access to social care service and social isolation. Limited social support contributed to deficits in social health and well-being of the targeted group.

Conclusions: The obtained results indicate the importance of the current global epidemiological situation in the context of social health among people at higher risk, especially those living with dementia.

POS1-06. Online Adaption of Accelerated Experience-Based Co-Design Methods for use in Dementia Carer Research Following the Covid 19 Pandemic

Jl Cross, Jane L Cross, Eleanor Masters, Yasha Najafi

University of east anglia

E-health interventions improve carer well-being, reduce costs and assist moving to digital health post-COVID-19. CARECOACH NIHR programme, is adapting a Dutch dementia carer intervention for the UK. Accelerated experience-based co-design (AEB CD) was chosen to engage dementia experienced staff (DES) and carers of people with dementia (PWD) in this adaption. AEB CD gathers carer and staff experiences, using them for co-design workshops. Face-to-face sessions were impossible with COVID-19, so we tested video call software for usability, accessibility and cost, then explored data gathering online following AEB CD principles.

We tested Microsoft Teams, Zoom, and Blackboard Collaborate for usability and accessibility with a carer of a PWD. A second meeting tested the proposed AEB CD protocol with remote-control given to them to engage with the intervention and feedback on usability, design, and relevance. Our DES engaged with the coach training in the same way. Audio and visual data from the session recordings was transcribed post-hoc and thematically analysed.

Zoom was preferred by both for usability, accessibility, practicality, and lack of cost. The remote-control function was simple and allowed independent exploration of the intervention. Font size was small, and participants need a larger

screen. Scrolling on a tablet was problematic. Older carers may require technical help. The DES reported a time delay when scrolling. Both reported feeling pressure with researchers watching.

Researchers found Zoom most practical, observing the participant browsing the intervention and recording the interview in multiple file formats for post hoc analysis. The '40-minute maximum call-time' plan had no cost, but interviews typically lasted longer necessitating multiple calls. Two researchers were essential to facilitate full engagement and record observational data.

Researchers/clinicians can engage service-users remotely to enhance services using AEBCD and Zoom. Participants can engage with materials, at no cost, in easily recordable sessions. Upgraded Zoom and a PC or laptop are preferable.

POS1-07. Telehealth and telecommunication in nursing homes during COVID-19 anti-epidemic measures in The Netherlands

Ruslan Leontjevas¹, Inge Knippenberg¹, Christian Bakker², Raymond Koopmans², Debby Gerritsen²

¹Open University, ²Radboud University Medical Centre

Our study on challenging behavior in nursing home residents in The Netherlands showed initiatives of nursing home staff regarding telecare during the first COVID-19 pandemic wave. Staff facilitated telecommunication to help residents in staying connected with their loved ones during the visitor ban. To improve the quality of nursing home care in the future, it is important to learn from these experiences. This survey during the second pandemic wave at the end of 2020 aimed to learn, from the perspective of treatment staff, about experiences with telecommunication during the COVID-19 pandemic, telecare for challenging behavior, and working remotely.

In total, 175 professionals participated, of whom 69 (39%) were psychologists, 61 (35%) therapeutic activities coordinators, 38 (22%) elderly care physicians or nurse practitioners and 7 other professionals. Responses to open and closed questions showed that face-to-face contacts were preferred above telecommunication. However, most professionals would prefer the continuation of telecommunication for residents and their loved ones after the pandemic in addition to face-to-face contacts.

Regarding the management of challenging behavior, psychologists, physicians and nurse practitioners considered it possible to continue several tasks remotely, e.g. consultations, evaluations, and meetings and mutual consultations. The majority of activities coordinators reported that they could not work remotely.

In general, working remotely was considered efficient and workload-reducing. However, participants thought that it could worsen their job satisfaction, and the quality of care. The need for more technical support was expressed.

To conclude, the COVID-19 pandemic accelerated the move to telecare in nursing homes. It is important to provide a solid infrastructure, to educate and train the staff and residents regarding telecommunication, and to integrate telecare elements in daily workflows. Research is needed on the effects of telecare on job related outcomes, and on the quality of care and the quality of life of residents.

POS1-08. "Here for you"

Ioanna Alpertis¹, Ilektra Spyrou¹, Panayiota Strantzali¹, Kleantes-Konstantinos Pantelis¹, Nasia Paradisi¹, Efthymia Efthymiopoulou²

¹IASIS NGO, ²Panteion University

Connect your city application is an application for the mobilization of young people in terms of volunteering, which is constantly changing, renewing and transforming according to the needs of the times.

The Connect Your City app is a platform for meeting and searching for volunteers for individual and group activities related to the environment, support, education and entertainment. The application was particularly popular during the Pandemic and mobilized many young people to participate in various activities. One of them is the "Here for You" action invites young people who have a person with Alzheimer's who needs support to contact the Community Intervention Service. This Service is staffed by staff and a group of trained volunteers who help lonely people to meet their basic daily needs and a team of volunteer Psychologists who provide support either through tele-counseling or at home to those who do not have the means.

Beneficiaries receive free individual supportive care programs, as well as sessions of early assessment of cognitive functions and the creation of individual empowerment interventions via tablet or at home. Both for the direct beneficiaries and for the indirect ones, referring to their caregivers, regular weekly meetings have been created through zoom with the aim of support, psychoeducation and the creation of a support network between them. Every day there is telephone monitoring and monitoring (follow up) of the beneficiary's condition.

The period from April 2020 until today have been supported through this process of which are people with Alzheimer's disease. The volunteers of the program amount to about 100 people, of which 35 are Psychologists. There have been a total of tele-counseling sessions and psycho-educational activities for their caregivers.

The Connect your city application is here to bring people closer through technology so that there is more meaningful communication and support.

POS1-09. WITHDRAWN

POS1-10. Staff's attitude towards the use of telepresence robots in Canadian long-term care homes

Lillian Hung¹, Mineko Wada², Joey Wong², Evangeline Tsevis², Chantelle Recsky¹

¹University of British Columbia, ²IDEA lab University of British Columbia

Social isolation is a common issue in Long-Term Care (LTC) and is associated with adverse outcomes such as reduced well-being and loneliness. During the COVID-19 pandemic, the loss of connections of older people with their families in LTC has been detrimental and severely impacted quality of life. Since the public health order restricted non-essential outings and social gatherings, technology that allows remote communication has been increasingly considered in long-term care (LTC) homes to address loneliness in older adults and reduce residents' and healthcare workers' risk of infection. This study investigates the attitudes of healthcare workers and staff towards the use of telepresence robots in LTC in Canada. We designed a cross-sectional online survey examining attitudes towards the acceptance, usability, prospected impacts, safety, and costs of using telepresence robots in LTC. 180 staff participated in the survey. They are point of care staff and leaders in two Canadian LTC homes. We applied descriptive and inferential statistical analysis to investigate how healthcare professionals, care staff, and administrators perceive the usability, impacts (e.g., care, residents' quality of life), technology acceptance, safety, and costs of using telepresence robots. In this presentation, we will explain the associations between those variables and participants' demographic characteristics. We will discuss how telepresence robots are perceived as feasible and acceptable by staff in LTC settings. Concerns, strategies and recommendations will be examined to inform implementation in LTC homes.

POS1-11. Reviewing the impact of the COVID-19 pandemic on Join Dementia Research volunteer registrations and study recruitment in the United Kingdom

Adam Smith, Professor Martin Rossor

University College London

Since its launch in February 2015, Join Dementia Research (JDR) has played a key role in delivering the UK Government's Challenge on Dementia. This had a stated ambition that England should be the best country in the world for dementia care and support, and for research into dementia and other neurodegenerative diseases.

By entering basic demographic and health information, JDR matches members of the public to research studies, making it easier to participate in research, as well as streamlining the recruitment process for researchers. Anyone aged over 18 can volunteer, people with and without dementia and carers. Studies recruiting through JDR range from clinical trials of new treatments to surveys identifying improvements to the quality of life of people with dementia.

JDR relies on a flow of new volunteers registrations, to provide researchers and their studies with sufficient participants. The service is promoted in various ways, however the primary source of referrals for people living with dementia is NHS Memory Clinics.

Since launch the service has enjoyed steady growth; in December 2019 the service had reached a monthly average of 103 volunteers with dementia and 504 without. With a one month maximum of 160 people with dementia and 1000 people without. Since January 2020, when the impact of the pandemic was first being felt, registrations fell to a monthly average of 50 people with dementia and 250 without – representing a 50% decrease.

Despite the decrease in new volunteers, study recruitment from the service increased in 2020 particularly to observational studies, and large survey studies.

In this presentation we present new data, to demonstrate the impact of the COVID-19 pandemic on research volunteering and study recruitment and consider the increasing importance of JDR and similar services in a changing landscape which is moving towards remote and digital delivery

POS2. (Poster presentation) Care and support

POS2-01. Recommendations for Implementing Pet Robots for People with Dementia in Nursing Homes: A Mixed Methods Study Protocol

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Background: Social robots, including pet robots, are promising technological interventions to benefit the psychosocial health of people with dementia (PwD). Pet robots have been found to improve mood and social engagement and reduce psychotropic drug use among PwD. Nevertheless, very few studies have investigated factors that affect their application in the real-world. This highlights the need for implementation research to bridge the gap between research and practice.

Objectives: The objectives of this study are to (i) understand multilevel barriers and facilitators to the implementation of pet robots for PwD in nursing homes, and (ii) establish consensus among multilevel stakeholders regarding corresponding implementation strategies.

Methods: A sequential exploratory mixed method design will be used. First, a descriptive qualitative study will be conducted to understand multilevel stakeholders' perceptions of barriers and facilitators to the implementation of pet robots in nursing homes for PwD. This study will be guided by the Consolidated Framework of Implementation Research (CFIR). Semi-structured interviews will be conducted with PwD, care workers and organisational leaders in nursing homes. Next, a modified Delphi study will be conducted to gather expert consensus on implementation strategies to address barriers identified from the qualitative phase. The Expert Recommendation for Implementing Change (ERIC) will be used to guide the selection of implementation strategies to constitute the initial statements. The expert panel will comprise four groups of stakeholders.

Discussion: This will be the first study to develop recommendations for implementing pet robots. This study is expected to be completed by autumn 2022. Findings will be relevant to identify priority areas for future research, and to guide the application of pet robots in real-world practice to benefit the psychosocial health of PwD in nursing homes.

POS2-02. The Danish version of QUALIDEM- a dementia-specific quality of life instrument

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Background: To target factors of importance among individuals with dementia, the concept of quality of life (QoL) needs to be embraced. QUALIDEM is a dementia-specific QoL instrument that allows a proxy-based QoL rating in all stages of dementia. This study aimed to translate, cross-culturally adapt, and test the psychometric properties of the Danish version of QUALIDEM.

Method: All items underwent forward and backward translation by bilingual academics. Persons with dementia were recruited from 28 health care units in a Danish municipality. The severity of dementia was determined using a pragmatic approach allowing the site team to trichotomize the disease (mild, moderate-severe, and very severe) before scoring the QUALIDEM. The psychometric properties of item characteristics, construct validity, internal consistency, test-retest reliability, measurement error, and floor and ceiling effects were determined.

Results: A total of 169 persons with dementia, aged 51-103, were included. The construct validity testing showed that the overall proportion of correctly hypothesized correlations was 83%. Testing for internal consistency, Cronbach's α ranged from 0.65-0.85 in mild-severe dementia with three out of nine subscales having values below 0.7. For very severe dementia, Cronbach's α ranged from 0.44-0.81, with three out of six subscales having inadequate values. For test-retest reliability, the ICC ranged from 0.56-0.86. Using the "scale width" method, there was a marked ceiling effect in all subscales ranging from 30.6% to 87.7%.

Discussion: The QUALIDEM was successfully translated and cross-culturally adapted into Danish. Most subscales show acceptable internal consistency and test-retest reliability. However, substantial measurement error and ceiling effects were present in most subscales.

Conclusion: With few exceptions, the subscales of the Danish version of QUALIDEM appear to have acceptable validity and reliability. Future research should address the ceiling effects as they may impede the detection of clinically relevant change over time.

POS2-03. Barriers and facilitators to digital health solutions: Perceptions of older adults with mild cognitive impairment and caregivers of people living with dementia

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¹Université Laval, ²Vrije Universiteit Brussel, ³Université du Québec à Chicoutimi

Background: The prevalence of mild cognitive impairment and dementia is steadily increasing for older Canadian adults. Digital health technologies offer solutions to promote home care and autonomy for this population, and support informal caregivers in their roles. The goal of this research project is to develop a web-based multicriteria decision support tool to support the implementation of digital health solutions adapted to their needs and preferences for older adults with mild cognitive impairment or dementia and their informal caregivers.

Methods: This study followed a qualitative descriptive design. We conducted semi-structured interviews with elderly people with mild cognitive impairment (N = 10) and caregivers of people with dementia (N = 7) to develop a portrait of their current knowledge and perceptions regarding the use of digital health solutions. We completed thematic analysis, using audio recordings. We coded in double and compared themes of one interview for each sample (n=2) to improve the quality of the data analysis.

Results: Digital health solutions have several benefits to promote home care and autonomy for people with cognitive disorders. The major benefits identified are the sense of security and peace of mind, especially for caregivers, and the possibility to support independent living. Barriers identified by our samples included: complexity of usage and implementation, high cost, lack of reliability and lack of social support to help in their use.

Conclusions: People living with cognitive impairments and their caregivers are in favour of technological developments and would use digital health solutions to support their daily activities. Although digital solutions are promising to support the independent living of older adults with cognitive impairments, our results show that implementation could be facilitated by increasing affordability, ease of use and reliability.

POS2-04. Effects of holistic program on cognitive function and CSF neurodegenerative biomarkers in Alzheimer's disease: a randomized, double-blind, placebo-controlled trial

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Objective: Our study aimed to assess the effect of a 12-month holistic program on cognitive function and cerebrospinal fluid (CSF) amyloid beta (A β)-tau related biomarkers in subjects with Alzheimer's disease (AD).

Methods: This was a randomized, double-blind, placebo-controlled trial from 2 Greek geriatric clinics Maison Sofos and General Hospital of Santorini. 40 AD subjects were randomly divided into intervention and usual care groups. Participants received 12-month 1000 IU/day of vitamin D or starch granules as placebo, cognitive empowerment and yoga exercise twice/week. Cognitive assessment included Hopkins verbal learning test, Stroop test, Trail Making Test (A&B), Frontal assessment battery, clock drawing test, Geriatric Depression Scale, Brief Visual Memory Test. A β -related biomarkers were measured at baseline, 6 months and 12 months.

Results: Significant lower CSF A β 42 and tau levels were found in the intervention group over the control group after 12 months follow-up ($p < 0.001$). Significant lower scores in Hopkins verbal learning test, Stroop test, Trail Making Test (A&B), Frontal assessment battery, clock drawing test, Geriatric Depression Scale, Brief Visual Memory Test intervention group over the control group after 6 months follow-up ($p < 0.001$). According to mixed-model analysis, intervention group had a significant improvement in Hopkins verbal learning test scale during the 12month follow-up period ($p < 0.001$)

Conclusions The proposed holistic program significantly improved the cognitive function, mood and neurochemical status, and the positive changes were maintained at the 3-month endpoints in subjects with AD. Larger scale longitududes trials are needed to confirm these results.

POS2-05. Self-experience practices in dementia care: A qualitative study in four European countries

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Martin Luther University Halle-Wittenberg, Institute of Health and Nursing Sciences

Self-experience or simulation practices are widely used in education and training for healthcare professionals, but rarely for the specialized care for people with dementia. These interventions such as Virtual Dementia Tours (VDT), role-playing games and theatre laboratories can enhance the empathy and understanding of healthcare professionals and informal caregivers for the lived experience of dementia and thus improve the quality of dementia care.

As part of the transnational Erasmus+ project INTenSE (including Germany, Ireland, Italy and the Netherlands), focus groups were conducted to explore self-experience practices and to enhance the understanding of developing, implementation, conducting and evaluation of self-experience/simulation practices in dementia care. Interview guidelines for specific target groups were developed and tested.

Across all countries, 13 focus groups and two single interviews with 48 participants were conducted. Participants were (healthcare) professionals, informal caregivers and people with dementia. A summarising qualitative content analysis was performed.

Professionals explained the need for improving competencies like empathy, communication skills and dementia specific knowledge. People with dementia emphasized that their life is determined not only by the dementia. They also stated that they experience situations which could not be explained. Informal carers pointed out that simulation might stress participants and that the technical competence should be taken into account. Throughout all perspectives, participants expressed open-mindedness for innovative, technology-based interventions to improve understanding for people with dementia. Overall, the focus groups' results emphasize that simulations should be combined with knowledge transfer. Furthermore, it is important to acknowledge the individuality of dementia. Self-experience training or simulation interventions must be carefully prepared, and participants should consistently be accompanied before, during and after the simulation experience.

The perspectives of (healthcare) professionals, people with dementia and informal caregivers still have to be included in the development and implementation of a self-experience training or simulation intervention to fit their needs.

POS2-06. Does getting entangled with thoughts influence the relationship between perceived burden and carer anxiety?

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¹University of East Anglia, ²

Introduction: Cognitive fusion refers to our tendency to become entangled with thoughts and inability to step back from such restricting beliefs. Cognitive fusion is known to moderate the relationship between caregiving-related stressors and depression. However, the moderating role of cognitive fusion on the relationship between stressors and carer anxiety is not fully explored. To inform future carer interventions, this study aimed to explore whether cognitive fusion moderates the relationship between perceived burden and anxiety in family carers of people with dementia.

Method: This study used a cross-sectional design with a sample of seventy-nine family carers, with a mean age of 63.59 (SD=10.53). Most of the carers were female (72%) spouses (49%) taking care of a person with Alzheimer's Disease (42%). The PROCESS computation macro was used to analyse the moderating effect of cognitive fusion (CFQ-7) on the relationship between care burden (ZBI-12) and carer anxiety (GAD-7).

Result: The overall model was statistically significant ($R^2 = .58$, $F(3,74) = 34.64$, $p < .001$), with both cognitive fusion ($b = .25$) and care burden ($b = .15$) positively associated with carer anxiety. The findings also demonstrated a significant interaction term between cognitive fusion and care burden ($b = .01$, $SE = .00$, $p < .05$). When the standardised slope for predicting anxiety from care burden was compared across three different levels of cognitive fusion, a statistically significant slope was found when cognitive fusion was one SD above the mean ($b = .28$) and at the mean ($b = .15$), but not at one SD below the mean ($b = .01$).

Conclusion: Cognitive fusion moderates the relationship between care burden and carer anxiety. Moreover, as the level of cognitive fusion increases, it seems that the relationship between care burden and carer anxiety becomes more robust. This indicates that interventions that undermine cognitive fusion such as Acceptance and Commitment Therapy may be beneficial for preventing increased anxiety among those experiencing high levels of care burden.

POS2-07. MOre NURtering and More Empowerment Nested in Technology (MONUMENT)

Leentje De Wachter¹, Kalina Mikolajczak-Degrauwe², Alexandra Bertrand³, Annabelle Fortuna⁴

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Dementia is a growing social challenge resulting in rising care demands and healthcare costs. While there are efforts to expand formal long-term care services to respond to this growing demand, informal care forms the backbone of long-term care. However, not only is the pool of potential informal carers fast decreasing with an older demographic shift, but informal caregivers also experience a higher caregiver burden. A strong network, more knowledge, insight and skills amongst informal carers as well as engagement in leisure can be promising interventions to relieve this burden of care. Technological applications to support people living with dementia and their informal carers exist, but are often unfamiliar, not adjusted to their specific needs and not introduced at the optimum time in their dementia journey.

The MONUMENT project is a European Interreg 2Seas project (2020-2023) that aims to alleviate the burden of informal carers of people with dementia. Its overall objective is to enable people living with dementia to stay at home for longer by increasing caregivers coping skills and improving their mutual well-being and the quality of their relationships. This will be realised by (1) the implementation of five distinct pilots offering support to informal carers based on the Odense concept; (2) a multilingual digital platform by and for informal carers, consolidating information on dementia-friendly services, and enhancing exchange with peers; (3) the testing and co-creation of technological solutions tailored to the needs of informal carers of people living with dementia; and (4) a socio-economic feasibility study on the MONUMENT model for policy makers and solution actors.

MONUMENT acknowledges the informal carer as an important actor within an effective and integrated care service for people living with dementia. Our poster provides an overview of the actions to be taken.

POS2-08. Effects of individual music therapy on behavior problems and quality of life in people living with dementia in nursing homes: A randomized controlled trial

Anna-Eva Prick¹, Peter Van Domburg², Peter Verboon³, Sietze Zuidema⁴, Annemieke Vink⁵, Jos Schols⁶, Susan Van Hooren³

¹Zuyd Hogeschool, ², ³Open Universiteit, ⁴Rijksuniversiteit Groningen, ⁵ArEZ, ⁶Universiteit Maastricht

Behavioral problems, such as agitation, depression, apathy and aggression, are highly prevalent in people with dementia. These problems have a negative impact on quality of life of both people with dementia and their caregivers and are difficult to manage in healthcare. Psychosocial interventions, such as individual music therapy, to reduce behavioral problems are more preferred than the use of psychotropic medication. An individual music therapy intervention and a receptive music intervention were developed for people living with dementia in nursing homes with symptoms of problem behavior. The music therapy intervention was characterized by active use of music which was constantly tailored to the needs of the person with dementia by the music therapist. The receptive music intervention was characterized by passive listening to personalized music through an iPod with headphones. A randomized controlled trial (N = 172) with three groups, i.e. individual music therapy, receptive music intervention, and control group, was applied in order to examine the effects on problem behavior and quality of life using multilevel analyses. The interventions were given during 3 weeks, 3 times a week on non-consecutive days during 45 minutes. The music interventions and the results will be presented at the congress.

POS2-09. Designing a virtual reality familiarisation environment for older adults living with dementia

Aisling Flynn¹, David Healy¹, Gearóid Reilly¹, Margueritte Barry², Sam Redfern¹, Attracta Brennan¹, Dymphna Casey¹

¹NUI Galway, ²University College Dublin

Introduction: Virtual reality is a technology increasingly being used in the field of dementia care. The emerging nature of this technology calls for the design of virtual spaces which are suited to the dynamic needs of older adults living with dementia. Research calls for adequate introduction and training relating to the technology. Therefore, the design of a familiarisation environment as a pre-requisite to extended VR use was considered important.

The familiarisation environment aims to:

Design a VR space which is evidence-based and tailored to the needs of older adults living with dementia.

Expose older adults with dementia to the basic functionality and interactions associated with fully-immersive VR.

Methods and Analysis: The design of the VR space was informed by the findings of two systematic reviews (Flynn et al., 2021; Healy et al., 2021). The review findings were used to establish design guidelines and considerations for the VR space. These guidelines were used to inform a first-iteration prototype. The prototype was trialed by an advisory partnership which consisted of two people living with dementia.

Results and Findings: Through iterative refinement of the prototype and incorporation of the views of the advisory partnership, the final prototype has been refined. This prototype will be evaluated as part of a participatory action research project. It is anticipated that the training environment will be used as a familiarisation tool for older adults living with dementia and their support person. The environment will be evaluated to explore its perceived usability. This will provide useful information for the design of future VR spaces.

Conclusion: The design of a VR training environment may provide a means of familiarising older adults living with dementia with the basic functionality of the technology and allow them to better engage in subsequent VR spaces.

POS2-10. An integrated digital care collaboration platform to support home-based dementia care: A mixed-methods evaluation

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Background: While extended independent living is preferred by most people with dementia (PwD), it also puts more pressure on their informal caregivers such as spouses or children. The increasing need for support of informal caregivers of PwD has led to solutions including digital platforms to facilitate the organization of care and collaboration among the (in)formal care network. In the Netherlands, the free platform "Caren" has become one of the largest care collaboration platforms supporting informal care. However, insight into its added value and boundaries is still lacking. This study therefore aimed to analyse the experiences of informal caregivers of PwD with the care collaboration platform "Caren".

Method: A large-scale cross-sectional online survey was offered to users of Caren, covering questions related to a set of evaluation criteria: usability, impact on caregiver-caregiver communication, impact on the organization of care, trust in the platform, and intention to continue using it. A number of users was invited to take part in interviews to provide more context to the survey results.

Results: 7118 informal caregivers of community-dwelling PwD (M(age)= 58.7; 97% caring on distance) completed the survey. Most of them used the platform more than 6 times per week (68%). Overall, participants judged the platform positively regarding its usability and trustworthiness and reported a positive impact on caregiver-caregiver communication and the organization of care. Participants with high burden of care evaluated the platform significantly less positive than those with low burden of care ($p=.00$). Results of the interviews ($n=7$) mirrored those of the survey but also revealed that asynchronous communication with care professionals was not always seen as helpful, especially in case of urgent matters.

Conclusion: The study showed that integrated digital care collaboration is promising. Future research is needed to determine optimal ways of digital communication between informal and professional caregivers of PwD.

POS3. (Poster presentation) Policy and societal aspects

POS3-01. Integrating digital platforms to deliver a biopsychosocial rehabilitation approach in Dementia

Wendy Chambers¹, Elaine Hunter², Alison McKean³

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Training and education of health and social care workforce is key to transformational changes required to improve experience, outcomes of care and treatment for people living with dementia and their families in Scotland (Alzheimer Scotland 2017). Ensuring recovery and rehabilitation post Covid-19 is inclusive of needs of people with dementia requires collaboration and an openness to learn (Scottish Government 2020).

One strategic approach, contributing towards a workforce skilled in biopsychosocial rehab approaches in dementia, has been the AHPDementia Webinar series.

The National AHP Dementia Forum established a successful Webinar series in 2019, delivering new and innovative online learning sessions. Webinars are understood to be an acceptable, accessible learning platform (Holdsworth et al 2020); promoting practice change, contributing to improving care outcomes for people living with dementia.

2020 saw global transformation and digital engagement as services across sectors responded to the pandemic. The AHPDementia Webinar series was well positioned to respond, contributing to the development of both a digitally & dementia skilled workforce.

Over 12 months, twelve, 60-minute AHPDementia Webinar sessions were delivered, sharing evidence informed AHP rehab approaches in dementia, from across Scotland. Presentations were recorded and shared online and via our AHP Blog, capturing impact. The Forum are also developing skills to use webinar platforms to deliver focused AHP rehab self management activities and programs to various staff groups and people living with dementia. Engagement with AHPDementia webinars dramatically increased in 2020, contributing to a digitally and dementia skilled workforce. Recording doubled reach and participation at individual sessions. Webinars continue to support learning in Dementia for diverse groups of learners, enabling AHPs to share rehab expertise and best practice. Participants at webinars report applying learning and improvements in their settings. Continue developing new ways of working using Webinars, sharing collaborative learning and AHP biopsychosocial rehab approaches in Dementia.

POS3-02. Dementia Photo Exhibition as an Awareness Tool

Marc Wortmann

Marc Wortmann Consultancy

A photo exhibition called "Love, Loss and Laughter", developed by Cathy Greenblat from USA has been used for two local exhibitions in the Netherlands during World Alzheimer's Month 2021 in Amsterdam and Zeist. The exhibition has been combined with other activities like a symposium, art and music therapy, public lectures, films, theater play and Alzheimer Café sessions. The aim was awareness raising, creating better understanding of dementia and show that living with dementia is possible with good care, love and understanding. Finally there was attention for initiatives to make society more dementia friendly, including training for staff of local companies. The approach and outreach will be discussed and results shown.

POS3-03. The experiences of people living with dementia, informal carers and healthcare professionals of utilising integrated care: findings from a qualitative evidence synthesis

Raymond Smith, Anne Martin, Toni Wright, Sabina Hulbert, Eleni Hatzidimitriadou
Canterbury Christ Church University

Integrated dementia care services are frequently being developed in Europe and further afield. However, little is known about how people living with dementia, their families and healthcare professionals experience integrated care. This presentation reports on the findings of a qualitative evidence synthesis which investigated peer reviewed literature covering the experiences of people living with dementia, informal carers and healthcare professionals. A comprehensive search involving five electronic databases, journal handsearching, and reference list searching of relevant literature reviews and the final included studies was conducted. Twenty-three studies fitting the inclusion criteria were retrieved and included in the evidence synthesis. From these, three overarching themes were identified: 1) ways of working which facilitate the delivery of integrated dementia care; 2) informal carers as equal partners in care provision and decision making; and 3) challenges leading to fragmented and disjointed integrated dementia care. For integrated care to be successful, communication and collaboration between healthcare professionals, and the involvement of informal carers is vital. Multidisciplinary teams and employing case managers to coordinate care provision can improve communication and collaboration. However, distrust between healthcare professionals and a lack of centralised databases to access and share information often hinders the development of integrated care. It was concluded that integrated dementia care can be successful and well received by people living with dementia and their families when certain conditions are met. However, given the negative consequences fragmented care can have on people living with dementia and their families, action is needed to further support the development of effective integrated dementia care services. Further, research is needed to explore the impact of the COVID-19 pandemic on integrated dementia care service provision and how it has affected those reliant on important post-diagnostic services. This review forms part of the CASCADE project, funded by the EU Interreg 2 Seas programme.

POS3-04. A Combined Model of Guardianship and Supported Decision-Making to Protect Elderly People with Dementia: Cases for Australia, Europe, and Japan

Yukio Sakurai

Yokohama National University

We live in an aged society with an increasing population of elderly people with dementia. Article 12 and General Comment No. 1 of the CRPD recommend that state parties proceed with the paradigm shift from substituted decision-making to supported decision-making to respect the rights, will and preferences of the principals. Since then, state parties have considered how to accommodate the values of the CRPD in their laws and policies without radically changing the status quo. They adopted different models by law reform, legislation, or establishing guidelines. However, a similarity can be seen in their choices, with most states going for a combination of guardianship and supported decision-making (SDM) in dealing with people with insufficient mental capacity. No state parties have abolished the guardianship system yet, and the difference between different states' approaches lie in where and how they accommodate SDM in their laws and policies. This article reviews three types of models in Australia, Europe, and Japan. The Australian model is represented by the Victoria State Act 2019 to fully incorporate SDM in supportive guardian/administrator system while keeping the guardianship system as a last resort. The European model is represented by Alzheimer Europe's Ethical Report 2020 to offer the combined SDM model by taking six steps. This model can be materialized by law reform, legislation, or establishing guidelines according to the state party's legislative intention. The Japanese model is so unique that it promotes the adult guardianship system by establishing community collaboration network and improving guardianship practices, unlike in other developed countries, while providing legal/welfare practitioners with guidelines for implementing SDM as a method that respects the will and preferences of the principals. It can be provisionally understood that there is a diversity of laws and policies in countries that share the same values of the CRPD and democratic procedures.

POS3-05 Access to dementia services for refugees and people from minority ethnic groups in Greece

Efthymia Efthymiopoulou¹, Anastasia Bougea², Konstantinos Lavdas³

¹IASIS NGO, ²Eginition Hospital, 1st Neurology Clinic, Athens, Greece, ³Panteion University of Social & Political Studies, Department of International, European and Regional Studies

Objectives: Ethnic minorities and cultural groups such as refugees are not diagnosed in time and do not receive Alzheimer's assessment services on an equal footing, as they do not have easy access to health services and especially dementia. The reasons behind the misuse of dementia services have not been extensively investigated in Greece.

Methods: Telephone interviews were conducted with 120 refugee-caregivers to record their seeking help for Alzheimer's disease over the past 2 years, especially the elderly, for the barriers they face. The interviews were conducted by an interpreter for the reliable and valid recording of the answers.

Results: The barriers mentioned are language at a rate of 57%, lack of information to refugee groups on the prevention of Alzheimer's disease at a rate of 65% and difficult access to the country's health services at a rate of 75%. The absence of interpreters in hospitals and health centers answered that it is difficult for them up to 80%, as due to language, patients can not pass the neurological and neuropsychological examination for Alzheimer's disease. Misunderstanding of medical instructions is recorded at 68% and their difficult cooperation with social services for information and receiving medical care was recorded at 57%. The social stigma they experience was recorded at 62% and the fear of seeking help in the services of the host country in 37%.

Conclusions: Awareness of Alzheimer's disease in disadvantaged groups has the potential to increase the need for help. To address inequality in the use of Alzheimer's services among refugee groups, targeted health policy interventions should be developed and implemented by providing interpreters to hospitals and health centers, combating the social stigma of refugees through campaigns, psychoeducation in the community and the promotion of mental assessment and rehabilitation services in refugee structures.

POS3-06. Factors affecting the social stigma of Alzheimer's disease in Greek population

Efthymia Efthymiopoulou¹, Anastasia Bougea², Konstantinos Lavdas³

¹IASIS NGO, ²Eginition Hospital, 1st Neurology Clinic, ³Panteion University for Social and Political Sciences, Department of International, European and Regional Studies

Objective: The social stigma associated with the diagnosis can have implications for how a patient and caregiver respond to the diagnosis. It hinders their daily lives and well-being, leading to depression and isolation. This study examined the factors that affect the social stigma associated with Alzheimer's disease (AD) in Greek population.

Methods: 200 caregivers of people with AD were interviewed. The factors of compassion, social networking, dismissal, information about the disease were evaluated and the effects of socio-demographic characteristics were examined.

Results: The results show that caregivers experience 60% of social stigma. Their social networking has been reduced by 70%, as society is unfamiliar with the disease. The pity they experienced from the society was recorded at 60% of their social circle, while 78% stated that they had work difficulties with 30% having reduced working hours and 10% declaring dismissal. 40% stated that they do not have sufficient information about the disease from the state, a fact that causes insecurity. The educational and economic level seems to affect the social position by 51%. 48% said they were disappointed with the health policies for dealing with the disease.

Conclusions: In addition to the emotional and physical burden, caregivers are also faced with the social stigma of the disease. The findings of various stigma-related factors can be taken into account in trying to reduce certain stigma-related beliefs and behaviors associated with AD, through social awareness and disease awareness campaigns. Finally, it is necessary to raise the awareness of the political leadership and to implement government measures to eliminate the social stigma and marginalization of caregivers with AD from their work and social life, with the aim of forming a society friendly to Alzheimer's disease.

POS3-07. WITHDRAWN

POS3-08. WITHDRAWN

POS3-09. WITHDRAWN

POS3-10. Dementia in Cultural Mediation - Improving quality of life through arts and culture

Olivier Constant¹, Herlinde Dely¹, Free De Backer², Sara Marsillas³

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'Dementia in Cultural Mediation' (DCUM) is a transnational project driven by the increasing number of people living with dementia in Europe. The initiative is based on the great potential of cultural and artistic activities as an innovative and dynamic approach to achieve social inclusion of people with dementia in local communities and to improve their quality of life. 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, accompanying 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 results which are continuously reviewed by a European reference group consisting of highly experienced experts in the field of dementia, research and the arts and representatives of the end-user group (informal caregivers and people living with dementia). In the presentation we will look ahead to the project's finalization in August 2022 and give a sneak preview of the project's current status and deliverables.

Expertisecentrum Dementie Vlaanderen (Flanders Centre of Expertise on Dementia), Belgium

Vrije Universiteit Brussel, Belgium

Odense Libraries and Citizens Service, Denmark

Fundacion Instituto Gerontologico Matia-Ingema, Spain

Healthy Ageing Network Northern Netherlands, The Netherlands

POS3-11. ALZINed Online Sessions: Maintaining support for people with dementia and caregivers during COVID-19 pandemic

Manik Kharismayekti, Tania Setiadi, Amalia Fonk-Utomo

Alzheimer Indonesia Nederland

Background: A series of online sessions, which comprised various activities, was organized by Stichting Alzheimer Indonesia Netherlands (ALZINed) since April 2020. It covered three main cores of our programs: meaningful engagement (e.g. intergenerational sing-along, colouring session, cooking class); education (e.g. music and the brain, elderly migrants, spiritual in elderly care); and risk reduction (e.g. yoga, brain gym, low impact exercise). All sessions were performed using the platform Zoom, and streamed through a YouTube channel. Impact measurement is needed to find out the impact of online sessions.

Methods: Two mini surveys which include several questions (e.g. general participant data, frequency of following online sessions, suggestions, comments), were conducted in September 2020 and in June 2021 to measure the impact of the online sessions

Result: From April 2020 to April 2021, 35 various online sessions were conducted. The diversity of activities made these activities interesting to follow. In total there were 1387 participants in Zoom and 3041 in YouTube channel. Participants were varied in background (i.e. older persons, Person with Dementia (PwD), caregivers, students) and origin (i.e. The Netherlands, Switzerland, Austria, Germany, Brunei, Qatar, Taiwan, and Indonesia). About 23.8% participants attended more than 5 online sessions. Some ideas for activities were suggested, including special activities for PwD, arts and caregiver tips. Through these activities, a PwD has found a new hobby, colouring, and reported that she has coloured more than 300 pictures in a year. In addition, participants expected that the online session will continue even after the pandemic has ended.

Conclusion: ALZINed online sessions was a means in maintaining support for PwD and caregivers during the COVID-19 pandemic. It enabled participation and increased social interaction among participants. It gave positive impacts on improving quality of life and activating engagement between PwD and caregivers during the pandemic.

POS3-12. On the way to a Dementia-competent society in Austria: E-learning for different professional groups

Stefanie Auer¹, Markus Richter², Lisa Bauer², Eduard Dernes², Petra Warisch², Martina Stöfflbauer², Paolo Drexler², Deniz Sarikaya², Paul Pürcher¹, Margit Höfler¹, Marc Wortmann³

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Background: Police officers and Persons working in the public administration often serve as a first point of contact in critical situations for both persons with dementia and their support providers. In order to be sensitive to the special needs of persons with dementia, training is essential. Therefore, E-learning programs for these important groups were initiated.

Methods: In order to specifically target the needs of specific professional groups (Police Officers, Community Employees), focus groups were organized in which experiences and needs of the respective professional groups were discussed. Contents of the discussion were analysed, important topics were defined and teaching contents developed. Additionally, different certification processes for the different groups were developed. The learning programs were implemented on the E-learning platform of the Federal Ministry of the Interior and are easily accessible.

Results: Taking the results of the discussions into account, internet-based learning modules were developed and evaluated in the respective groups. Currently, there are two E-learning programs available, "Mission Dementia" for the Police and "Active Community" for community employees". To date, over 14,000 Police Officers have been trained and 250 Police Stations are certified "Dementia-competent". A similar certification process for community employees just started.

Discussion: E-learning programs are well-accepted by police officers and community employees and may be an effective and economically interesting method for awareness building when implemented on easy-to-reach internet platforms. This method could be further extended to other professional groups.

POS3-13. Brain Health in Scotland: Current Landscape and Future Directions.

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¹Brain Health Scotland, ²University of Edinburgh, ³Brain Health Scotland/University of Edinburgh

Cognitive clinics (also known as memory clinics or dementia assessment services) were established sporadically throughout Scotland in the latter half of the 20th century, with a later broadening of service provision occurring in response to the approval of cognitive enhancer medications (e.g., acetylcholinesterase inhibitors). As a result of the nonuniform development of clinical services for the assessment and treatment of cognitive decline in Scotland, very little data about service provision is held centrally and there appears to be significant variation in clinical service provision across Scotland. What is clear is that the most commonly available clinical services are provided for older adults with established cognitive decline, and that opportunities to reduce neurodegenerative disease risk and for the early detection of neurodegenerative diseases are being missed. These missed opportunities were the catalyst for the establishment of Brain Health Scotland in 2020, in partnership with Alzheimer Scotland and funded by Scottish Government. Brain Health Scotland's aim is to reduce the incidence of dementia in Scotland in ten years through personalised prevention and risk reduction, early disease detection, and ambitious public health initiatives. Here, we share insights from our benchmarking exercise of the current clinical services available to individuals in Scotland living with or at risk of neurodegenerative disease and discuss future directions. Our findings are derived from novel data collection (a census of Scottish cognitive clinics) and from secondary data analysis (open-access data, literature review, Freedom of Information requests). We summarise the current landscape of clinical services for individuals living with neurodegenerative disease, and introduce our 'Scottish Early Alzheimer's Disease Detection' (SEADD) programme within the context of the broader Scottish model of brain health.

POS3-14. The Krems Arts Education & Dementia Initiative (KAEDI) – Increasing Scientific Evidence

Hanna Brinkmann¹, Margit Höfler², Anja Grebe¹, Stefanie Auer²

¹Department of Arts and Cultural Sciences, Danube University, ²Department for Neuroscience and Preventive Medicine, Center for Dementia Studies, Danube University

In May 2021, we established the Krems Arts Education & Dementia Initiative (KAEDI). This Austrian initiative aims to encourage the exchange between universities, museums as well as institutions and associations for and by Persons with Dementia. A major emphasis will be on the potential impact of museums and arts education in the field of Dementia prevention.

There is scientific evidence that engagement in arts and culture can improve the quality of life of Persons with Dementia and their support providers (Thomson et al., 2018). Thus, strengthening the cooperation of museums with organizations from the social and care sectors is important. Furthermore, academic knowledge is necessary to jointly implement and evaluate these programs in order to increase scientific evidence and acceptance for effective programs.

Approach: To gain an overview of available programs in different museums, we organized the online symposium "Arts Education and Dementia. Enabling cultural participation in museums on May 11th 2021. 15 abstracts were submitted and finally 12 art programs from Austria, Germany, Romania, and the USA were presented.

Results: Some museums already have long-standing experience in arts education for Persons with Dementia (Ganß et al., 2016), others have just started their programs. Due to the current health crisis (COVID 19), programs in digital form were developed and two digital approaches were presented. Scientific evidence for the benefits of arts educational programs is largely missing.

Conclusion: In order to build an evidence base, KAEDI will initiate interdisciplinary research studies to evaluate specific arts educational programs. It aims to combine academic research with experience from art museums that provide such programs for Persons with Dementia and Persons at risk for Dementia. The study results will form a basis for the development of future initiatives of museums to enhance the quality of life of Persons with Dementia and their support providers.

POS3-15. Case management for people with dementia in the home setting: a systematic review of randomized controlled trials

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Background: Dementia is one of the main causes for a need of care in old age, however most people in Germany want to live in their home environment as long as possible. Case management (CM) can make an important contribution to ensuring that people with dementia (pwd) remain in their homes. The aim of this study is to systematically examine the impact of CM approaches on the retention of pwd in their home environment.

Method: A systematic literature search in the databases Pubmed, CINAHL, PsycINFO, Scopus, CENTRAL, Gerolit, ALOIS for randomized controlled trials (RCTs) was performed. RCTs published in German or English between 2010 and 2020 were included. The endpoint was statistical evaluation on the pwd's move to an inpatient residential or nursing setting. Reporting and study quality of included studies were assessed by CONSORT checklist and modified Jadad scale.

Results: Included were 6 RCTs from 5 different health care systems (Germany, USA, Netherlands, France, China). 3 RCTs showed significant, 3 nonsignificant delays in institutionalization or significantly lower rates of institutionalization in favor of the intervention groups. Intervention periods ranged from 6 to 24 months. All RCTs showed high reporting quality. Five RCTs showed low to moderate study quality.

Conclusion: The results suggest that intensive and regionally well-connected case management approaches have the potential to promote retention of people with dementia in their own homes. Several efficacy parameters, such as intensity of care, need to be considered when assessing the effectiveness of case management approaches. When planning case management approaches in specific local care settings, barriers, and opportunities for sustainable implementation in existing care chains should be considered from the outset.

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POS3-16. Rehabilitation in dementia: Designing digital self-management support with people with dementia

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Emerging evidence exists which highlights the benefits of the Allied Health Profession's (AHP) contribution to support early intervention, supported self-management and rehabilitation for people living with dementia and their families. There is also a growing need for AHPs to develop new and innovative ways of working that are technology based and co-created, Connecting People, Connecting Support On-line, is one such example.

This web platform was designed by a group of occupational therapists and designers, in response to the devastating impact of the pandemic. However, since the launch of the web platform in March 2020, we have begun to embed the online resource to the day to day rehabilitation approach of AHPs in Scotland and beyond. The web platform will be shared, outlining:

How it has supported people living with dementia and their families with over 65,000 page views and embedded use of an online advice clinic

How it formed the basis of a service development led by occupational therapists within Alzheimer Scotland to support the transformation of rehabilitation in dementia

The 32 resources and activities that have been tried, tested and recommended by people living with dementia and their families

The integration of a social media strategy to support the dissemination of the platform

The formal evaluation of the platform to measure the impact and reach of the self-management resource

We will describe some of the learning that has emerged from this practice innovation, particularly in relation to what can be achieved through inter-sectorial working and the value of an online platform to support people's rehabilitation. We will end by sharing reflections of learning about best practice in design to support engagement and how insights developed from the project could potentially shape how and where rehabilitation in dementia can be delivered in the future.

POS3-17. Respiratory Muscle strength dysfunctions Induce Pneumonia In Alzheimer's disease

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Background: The aging trend is accompanied by an increasing number of patients with dementia, which is becoming a major healthcare challenge. Dementia covers a wide range of symptoms and encompasses a group of related neurodegenerative disorders. Advanced dementia typically is the end result of a variety of neurodegenerative disease. Swallowing and respiratory muscle strength problems in patients with advanced dementia are multifactorial.

Methods: As the reduction in the sensitivity of pharynx, the reduction in the capacity to produce saliva, and the slowing of the oral-pharyngeal reflex are sign common to old age, the structural alterations that occur in the brain of the patient with AD [with apoptosis and neuro-fibrillary tangles in cortical and sub-cortical regions]. These results indicated that patients with dementia may have weaker defence mechanisms for overcoming respiratory tract infections. Respiratory muscle strength is determinant of vital capacity, and its decline can lead to inadequate ventilation and secretion retention.

Results: Silent pneumonia may have a greater impact as the direct cause of death than clinical presentation among older adults, especially those with advanced stages of dementia in the hospital setting.

The important physical changes associated with aging include decreases in the elastic recoil of the lungs, compliance of the chest wall, and strength of the respiratory muscles.

Conclusions: Measuring maximum muscular strength for two reasons: it represents a highly sensitive method for cases of inspiratory muscular weakness maximal inspiratory pressure (P_Imax), and reflects a parameter of the subjects' effectiveness of cough and expectoration maximal expiratory pressure (P_Emax). Greater compromise of maximum RMS (inspiratory and expiratory) understanding respiratory physiology and the influence of nosological conditions on this process is fundamental for reflection on the clinical findings. Patients with dementia in the terminal stages urgently require careful clinical management of pneumonia, to maximize patient life expectancy and quality.

POS3-18. Advance Decisions and Their Influencing Factors for People with Dementia and Their Families in Taiwan

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Objective: To investigate the dementia patients in the geriatric center and their families for awareness, past experiences, attitudes and willingness to decide advance decision, as well as considerations and intentions of decision-making in advance decision, and the associated factors.

Methods: A cross-sectional and descriptive study with purposive sampling was conducted at geriatric center in Taipei. Patients aged ≥ 65 years and admitted at geriatric center and their families were enrolled. A total of 30 patients and 55 family members were enrolled. A structured questionnaire was designed for further analysis of the associated factors of deciding advance decision. Data were recorded and analyzed by SPSS 22.0 statistical software.

Results: The majority of participants were not aware of advance decision. Less than 10% of patients and family members had ever contacted about the advance decision. Most of the patients and family members had ever heard of or seen CPR. Less than 5% of patients and family members had ever contacted about the advance decision. About 15% of patients and 55% of families had discussed about advance care planning. The predictors of the behavioral intention toward Advance Directive included positive attitude and good quality of life. The factors affecting willingness of the elders for advance decision included receiving the messages related to advance decision, understanding the regulations of the relevant laws, knowing that they could change the contents and decision of the advance decision at any time. As to directions of decision-making, 50.3% of patients and 65.6% of family surrogate agreed to sign DNR.

Conclusion: The conclusions of this study are hoped to provide relevant units with a more reliable basis for the implementation of advance decision, and to provide more appropriate care in clinical practice.

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