

35th Alzheimer Europe Conference
Connecting science and communities:
The future of dementia care
Bologna (Italy), 6 - 8 October 2025 #35AEC

35AEC

ABSTRACTS BOOK

QUICK ORAL PRESENTATIONS

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-01 - A Self-management resource : Our "Top Tips" for living well with dementia

Scottish Dementia Working Group Members[1], Fran Hamilton[2], Elaine Hunter[3], Stuart Dougall[3], Margaret McCallion[3]
[1]Scottish Dementia Working Group, [2]Independent Occupational Therapist, Consultant and Trainer, [3]Alzheimer Scotland

The Scottish Dementia Working Group (SDWG) is a national member-led group, advocating for people living with dementia in Scotland. To be a member of the group you must have a diagnosis of dementia and hold a commitment towards the promotion of human rights for all those living with dementia.

The SDWG understand the many practical and emotional benefits of peer-to-peer support, which is shown to improve their overall wellbeing. People with lived experience are increasingly becoming key advocates of what is important to those living with dementia, ensuring that dementia strategies and new publications align with their needs.

In this session, SDWG members will share their collaborative work on updating the peer-to-peer booklet, Our "Top Tips" for living with dementia. This resource provides proven strategies from people living with dementia, aiming to inspire others to discover what works best for their unique circumstances. The clear message offered is that "While there's no one size-fits-all solution, we encourage you to explore and find what suits you best".

The dissemination strategy, designed by the SDWG, includes a short film, social media engagement, local community distribution, and presentations at national conferences. The booklet is also integrated into the post-diagnostic

rehabilitation offered by occupational therapists in Scotland and allied health professional student programmes. During the session, impact data on these strategies will be shared, alongside discussions about the value of peer-led support.

This resource demonstrates the power of peer support, offering hope and practical strategies to individuals newly diagnosed with dementia. By improving day-to-day wellbeing, it highlights the global importance of peer-to-peer initiatives. We hope that by reaching a wider audience at the Alzheimer Europe Conference the booklet and film will encourage more people living with dementia to share their own practical ideas to live well with the condition.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-02 - Try to look again: a phenomenological study of recognising humanness in people living with advanced dementia

Jesper Bøgmose Hansen[1], Benjamin Olivares Bøgeskov[1], Tom Dening[2], Bente Martinsen[3]
[1]University College Copenhagen, [2]University of Nottingham, [3]Roskilde University

Background: Although maintaining personhood is well-acknowledged as fundamental in providing high quality dementia care, recognition of personhood in advanced dementia keeps challenging caregivers. However, research suggests that personhood in advanced dementia may be evident through expressions of humanness in everyday life.

Aim: This study aims to explore how personhood in advanced dementia can be recognised as their expressions as existential human beings.

Method: Following Galvin and Todres' lifeworld-led approach to care, personhood in advanced dementia was explored through the lived experiences of nursing home residents living with the condition. Participant observations with people living with advanced dementia were conducted at two nursing homes as well as semi-structured interviews with the care staff.

Ethical considerations: Process consent was used to assess residents' willingness to participate, and ethical approval was sought and granted by a research ethics committee.

Results: Based on a phenomenological analytic method by van Manen we found expressions of humanness in advanced dementia can be very ambiguous.

Our observation can be summarised in four themes conveyed as anecdotes describing how people living with advanced dementia enact their *historic agency*, seek a sense of *embodied homeliness*, form and nurture *candid relationships*, or try to understand the *situated presence*. We argue that embodied engagement in understanding the lived experiences of care recipients' ambiguous expressed humanness can assist formal caregivers to really see or feel them as existential human beings.

Conclusion: Approaching behaviours and enactments in advanced dementia as ways of expressing one's humanness can support formal caregivers' recognition of the personhood of their care recipients. And when such expression becomes disjoint and incomprehensible we must try to look again and find the existential human meaning in them.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-03 - "My Illness Does Not Define Me" Report on the Need for Personalized Activity Programs for People with Dementia

Marianne Næss
The Norwegian Health Association

Background: The Norwegian Health Association is the national patient organization for people with dementia and their caregivers. Through thousands of inquiries to our Dementia Helpline, we hear frustration about the lack of municipal, personalized activity programs. Meaningful activities may improve quality of life, sustain function for people with dementia and provide crucial respite for caregivers.

Aim: Identify key characteristics of meaningful activities and the consequences of inadequate programs, based on experiential knowledge from the Dementia Helpline, working group for people with dementia and peer supporters.

- Create a report highlighting our findings as a foundation for our advocacy work.

Method: The Dementia Helpline gathered all experiences from relevant inquiries. To deepen our understanding, we consulted our working group for people with dementia and our peer supporters.

Results and Impact: People with dementia identified the following key characteristics of meaningful activities: social contact, a sense of

purpose, enthusiasm, daily structure and connection to others living with dementia.

Functional decline in the person with dementia and increased emotional burden due to lack of personalized activity programs, were among the issues described by caregivers. As a cause of the emotional burden, caregivers highlighted the feelings of indignity, guilt, and powerlessness when accepting activity programs that do not suit the person with dementia. To be meaningful and provide effective respite, activities must be enjoyable for the person with dementia.

The report provides valuable insights which were shared through a webinar, where we invited affected individuals, healthcare professionals, leaders, politicians, and decision-makers. The report may serve as a knowledge base for the development of municipal activity programs.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-04 - A short film about friendship: When dementia challenges the friendship

Mirjeta Emini[1], Kari-Ann Baarlid[2]
[1]Norwegian Health Assosiation, [2]The Norwegian Health Association

Background: Dementia leads to challenges in relationships and friendships. The person changes and behaves differently than before. Some friends may interpret the lack of initiative as a sign that the friend may have grown tired of the friendship. Other friends may experience a feeling of grief since someone they care about has been diagnosed with a serious illness.

Aim: Friendship is strengthened through openness and dialogue, and friends get a closer relationship.

Method: We invited three people with dementia to bring along a close friend for a conversation about dementia and friendship. We had prepared questions that they would ask one another. None of the participants had seen or read these questions ahead of the shoot. This led to genuine and open conversations. Some even described it as a therapeutic session where they got the chance to talk about matters that were important for, and in, their continued friendship.

At the end of the film the viewers are presented advice on how to strengthen and maintain the friendship in the aftermath of a dementia diagnosis. Our panel of experts were involved in crystallizing six areas of focus: knowledge, openness, patience, communication, initiation and planning.

Results and Impact: The Norwegian Health Association has been working for more dementia friendly communities since 2013. This film is one of our tools in this important work and it is shown in different settings, like for example at a conference with 400 participants, all of whom work within the area of healthcare services. It is also frequently shown by municipalities and our local volunteers at meetings about dementia and dementia friendliness.

The feedback is that the film is an eye-opener for the possibility of maintaining friendship and closeness with friends, even when dementia presents challenges.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-05 - "She's my memory; and he's my legs!" The experiences of couples living with dementia and multiple health conditions

Rosie Dunn[1], Emma Wolverson[1], Andrea Hilton[2], Juliet Gillam[1], Katie Featherstone[1]
[1]University of West London, [2]University of Hull

Background: Dementia rarely travels alone. People with dementia often have multiple health conditions (multimorbidity) and experience poor quality, fragmented care. Over two thirds of carers of people with dementia are spouses, half of which are 85 years old or above. Age is strongly associated with increased multimorbidity; therefore, carers also commonly experience multimorbidity. Thus, living with dementia alongside multimorbidity is a shared experience for couples. However, no studies have explored this or sought to understand couples' needs. Consequently, the aim of this research is to address this significant gap in knowledge.

Method: A multi-modal, qualitative research design using a combination of photo-diaries, photo-elicitation, and semi-structured interviews was employed. Couples were interviewed together and their accounts analysed using Interpretative Phenomenological Analysis.

Findings: Six married, heterosexual couples participated. Couples did not prioritise one health condition over another. Symptoms experienced as tangible, acute, uncontrollable and unnatural were most problematised. For some, the combination of dementia and multimorbidity led to a sense of disembodiment. Consequently, some couples experienced emotional distress due to a lost sense of self, which impacted on couple identity, and created tensions in their

relationship. Other couples, however, did not report significant distress and approached their dementia and multimorbidity with acceptance, stoicism, gratitude and a positive outlook. Despite their health challenges, all six couples felt they had become closer to each other *because of* their dementia and multimorbidity and found ways to adapt and normalise everyday life, preserving their couple identity.

Conclusion: Couples varied in their ability to adjust and cope living with dementia and multimorbidity. All couples experienced the complex, fluctuating symptoms of their various health conditions, which were hard to disentangle, and required couples to adapt and work together. A relationship-centred, integrated care model is needed to provide holistic support to couples living with dementia and multimorbidity.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-06 - Unheard and unbelieved: exploring epistemic injustice in people living with dementia through qualitative research

Lara Calabrese, Marco Brigiano, Martina Quartarone, Ilaria Chirico, Sara Trolese, Ludovica Forte, Alice Annini, Rabih Chattat
University of Bologna

Background: Epistemic injustice, a concept introduced by the philosopher Miranda Fricker in 2007, refers to a harm done to individuals specifically in their capacity as knowers. This form of injustice arises from social prejudices and stereotyping, thus leading to the partial or complete exclusion of certain individuals from knowledge building. People living with dementia are particularly vulnerable to epistemic injustice due to their impairments in cognitive functions (e.g., memory, language and information processing), which can reinforce societal assumptions about their diminished credibility or abilities, thus marginalising their voices in interpersonal, social and clinical contexts.

Aim: This research aims to deepen current understanding on how people living with dementia encounter and experience epistemic injustice in their everyday lives.

Methods: To investigate this phenomenon, a qualitative study was conducted using semi-structured interviews, favouring an approach as conversational as possible. Participants included persons with a diagnosis of dementia who were interviewed at home or in residential care facilities according to their availability. The interviews were audio-recorded, transcribed and thematically analysed to identify recurring patterns and meanings in the participants' narratives.

Results: The results revealed that experiences of epistemic injustice are both prevalent and deeply embedded in the everyday lives of people living with dementia. However, these instances were often perceived not as unfair, but as appropriate or expected, thus reflecting the internalisation of epistemic marginalisation. Many participants expressed the feeling that their perspectives were no longer valid or necessary, reinforcing their withdrawal from active roles in care and communication processes and in the society.

Conclusions: This study highlights the urgent need to recognise and address the epistemic dimensions of dementia care. The normalisation of the presence of epistemic injustice contributes to self-silencing people living with dementia, thus perpetuating cycles of disempowerment and exclusion from the society.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-07 - A Disrupters Guide To Dementia Practice, Thinking, & Activism

Ron Coleman, Karen Taylor, Howard Gordon
Deepness

Drawing from their lived experiences, Coleman, Taylor, and Gordon will share their discoveries as they navigated through their personal dementia journeys. They will present a radical reimagining of dementia as a human experience rather than merely a medical condition.

As individuals directly navigating cognitive changes, Ron and Howard will articulate how their personal journeys have become powerful tools of systemic disruption. Karen, as a life and care partner, will illuminate the critical role of supportive relationships.

They will weave together personal testimonies, systemic critiques, and innovative approaches that will disrupt traditional medical and societal frameworks. By centring the voices of those experiencing cognitive changes, they will expose the profound limitations of clinical perspectives that have historically marginalised individuals with dementia.

Key disruption strategies will emerge across multiple domains: healthcare practice, social policy, community engagement, and personal empowerment. The presenters will demonstrate how patient-led movements can reshape understanding.

Critical to their approach will be the recognition of dementia as a complex, nuanced human experience. They will argue that true innovation comes not from technological interventions, but from radical empathy, systemic listening, and a commitment to preserving individual agency and dignity.
From global awareness initiatives like "Walking the Talk" to community-based research, they will illustrate how disruption manifests through collective action, personal narrative, and a steadfast rejection of predetermined limitations. This will be more than a presentation—it will be a manifesto of transformation, challenging audiences to reimagine what is possible when human experience is centred over clinical categorisation.

Provocative, compassionate, and unapologetically bold, their presentation will offer a blueprint for systemic change that extends far beyond dementia, inviting listeners to fundamentally reconsider how we understand human vulnerability, resilience, and connection.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-08 - Maintaining Couplehood in the Face of Dementia: A Qualitative Evidence Synthesis Combined with Interviews with People with Dementia

Marine Markaryan[1], Sara Laureen Bartels[2], Sunny Tan[3], Patricia Masterson Algar[4], Niels Hendriks[5], Marjolein De Vugt[2]
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Background & Objectives: The sense of connection between partners in romantic relationships affected by dementia is closely linked to their well-being. Research on how couples experience changes in relationship dynamics and the understanding of relational needs in the context of dementia has been steadily growing. It is now timely to provide an overview of accumulated knowledge. Importantly, the literature on relational needs is dominated by the views of caregivers. Therefore, we aim to i) synthesize existing evidence on the needs that people living with dementia (PLwD) and their partners have when it comes to maintaining couplehood, and ii) ensure that the voices of PLwD are well represented.

Methods: A systematic search and qualitative evidence synthesis of available literature across four databases (PubMed, CINAHL, PsycINFO, Web of Science)

has been performed by means of thematic synthesis. To balance off the well-documented perspective of carers with the underrepresented voice of PLwD, semi-structured interviews with PLwD were conducted. Visual and text prompts were used to stimulate the engagement of PLwD in a conversation. The approach to interviews was piloted with the European Working Group of People With Dementia in December 2024.

Status and preliminary results: 7430 records were screened after removing duplicates, resulting in 36 relevant papers. Data synthesis is in progress, with three major themes having emerged thus far: i) connection and intimacy; ii) maintaining autonomy and selfhood; iii) managing dementia. Five interviews have been conducted and transcribed up to now. The combined findings from the review and the interviews will be further aggregated by summer 2025. Future directions for interventions to support couples affected by dementia, as well as the agenda for further research will be outlined in light of these findings. Methodological reflections on the use of prompts for conducting the semi-structured interviews with PLwD will also be shared.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-12 - Social Stigma in Dementia: Italian Validation of the Dementia Public Stigma Scale (DEPSS)

Roberta Sturaro[1], Silvia Gonella[2], Isabella Santomauro[2], Daniela Berardinelli[3], Roberto Quarisa[4], Sarang Kim[5], Valerio Dimonte[2], Sara Campagna[2]
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Introduction: The prevalence of dementia has been increasing, with over 55 million cases worldwide. Dementia-related stigma is believed to be a significant barrier to supporting people with dementia (PwD) and promoting their social inclusion. The Dementia Public Stigma Scale (DePSS) is a tool that measures the dementia-related public stigma and can guide educational interventions.

Objective: To validate the DePSS in Italian.

Method: The study consisted of two phases: translation and cultural adaptation, followed by psychometric validation. The scale was translated following Beaton's guidelines, with an initial assessment of clarity and relevance conducted by 5 experts and 41 lay participants. Subsequently, the DePSS was tested on a sample of 1,329 participants,aged 14-93 years. Analyses included

Item-total correlations (r), reliability (McDonald's Omega), test-retest (r), and confirmatory factor analysis (CFA).

Results: The Italian version of the DePSS demonstrated satisfactory semantic and conceptual equivalence, with good internal consistency (omega = 0.776) and reliability (r=0.725, p<0.001). Item-total correlations ranged from 0.3 to 0.7. The CFA supported the original five-factor structure (fear and discomfort, inability and loss, personality recognition, burden and exclusion) with good fit indices (CFI = 0.941, TLI = 0.923, RMSEA = 0.050 and SRMR = 0.045).

Discussion and Conclusions: The DEPSS is a brief 16-item scale that explores all components of stigma—stereotypes, prejudice, and discrimination—unlike other tools that assess only positive attitudes toward people with dementia, while neglecting negative ones. The Italian version of the DEPSS is a valid and reliable instrument for measuring dementia-related stigma and may be useful for healthcare policymakers.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-09 - Experiences of people with dementia and their informal caregivers before, during, and after disasters: Systematic review of qualitative studies

Özlem Çiçek Doğan, Seda Güney
Koç University

People living with dementia (PLwD) and their informal caregivers are uniquely vulnerable when hurricanes, floods, wildfires or earthquakes strike, yet no previous systematic review has examined their experiences. Guided by Joanna Briggs Institute (JBI) methods, we searched PubMed, Web of Science, Scopus, CINAHL, Cochrane Library and ProQuest for qualitative studies linking "dementia" and "disaster."

From 1978 records, six studies met the inclusion criteria. Two reviewers independently extracted data and appraised methodological quality with the JBI tool for qualitative systematic reviews. Meta-aggregation produced three overarching insights.

- First, during preparedness, caregivers bore a double burden: protecting themselves and the person with dementia while working with limited hazard knowledge; as cognitive decline advanced, all planning decisions shifted to the caregiver and workload escalated.
- Second, throughout response and early recovery, evacuation resistance, dementia-unaware shelters, power outages, disrupted health services and behavioral flare-ups compounded caregiver stress.

- Third, family and peer support, faith, swift restoration of familiar routines, access to day-care or respite options and simple aids such as portable generators buffered strain. Dementia-specific preparedness guidance, dementia-friendly shelter capacity and integrated post-disaster psychosocial supports emerge as urgent practice and policy priorities.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-10 - Living with dementia – 1,000 people with dementia in the Netherlands telling us about their life, care and support

Susanne van den Buuse
Alzheimer Nederland

Personal contact, doing activities and receiving understanding and respect from others is what people with dementia need the most to be able to continue to participate in society. Yet, only 37% indicate that they meet other people for social talk less than once a week. Whereas the majority says they receive understanding and support from their social environment, only less than half receive understanding and support from people in public places. Alarming is that both the quality of life and the quality of social life of people with dementia has slightly declined compared to 2022. According to people with dementia, the case manager dementia is their most important means of care and support, followed by the GP and domestic help.

These are the highlights of the results of the Dementia Monitor 2024 by Alzheimer Netherlands and the Nivel research institute. A stunning amount of 1,000 people with dementia participated in the monitor by filling out a survey. As the perspective of people with dementia is rarely included in studies, this study is unique for doing so and to such a large extent. The sample consisted of 66% people with dementia living together with someone, 24% people with dementia living alone, and 9% who were living in a care or nursing home. The report was published in April 2025 on www.dementiemonitor.nl.

Alzheimer Netherlands uses the results of the study to advocate for better care and support for people with dementia. In this presentation, we will show the

most important results of the Dementia Monitor and how we use these in our advocacy.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - People with dementia

06/10/2025 - 15:30-16:45 - QOP1. People with dementia

QOP1-11 - Participants in Dementia-Friendly Initiatives. Who Benefits, Who's Left Out?

Marjolein Thijssen[1], Nanami Pronk[2], Linda Dauwerse[2]
[1]HAN University of applied science, [2]Radboudumc

Dementia-friendly initiatives (DFIs) are increasingly promoted as community-based responses to support the inclusion, autonomy, and well-being of people with dementia and their caregivers. A rapid realist review by Thijssen et al. showed that DFIs contribute to emotional support, social engagement, and reduced caregiver stress. This study explained how DFIs support people with dementia and carers by providing shared experiences (emotional relief), meaningful involvement (a sense of agency), and tailored support (stress reduction)——positioning them variously as patients, group members, or citizens.

However, little was known about who actually participates in these initiatives. This study builds on the original review through a secondary analysis of participant characteristics across the same 22 studies.

This follow-up study examined participant characteristics across the 22 studies included in the original review. Of these, 19 were eligible and 13 contained usable participant-level data. Descriptive analysis revealed that most participants were home-dwelling people with mild to moderate dementia, accompanied by a caregiver—primarily a female partner. Women were highly represented overall. Those with advanced dementia, from ethnic minority backgrounds, or who spoke a non-dominant language were notably underrepresented. Caregivers often functioned as gatekeepers to access, and participation without caregiver support was rare.

These findings raise critical questions about the reach and inclusivity of DFIs. Barriers such as mobility limitations, language, or the absence of caregiving support may be excluding vulnerable groups. The role of caregivers as enablers—or filters—of participation deserves further attention.

The presentation will explain who currently benefits from DFIs, who is left out, and why. It will discuss the implications for design, accessibility, and equity in future DFI development, and propose directions for research and practice to ensure that dementia-friendly truly means inclusive.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-03 - Personalized prediction of the response to Alzheimer's Immunotherapy: An Agent-Based Approach

Liad Doniza[1], Kuti Baruch[2], Shai Braiman[2], Andrea Del Val[2], Sophia Krix[2], Stefan Kirsch[2], Holger Froehlich[2], Omri Matalon[2], Neus Falgas[2], Raquel Sanchez[2], Avner Priel[2], Uri Nevo[2], Shir Bahiri[2]
[1]Tel Aviv University, [2]

Targeting immune checkpoint pathways has emerged as a potential therapeutic strategy for Alzheimer's disease (AD). Antibodies that block the PD-1/PD-L1 pathway have been shown to reduce brain pathology and improve cognitive performance in various rodent and primate models of AD (Baruch et al. Nat. Med. 2016). However, as in oncological immunotherapy, a priori discrimination of responders and non-responders remains an open problem, with direct implications on treatment optimization. We addressed the responders-prediction problem by developing an Agent-Based Model (ABM) simulation of personalized mixed lymphocyte reaction (MLR) in-vitro experiments.

Blood samples from 36 healthy donors (HDs) were used for immunophenotyping of peripheral lymphocyte and monocyte populations. The same samples were then used for personalized MLR experiments that captured the dose-response kinetics to anti-PD-L1 treatment. In parallel, personalized ABM simulations, based on the immunophenotypes, were developed and their predictions were compared to the 'wet' MLR experiments. This modelling approach predicted immune outcomes and identified specific biological parameters and cellular mechanisms underlying differential responses.

In a second stage, the model was expanded using blood samples from 75 individuals, comprising three equal-sized groups: HDs, patients with mild cognitive impairment (MCI), and patients with AD. Half of this dataset was used as a training-set where immunophenotypic and demographic data were analysed to identify features incorporated into the simulation framework to refine the immune ABM simulation for this diverse population.

When compared to machine-learning methods across 10-fold cross-validation, the simulation demonstrated a significant improvement in predicting immune activation in culture. Preliminary results show a median correlation of 0.88 and a mean absolute error of 5.29±3.67% between 'wet' experiments and the predictions of the ABM. Machine-learning on this small dataset resulted in a median correlation of 0.61.

These results propose an ABM based on personalized immunophenotyping as a novel tool to predict response to immunotherapy counter AD.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-10 - Health determinants of Clusters of Neuropsychiatric Symptoms in an Italian Geriatric Population: A Memory Clinic-Based Study

Anna Giulia Guazzarini[1], Anna Marseglia[2], Patrizia Mecocci[3], Eric Westman[2], Evangelos Glarios[2], Francesca Mancinetti[3], Virginia Boccardi[3], J-Sebastian Muehlboeck[4], Carmelinda Ruggiero[3]
[1]Università degli studi di Perugia, Dipartimento di medicina e chirurgia, Sez. Gerontologia e Geriatria, [2]Division of Clinical Geriatrics, Center for Alzheimer Research, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet., [3]Division of Gerontology and Geriatrics, Department of Medicine and Surgery, University of Perugia, Italy, [4]Montreal Neurological Institute, McGill University

Intro: Neuropsychiatric Symptoms (NPS) are well documented in dementia, but whether distinct patterns are already present in preclinical stages remains unclear. They are highly heterogeneous, and tend to clinically co-occur, often clustering into distinct "subsyndromes", reflecting possible shared underlying mechanisms. This study identified NPS clusters in a geriatric clinical population and their health determinants.

Methods: We conducted a cross-sectional analysis of 1,234 participants from the Italian GERICO memory clinic cohort with available Neuropsychiatric Inventory (NPI) assessment. Data on sociodemographic, medical conditions, medication use, cognitive functioning, and blood sampling were collected. NPS

frequency and severity were evaluated using the NPI. A machine learning approach derived clusters from the 12 NPS domains separately for dementia and dementia-free participants. The optimal cluster number was determined via K-Means and the Elbow methods. Multinomial logistic regression estimated Odds Ratios (OR) and 95% CIs for associations between cluster allocation and potential sociodemographic and health-related determinants.

Results: Across 1,234 participants (median age 80 years, IQR = 76–84; median NPI score 16, IQR = 8–26; 64.3% female; 51,2% had a dementia diagnosis), four NPS clusters were identified: Cluster 0 (absent/minimal NPS), Cluster 1 (Depression-Anxiety-Apathy), Cluster 2 (Depression-Anxiety), Cluster 3 (Delusions-Agitation-Irritability). Cluster structures varied across the overall sample and dementia/no-dementia subgroups. Compared to Cluster 0, the Depression-Anxiety Cluster was associated with female sex (OR=2.14, 95% CI 1.40-3.29) and poor glycemic control (OR=2.42, 95% CI 0.94-6.23), with consistent findings in the no-dementia group. In the dementia group, the Delusions-Agitation-Irritability Cluster also showed an association with poor glycemic control (OR 2.04, 95% CI 0.61-6.75).

Conclusion: Associations between NPS groups delineate different symptom profiles in individuals with dementia or in prodromal stage. Poor glycemic control emerged as a key risk factor for anxiety-depression symptoms, underscoring the need for blood sugar management in overt dementia care but also in preclinical/prodromal stages.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-04 - Diagnostic pathways before a dementia diagnosis: applying sequence analysis to a Dutch real-world data cohort

Yara Meijer[1], Brenda N. Baak[2], Casper de Boer[3], Judith E. Bosmans[3], Pieter J. Van der Veere[3], Ron M.C. Herings[3], Wiesje M. Van der Flier[3], Hana M. Broulikova[3]
[1]Vrije Universiteit Amsterdam, [2]PHARMO Institute for Drug Outcomes Research, [3]

Background: Although early dementia diagnosis is often promoted, limited empirical data exist on the characteristics of the pathways leading to such diagnoses. By leveraging Dutch real-world data from general practitioners (GPs) and hospitals, this study will aim to cluster diagnostic pathways leading to a dementia diagnosis and examine associated patient characteristics.

Methods: We selected 38,867 persons with dementia between 2017-2022 in the PHARMO Data Network, based on GP and hospital diagnoses, and anti-dementia prescriptions. Applying a "6W" multidimensional framework, we will analyze diagnostic pathways of patients with dementia ("Who") by examining sequences of dementia-related healthcare use over three years ("When") preceding the first recorded dementia diagnosis ("Why"). We will apply multidimensional state sequence analysis to cluster diagnostic pathways based on three dimensions: the care setting ("Where"), including urgent/non-urgent hospital admissions, outpatient clinic, and GP consultations; the type of consultation ("What"), including diagnosis (primary, secondary, outpatient), diagnostic imaging, Mini-Mental State Examinations (MMSE), and memory complaints; and the involved care provider ("Which"), including GPs and specialists. Characteristics such as

age, sex, comorbidities, socioeconomic status, and MMSE scores will be examined by cluster. MMSE scores will serve as a proxy for disease severity to evaluate diagnosis timeliness within each cluster.

Results: The study population had a mean age at diagnosis of 81 years (± 9) and included 58% women. By applying cluster analysis, we expect that these patients can be grouped into diagnostic trajectories that differ in care intensity, provider involvement, and diagnostic timing. We anticipate that each cluster will demonstrate different characteristics in terms of patient demographics, comorbidities, and MMSE scores.

Conclusions: To our knowledge, this is the first study to apply sequence analysis to dementia diagnostic pathways using real-world data. This method offers a structured approach for understanding current diagnostic practices and identifying patient characteristics within these pathways.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-05 - Experiences of a dementia diagnosis disclosure: a qualitative analysis using the SPIKES D framework

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Previous research highlights the importance of the diagnosis disclosure process for people's ability to live well with dementia. However, there is an evidence gap concerning the clinician competencies that make for a successful or unsuccessful disclosure from the perspective of people living with dementia (PLWD) and their carers, and no studies that assess these experiences within the context of SPIKES D framework, a five-stage protocol developed to aid clinicians in delivering a dementia diagnosis.

Thirteen semi-structured interviews were conducted with PLWD and/or their carers. These interviews concerned the entirety of the peri-diagnostic process (pre-, during and immediately post-diagnosis); a critical incident technique was employed to focus on the experience of the disclosure meeting and clinician competencies when delivering the dementia diagnosis.

Data were analysed using Braun and Clarke's thematic analysis technique. Three themes were constructed from the analysis: (i) clinician characteristics

and body language (attitudes, attributes and behaviours of the clinician that were perceived positively or negatively by the PLWD and/or their carer such as empathy (or a lack thereof)); (ii) emotions experienced (a wide variety, including confusion, frustration or reassurance which could be influenced by the clinicians characteristics); and (iii) explanations and support (the information (or lack thereof) provided to the PLWD and/or their carer by the clinician). These themes were then applied to and shown to be supported in the five stages of the SPIKES D framework.

A successful disclosure of dementia diagnosis is dependent on the characteristics, knowledge and support demonstrated by the clinician and can impact the emotions experienced by the PLWD and their carers. This lends support to the SPIKES D framework and the growing need to measure and therefore improve the diagnostic disclosure of dementia.

Keywords:

Dementia; Diagnosis; Disclosure;

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-06 - PREDICTOM interim results: Early detection of Alzheimer's disease using an AI-based screening platform

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Background: Early prediction of Alzheimer's disease (AD) represents a critical healthcare challenge. PREDICTOM aims to develop and evaluate the accuracy of an artificial intelligence (AI)-driven screening platform for the early detection of AD, expanding the clinical pathway through home-based assessment using both established and novel biomarkers.

Method: PREDICTOM is a European cohort study aiming to recruit 4,000 individuals aged 50 and older who are at increased risk of developing AD. Recruitment is expected to begin in May 2025 across seven European centers. Level 1 involves a home-based assessment including digital biomarkers (cognition, hearing, eye-tracking, questionnaires) and physiological samples (finger-prick blood and saliva). Using AI-driven algorithms, participants will be stratified into high-risk (N=415) and low-risk (N=200) groups, who will proceed to Level 2, an in-clinic assessment

including EEG, MRI, blood sampling, cognitive testing, hearing assessment, stool collection, and eye-tracking. In Level 3, the presence of AD pathology will be confirmed or ruled out using established biomarkers such as cerebrospinal fluid analysis, plasma markers, or amyloid PET. Demographic, clinical, and biomarker data will be analyzed and compared between participants with and without AD pathology using ANCOVA and hierarchical multiple regression, controlling for age, education, and sex.

Results: The interim analysis of Level 1 data will include N~1000 across the spectrum from high to low risk of AD.

Conclusions: The PREDICTOM study offers unique insights into the diagnostic accuracy of at-home assessments for the early detection of AD. Initial findings will highlight the potential of these measures to distinguish between different risk levels, particularly between high- and low-risk individuals. We will present a comprehensive analysis of data from the first ~1,000 participants enrolled in the study.

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35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-01 - The development of a dementia diagnosis referral form: An e-Delphi consensus study

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Background: General Practitioners (GPs) play an important role in the diagnosis of dementia, including referring patients to secondary care memory clinics for further assessment and confirmation of the diagnosis. The inclusion of essential diagnostic information can enhance clinical assessment, referral and

triage of referrals, supporting primary and secondary care clinicians. Internationally, a broad range of dementia diagnosis referral forms have been developed for use by GPs, however there is a lack of published evidence to support their design.

Aim: This study aimed to identify the critical components of a dementia diagnosis referral form to be used by GPs when referring their patients with suspected dementia to specialist memory clinics.

Methods: A two-round, modified e-Delphi was conducted to seek consensus from experts. Purposive selection of experts was undertaken. Participants included an expert panel of GPs, neurologists, psychiatrists of old age, gerontologists and allied healthcare professionals. An initial scoping exercise involved reviewing and examining 15 existing referral forms to identify items for inclusion in the first-round survey. Recognised Delphi methods were followed, using a 9-point Likert scale survey, with a cut-off for inclusion of 80% consensus.

Results: 85 experts participated in round one of the e-Delphi and 61 experts participated in round two. Out of 76 initial items included in round one, 39 items eventually reached consensus. A modified Nominal Group Technique approach was employed to further prioritise and refine the content and design of a bespoke dementia diagnosis referral form.

Conclusion: The findings of this research have informed the development of a practice-relevant, evidence-informed dementia diagnosis referral form. This offers the potential to streamline the flow of communication between GPs and memory clinics. Enhancing the quality of dementia diagnosis referrals from primary to secondary care may help to improve the timely detection and diagnosis of dementia.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-07 - Barriers and Facilitators to Early-Stage Dementia Care: A Qualitative Study on the Perspectives of Persons with Dementia, Caregivers, and Healthcare Professionals

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Background: While timely support can benefit persons with dementia (PwD) and their informal caregivers, many dyads experience a diagnostic delay. This study explored needs, barriers, and facilitators in seeking and accessing support in the early stages of dementia, and examined whether geographical context had influence.

Methods: This qualitative study used a cross-sectional design. We recruited 35 dyads of PwD (mean age 77.7±7 years; 51% female) and their informal caregivers (70.0±14 years; 60% female) through daycare centres and memory clinics in the Netherlands. Healthcare professionals (N=47; 87% female) were contacted via regional dementia networks. Open-ended questionnaires were used to assess dyads' experiences and needs. Healthcare professionals participated in semi-structured interviews on how to effectively reach dyads. All data was transcribed. Thematic content analysis was used by two independent coders to identify key themes.

Results: Key barriers to help-seeking included stigma, lack of awareness, misalignment of services and needs, bureaucratic complexity, and difficulty navigating the healthcare system. Dyads indicated a strong need for acquiring more knowledge, practical resources, and peer support in the early-stage.

Dementia case managers were seen as crucial for accessing support. Effective strategies for professionals to improve early-care acceptance included: community engagement and accessibility, increasing visibility through education and awareness, a personal approach based on patience and trust, and better collaboration with other care services for earlier symptom recognition. Professionals stressed the need for tailored outreach strategies, because effectiveness of strategies as well as dyads' needs varied between urban and rural regions.

Conclusion: Early-stage support should be made more visible in communities and tailored to individual needs. Reducing barriers such as stigma and bureaucratic complexity, while strengthening local facilitators, may improve access to timely and meaningful support. Early-stage care acceptance may improve quality of life for PwD, alleviate caregiver burden, and reduce long-term healthcare costs.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-12 - Assessing financial management in early stages of cognitive impairment: an objective app-based evaluation tool as part of the PREDICTOM study

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Background: Managing finances is an Instrumental Activity of Daily Living that often declines with cognitive impairment. The Banking App was developed as a digital test to simulate financial tasks and objectively assess performance. It has been employed in several studies, distinguishing individuals across stages of cognitive decline. In RADAR-AD (https://www.radar-ad.org/), it successfully differentiated healthy controls and individuals with preclinical Alzheimer's disease (AD) from individuals with prodromal AD and mild AD. Building on these results, the app was refined in the PREDICTOM study (https://www.predictom.eu/), to detect subtle cognitive differences and identify individuals at varying risk of developing dementia.

Methods: While the core approach was kept (users are prompted to enter a PIN, an amount and confirm their inputs), additional difficulty levels were added to the standard version (i.e., shuffled numpad, countdown timer, combination). Prompts, previously shown on printed bills, now appear on-screen. Each level includes two sublevels, resulting in eight PIN-Amount combinations, up from one, while keystroke actions are now recorded. The updated version was thoroughly reviewed.

Results: Internal testing confirmed the functionality of the new features. Considering all information and potential aggregation, the app yielded over 100 features. Apart from the increase in repetitions allowing for more representative results, the modifications enable extraction of granular features, complex tasks and keystroke analysis. Furthermore, positive feedback was received from the project's Public Ambassador Group regarding the updated app's feasibility.

Conclusions: The Banking app offers granular features, expanded task variations, and combinable elements, enhancing its utility for comparisons, detection, and for developing predictive machine learning / artificial intelligence models. Validation is underway in the PREDICTOM study, aiming to enroll 4.000 participants and utilize the Banking App among other (digital) biomarkers to assess cognitive health.

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35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-11 - Common practices in Diagnosis and Communication of Mixed Pathology Dementia in Clinical Practice: A Focus Group Study

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Background: In Dutch memory clinics, the second most common cause of dementia is 'mixed pathology' (multiple pathologies causing the syndromal diagnosis). There is currently no clear consensus on the diagnosis of mixed pathology dementia or how clinicians should communicate this diagnosis. Yet, with increasing use of biomarkers for etiological diagnoses and possibly treatment, mixed pathology is a key area of concern. This study explores

practices for diagnosing mixed pathology dementia and how clinicians communicate this to patients.

Methods: Three semi-structured online focusgroups were held, involving clinicians (e.g. neurologists, geriatricians, psychiatrists and (neuro)psychologists). Participants were asked to define 'mixed pathology'. Next, a fictional patient-vignette with vascular and Alzheimer's pathology was presented, and participants were asked to diagnose this patient. Clinical information was provided step-by-step, to explore how this affected the diagnosis. Finally, participants were asked how they typically disclose the diagnosis of mixed pathology dementia to patients. Audio-recordings will be transcribed and thematically analysed by two researchers to identify recurring themes.

Preliminary results: An initial focusgroup (n=6, 4 neurologists, 2 psychologists) indicated participants used various terms for mixed pathology. Most clinicians integrate clinical presentation with e.g. neuropsychological assessment, MRI, and lumbar puncture to diagnose mixed pathology dementia. Generally, clinicians requested additional testing in case of a symptomatic mismatch. Disclosing mixed pathology diagnoses was deemed important because of the consequences for the course of disease and treatment options. Communication about mixed pathology depended on patients' needs and characteristics (e.g. age, education level and family, need for information) and on treatment options.

Conclusion: These findings suggest that mixed pathology is an integration of clinical impressions and additional diagnostic workup. Various terms are used for mixed pathology by clinicians. Communication about mixed pathology is tailored to patients' needs and characteristics. These results may support guidance on the diagnostic process of mixed pathology dementia.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-08 - How patients and care partners view clinician communication about etiological diagnosis of dementia and related uncertainties: a qualitative study

Jolanda Dobbe[1], Leonie Visser[2], Tim Waagemans[2], Geert Jan Biessels[2], Floor Duits[2], Wiesje van der Flier[2], Marij Hillen[2], Evelien Lemstra[2], Gerwin Roks[2], Inez Ramakers[2], Ellen Smets[2]
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Background: Dementia is a syndrome with various underlying etiologies. Communicating an etiological diagnosis is challenging for clinicians, involving complex information and frequent uncertainties. We explored perspectives of patients with Mild Cognitive Impairment and dementia and their care partners, on *what* should be communicated about the etiological diagnosis of dementia and related uncertainty, and *how* this should be communicated.

Methods: This qualitative study included one focus group (3 patients, 2 care partners) and 21 interviews (19 patients, 19 care partners). Patients were recruited from three memory clinics (2 academic, 1 non-academic) and received a diagnosis recently (<4 months). Participants were first asked about their clinicians' communication regarding the etiological diagnosis, and their understanding. Next, they read scenarios of how a clinician could communicate when providing an etiological diagnosis, depicting various degrees and types of uncertainty. Participants' views on how these uncertainties should be communicated were explored. Data were analysed using content analysis.

Results: Participants showed poor knowledge of their etiological diagnosis, often mentioning risk factors (e.g., age, bad luck, genetics, lifestyle). During

the diagnostic disclosure, clinicians' communication efforts (e.g., visualization of test results) enhanced participants' understanding. Needs regarding etiological information varied: some desired detailed information to provide clarity and appropriate care, while others preferred minimal information because of limited added value and potential information overload. No clear demographic or clinical patterns were found in these preferences. Additionally, regarding the scenarios of uncertainty, many participants emphasized that clinicians should be explicit about the presence of uncertainty. Care partners indicated stronger information needs than patients.

Discussion: Findings reveal much variation in how (detailed) patients and care partners wish to receive information about the etiological diagnosis of dementia and related uncertainty, highlighting the need for a personalized approach. Further research should investigate which strategies to communicate uncertainty result in most optimal outcomes, e.g., understanding.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-02 - Reliable Repeated Online Measuring of Memory (Dys)function: The Seattle-Groningen Memory Assessment

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Sensitive and repeatable memory assessments are critical for the early diagnosis of dementia and to enable physicians to accurately monitor disease progression. However, the most commonly used memory tests today are not designed for frequent administration, with most clinics assessing patients only annually or biannually. This infrequent testing limits clinicians' ability to continuously track cognitive changes and to provide the personalized care that patients require. In this context, we present the Seattle-Groningen Memory Assessment (SGMA), a novel, computational tool developed to measure long-term memory performance through brief, adaptive online sessions.

Its design allows for repeat testing across short or long intervals without introducing retest effects. SGMA operationalizes this by estimating an individual's Speed of Forgetting (SoF), a parameter reflecting how quickly memory traces decay over time. This individualized metric is then normalized to produce a standardized SGMA index for ease of interpretation. In a longitudinal study, SGMA achieved a 91% classification accuracy in distinguishing individuals with mild cognitive impairment (MCI) from controls after a single 8-minute, online test,

equating accuracy of physician-administered, time-resource intensive alternative test.

To further evaluate its applicability in clinical settings, SGMA was administered to a cohort of approximately 1440 organ transplant recipients characterized by complex multimorbidity and increased dementia risk due to chronic kidney failure. Results indicated high retest reliability, and no training or retest effects.

Moreover, SGMA was sensitive to physical biomarkers associated with cognitive function. These findings support the utility of SGMA as a scalable, repeatable, and minimally burdensome tool for detecting subtle changes in cognition. Its design makes it well-suited for both research and clinical settings where detecting subtle cognitive changes is essential for monitoring disease progression and evaluating interventions.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Detection and diagnosis

06/10/2025 - 17:00-18:15 - QOP2. Detection and diagnosis

QOP2-09 - Hearing assessments for people with dementia: A feasibility study

Hannah Cross[1], Piers Dawes[2], Christopher Armitage[1], Laura Brown[1], Iracema Leroi[3], Rebecca Millman[1]
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Background: Age-related hearing loss is highly prevalent in people with dementia (PwD) and can contribute to communication difficulties, social interactions and relationships, exacerbated confusion, depression, falls and behavioural symptoms. Addressing hearing loss can improve the lives of PwD and their carers. Many PwD do not receive routine hearing tests and live with unaddressed and unsupported hearing loss.

Aim: To explore whether home-based hearing assessments are acceptable, tolerable and reliable for PwD. To examine the prevalence of hearing loss and earwax occlusion.

Methods: Thirty-three individuals with formally diagnosed dementia were recruited in the North-West of England. Participants completed demographic forms, the Clinical Dementia Rating scale and were scheduled for two home-based hearing assessments, 2-3 weeks apart. Hearing assessments are ongoing and involve case history with participants and caregivers, otoscopy and Pure-Tone Audiometry (PTA) to determine hearing thresholds. Attrition, assessment completion and PTA test-retest reliability using descriptive statistics and Pearson's r will be calculated.

Results: Mean age of participants= 78 (SD= 6) years; 61% male; 97% White; 67% had Alzheimer's. Cognitive impairment ranged from questionable (15%), mild (61%), to moderate (24%). Currently, attrition rate is 12%. All 29 participants who attended their hearing assessments had 100% completion rates for otoscopy, PTA, and show consistent responses to tones. No adaptations were required. Test-retest reliability of PTA will be reported. Currently, 95% of participants have at least mild hearing loss and 55% have earwax occlusion. Only 55% of participants self-reported difficulties hearing and 45% use hearing aids.

Discussion: Standard home-based hearing assessments are well-attended and well-tolerated by our sample of PwD. The high prevalence, and under-recognition, of hearing loss and wax occlusion underscores the need for regular hearing assessments and follow-up care. Future research involving an ethnically and cognitively diverse samples would further strengthen our understanding of the feasibility of hearing assessments for PwD.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-01 - Designing for Dementia: Engaging Undergraduate Students in Participatory Design for Cognitive and Social Inclusion

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This study explores pedagogical practices involving undergraduate design students, aiming to engage them in dementia research through participatory design processes with persons living with dementia. It seeks to raise awareness and educate future designers about the potential of design to foster a more inclusive society. The study argues that design can play a crucial role in communication processes for persons with dementia, particularly through the creation of mediating artefacts that stimulate personal expression, foster positive interpersonal relationships, and encourage participation in meaningful activities.

The research was conducted within the framework of the REMIND project—*Design for People with Dementia: Cultural, Contextual and Biographical Components in the Production of Artefacts for Cognitive Stimulation Activities*. Drawing on key concepts of personhood and person-centred care, the study hypothesises that integrating cultural elements from the biographical narratives of persons living with dementia can enhance reminiscence and encourage the sharing of life

stories and experiences - an approach that remains underexplored in the Portuguese context.

This hypothesis was tested through a design project implemented at a Day Centre specialising in dementia, managed by the Alzheimer Portugal association (a partner in this project), involving researchers, healthcare professionals, persons with dementia, and design students. The methodologies employed included visual and sensory ethnography, participant observation, focus groups, and informal interviews, alongside participatory design methods engaging persons with moderate to advanced dementia. The project culminated in the development of various cognitive and sensory stimulation artefacts, as well as ludic activities.

The findings underscore the significance of incorporating cultural elements embedded in the biographical narratives of individuals with dementia. These elements act as catalysts for reminiscence and affective memory, facilitating the sharing of personal stories while fostering social interaction, enjoyment, and overall well-being.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-02 - Advancing inclusive research approaches in involving underserved groups in dementia research: Co-creating the EMPOWER Dementia Network+ and Funding scheme.

Andy Bradshaw[1], Emma Wolverson[2], Chandrika Kaviraj[3], Faye Watson[3], Stefanny Guerra[1], Laiba Ahmad[2], Catherine J Evans[1]
[1]King's College London, [2]University of West London, [3]

Context: Inequalities in research and care prevent people with dementia from living meaningful lives. The EMPOWER Dementia Network+ addresses these inequalities by connecting people with dementia, their families, researchers, practitioners, and community partners through co-production. Key to our Network is funding projects that tackle inequalities.

Aims: In its first year, the Network aimed to: (i) co-create a vision for excellent and inclusive dementia care using creative approaches, (ii) identify priorities for project funding, and (iii) advance inclusive research approaches involving underserved groups.

Methods: A co-production approach involving people with dementia, family carers, community partners, practitioners, and researchers. The approach had three stages:

1. **Getting Creative:** In-person and online workshops with community leaders using creative techniques.
2. **Growing Our Vision:** Community partners running creative workshops with local groups to identify priorities.

3. **Co-Creating a Bold Vision:** Synthesising insights into a bold vision for change using template analysis.

Results: Workshops involved 44 participants in Stage 1 and 78 in Stage 2. Through co-production, we developed a metaphorical garden/ecosystem representing inclusive dementia care. Key elements included:

- **The Who:** Defining who we are and why dementia matters.
- **Pollinators:** Values for excellent dementia care such as compassion and a life worth living.
- **The Tree:** Priorities for care and research, such as reducing stigma and integrated services.
- **The Toolshed:** Tools needed for achieving our goals, including respite for carers and dementia-specific training.
- **The Compost Heap:** Barriers to remove, like resistance to change.

Integration into funding priorities: Our co-created vision directly informs funding priorities. Our four funding areas are: (i) raising public awareness and addressing stigma and exclusion, (ii) building a compassionate, skilled, and supported workforce, (iii) supporting families, friends, and unpaid carers, and (iv) inclusive uses of technology.

Implications: This co-production model offers an innovative method for engaging underserved communities, ensuring their voices drive dementia research and policy priorities.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-03 - Improving Research Engagement in the Care Home Community in Scotland

Denise Grassick-Munro, Rosalie Ashworth
ENRICH Scotland

Approximately, 63% of Scotland's care home residents are living with dementia, yet residents, families and staff are a significantly underserved demographic in research engagement in Scotland. This means research doesn't always effectively address what's most useful for them. Patient and Public Involvement (PPI) is notably challenging to develop and sustain within this group because traditional engagement methods often fail to overcome participation barriers. Understanding the unique and diverse needs of this population is crucial for developing inclusive research opportunities that recognise barriers and facilitate sustained and meaningful PPI.

To better understand and address the challenges, RICH Voices, a PPI group within ENRICH (Enabling Research in Care Homes) Scotland, implemented a dual approach. First, we conducted a survey among staff in 'Research Ready' certified care homes to evaluate engagement levels, types of research engaged in, and perceived barriers and facilitators. Second, direct community outreach was organised with care home relatives to gather insights into how best to support their involvement.

The findings from these activities have shed light on the current research engagement landscape in Scottish care homes. These insights are valuable to developing tailored initiatives that empower residents, families and staff to engage more confidently in research. The outcomes will guide RICH Voices in

developing engagement strategies to establish a supportive foundation for PPI in Scottish care homes and promote research that is more open to everyone. This initiative underscores the importance of improving PPI methodologies to include diverse and often marginalised populations more effectively and has potential for broader application in care home communities in the UK, and beyond. This presentation will focus on the insights learned and how they can be applied to support research engagement.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-04 - Co-designing equitable access and inclusion for participatory research, design and development

Kristina Niedderer[1], Rosa Almeida[2], Tom Dening[3], Federica D'Andrea[4], Michael Craven[3]
[1]Manchester Metropolitan University, [2]INTRAS, [3]Nottingham University, [4]University of West London

Successful dementia service and care development relies on the active involvement of all relevant stakeholders in the research and development process. Yet, it can still be a challenge for people with dementia to be meaningfully involved in large interdisciplinary, intersectoral and international projects.

This presentation explores models for fostering equitable, respectful and meaningful inclusion and collaboration through mindful, participatory design in dementia research with the aim to co-design better, more person-focused support and care services, environments and systems with and for people with dementia.

These ideas arose from the European MinD project 'Designing for People with Dementia: Mindful Self-empowerment and Social Engagement' (2016-2020), which worked with experts by experience in four countries to develop guidance and policy for mindful co-design (Dening et al. 2020; Niedderer et al. 2020). This work introduced a value-based, mindful co-design approach to promote dignity, respect and emotional wellbeing as well as inclusion, equality and citizenship.

To apply and promote these values in dementia research and design, the MinD network was formed in 2020 to explore models, through which to facilitate the collaborative working of all stakeholder groups in an equitable, respectful and accessible way.

We will present a multi-layered model that includes value-based, accessibility and practical considerations (MinD network, 2022). In particular, we propose a new, integrated practical model, the hybrid satellite model, for collaborating with different stakeholder groups across different countries to co-design more person-focused service systems for discussion and feedback.

References & Acknowledgements

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35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-07 - An Evaluation of The Alzheimer Society of Ireland's 'TeamUp for Dementia Research' service

Lauren O Mahony, Emma O Shea, Siobhan Fox
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Background: The Alzheimer Society of Ireland (ASI) coordinates TeamUp for Dementia Research (TUDR), a service matching people living with dementia (PwD) and their families/carers with opportunities for research participation.

Aim: To conduct an external evaluation of TUDR, to identify i) the experience and perceived value for service-users, and ii) areas for service development.

Methods: A mixed-method design was employed, through 1) an anonymous online survey of TUDR members & 2) semi-structured interviews with members and other key stakeholders (researchers, ASI staff, policymakers). Survey data were analysed using descriptive statistics. Qualitative interviews were thematically analysed.

Results: 49 members completed the survey (14% response rate); including PwD (16.3%), carers (current 40.8%; former 28.6%), and others (14.2%). Most respondents (61.2%) were female and aged 50-64 (44.9%), or 65-79 (34.7%). Before registering with TUDR, 73.5% reported not knowing how to participate in research. Two-thirds of those offered an opportunity (n=35) reported participating in a study through TUDR (68.6%). Members rated their overall experience as 'good' (42.9%) or 'excellent' (34.7%), describing they "feel valued" and that TUDR is "dedicated". Others rated their experience as

'modest' (18.4%) or 'poor' (4.1%), indicating there was no "relevant" research opportunity or that they had little interaction. Seven themes were identified through thematic analysis. Some qualitative findings bolster the survey findings, while others provide additional contextual insights, pertaining to: 'Hearing about TUDR'; 'Sign-up & communication processes'; 'Challenges in recruitment'; 'Understanding of what TUDR is and involves'; 'Navigating research relationships'; 'Value of TUDR'; 'Service development'.

Conclusions: TUDR enables person-centered opportunities for members to learn about and participate in dementia research, while supporting researchers' recruitment efforts and bolstering national dementia policy. Automating some aspects of the service may facilitate improved matching processes. For TUDR to develop, dedicated human and fiscal resources could support wider outreach/advertising and increased varied research opportunities for members.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-05 - Evaluating strategies for inclusive recruitment of citizens for digital dementia prevention research: a case study about a cross-sectional survey.

Kyra K.M. Kaijser[1], Tanja J. de Rijke[1], Elaine A.C. Albers[1], Thomas Engelsma[1], Ellen M.A. Smets[1], Awaale F. Rirash[2], Janne M. Papma[2], Leonie (N.C.) Visser[3]
[1]Amsterdam UMC, [2]Erasmus MC, [3]Amsterdam UMC / UMC Utrecht

Background: Public health (research) initiatives focused on dementia prevention are gaining attention. Strikingly, these initiatives often fail to engage individuals with increased dementia risk, i.e., those with lower levels of educational attainment, health literacy, and/or a migration background. We aimed to evaluate the success of various recruitment strategies in engaging those often-underrepresented groups, in the context of a survey study investigating citizens' intention to use digital tools for dementia prevention.

Methods: Four groups of recruitment strategies were applied: In-Person (e.g., researcher asking people at community centers), Champion (e.g., home care nurses inviting clients), Traditional passive (e.g., flyer distribution), and Online strategies (e.g., social media calls). Efficiency was examined by tracking our efforts, e.g., recruitment time, costs, staffing, and completion rates. Effectiveness was assessed for each strategy by comparing participant characteristics with the desired study sample profile.

Results: After ample efforts to engage as many (diverse) participants as possible, our recruitment strategies led to N=126 completed surveys. In-Person strategies accounted for 30.2%, Champion-strategies for 19.4%, Traditional

passive-strategies for 33.3% and Online-strategies for 16.7% of completed surveys. Across strategies, a relatively small proportion of participants reported to have a lower education (19-32%) or lower health literacy level (means of 1.9- 2.5, on a scale from 1 to 4 with higher scores indicating lower health literacy) and most participants reported being born in the Netherlands (66-93%).

Conclusions: Critical evaluation of our efforts and the resulting participant numbers and diversity highlights how none of our recruitment strategies were particularly efficient nor effective when it comes to engaging underrepresented groups on a large scale. Therefore, strategies for large-scale data collection and public interaction should be reconsidered, thereby exploring innovative methods tailored towards needs and preferences of underrepresented groups. This could enhance participant diversity and therewith quality of research and success of public health campaigns.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-06 - Creating a set of Involvement Principles: listening to what matters to people with lived experience.

Claire Garley[1], Jonathan Kaye[2], Martina Davis[2], Jane Buckels[2], Madeleine Aziz-Brook[2], Cheryl Elliott[2]
[1]Alzheimer's Society, [2]

This presentation will explore a collaborative project to develop a set of involvement principles for Alzheimer's Society, a UK-based charity supporting people living with dementia and their families. In a large organisation, the quality of the experience for those who get involved can vary, during this project we heard both good and not so good examples of this. Our purpose was to create a set of principles which would act as a guide for Alzheimer's Society and our partners reminding everyone what good involvement looks like. This project and presentation have been co-produced by the authors working with staff from Alzheimer's Society.

Our project group, consisting of people with lived experience and staff came together for an initial 5 months. The project started with a blank page and through a series of 1:2:1 and group discussions, members shared good and not so good examples of involvement. Through reflection and debate a series of themes emerged which were the starting point for our first set of principles. Feedback from teams and individuals in the organisation with an interest in involvement was requested and edits made. This process resulted in

the identification of 7 core principles that emphasise respect, inclusion, honesty, communication, trust and safety.

Our involvement principles provide a framework for Alzheimer's Society to ensure that the experience of people who are actively involved with us is a positive one. In this presentation, we will discuss the challenges and successes of the co-production process, including celebrating how allowing time for, and having respectful, honest conversations can bring clarity to an organisation's involvement activities. The project is ongoing, with group members continuing to be involved in embedding the principles across the organisation. Therefore, we will also share how these principles have been implemented in practice and any impact on organisational understanding.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-09 - From Insight to Impact: Public Involvement in Dementia Research Through a Contributor's Lens

Cíara O'Reilly, Brenda Buckley, Nuala Paley
The Alzheimer Society of Ireland

In Ireland, the landscape of Patient Public Involvement (PPI) in research has undergone significant transformation in recent years, marked by both advancements and ongoing challenges. This is due to the commitment of researchers, patient organisations, funders and PPI Contributors who recognise the value of embedding the lived experience throughout research.

As members of the Dementia Research Advisory Team, we are experienced PPI Contributors. We collaborate with researchers on specific projects, influence and inform the national research agenda through The Alzheimer Society of Ireland's research portfolio and contribute to the growth of PPI as a cornerstone of good research.

Demonstrating our continued efforts to foster equitable, respectful, and long-term partnerships between researchers and the public, this presentation will highlight the principles and values of authentic PPI from the perspective of PPI Contributors:

- **The community of research**: PPI Contributors gain knowledge, skills, confidence, and a renewed sense of purpose through research collaborations. Recognition for our efforts is evidenced

when throughout the research process we are invited to co-create, co-present and co-author.

- **Navigating the rural / urban divide:** Inclusive dementia research must create flexible, accessible involvement models to ensure rural voices are equally heard. These perspectives are essential to understanding how geography shapes dementia care and support, providing rich data that might otherwise be overlooked.
- **Improving research communication:** Working in partnership with the public strengthens research communication, enhances transparency, and ensures the research remains anchored in the lived experience. Public involvement contributes to a culture of reciprocal trust, where research is done *with* communities rather than *on* In dementia research, where the stakes are deeply personal, this shift is essential.

This presentation will provide a unique insight into PPI from the contributor's perspective, highlighting what meaningful involvement looks like in practice, and why it's worth getting right.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-10 - Pioneering Partnerships: The Irish Model for Embedding the Lived Experience of Dementia in Research and Policy

Cíara O'Reilly
The Alzheimer Society of Ireland

The Alzheimer Society of Ireland has a long-established reputation for centering sustainable knowledge in its research work. This commitment is reflected in the tailored support and advice provided to Early Career Researchers, ensuring the continuity of research by bridging the insights of established experts with evolving methodologies and priorities in dementia and health research.

A cornerstone of this work is embedding lived experience through the principles of Patient Public Involvement (PPI) across all research stages. Empowering individuals with lived experience of dementia as active PPI Contributors ensures research remains relevant, high-quality, and impactful. Through bespoke training and support, contributors are equipped to engage meaningfully in the research process while also gaining personal and professional benefits, fostering a more inclusive and dynamic research environment.

It is critical to recognise and build on the broader skills PPI Contributors bring, from public speaking to community development and the arts. Valuing these transferable skills enables individuals to take on leadership roles within research, shaping its design, delivery, and impact. Additionally, supporting the development of complementary research skills among PPI Contributors through training, workshops and co-facilitation opportunities enhances their contributions and strengthens their ownership of the research process. This

investment builds confidence, capacity, and leadership within the PPI community whilst simultaneously underscoring the bidirectional nature of PPI.

Future dementia research will depend on trust, respect, and the recognition of lived experience as a critical source of expertise, underpinned by improved public research literacy and transparent, respectful collaborations.

This presentation will explore how structured PPI frameworks, targeted capacity-building, and sustained collaboration, exemplified by Irish initiatives like the Dementia Research Advisory Team, can inform collective practices that strengthen the role of public involvement in dementia research and policy. These insights offer valuable learning for the international dementia research community seeking to embed lived experience meaningfully and sustainably.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Public involvement in dementia research

07/10/2025 - 10:30-11:45 - QOP3. Public involvement

QOP3-11 - Embedding Patient and Public Involvement in Developing an Online Intervention for Informal Caregivers of People with Dementia: Insights from a Doctoral Study

Qiuxia Li[1], Kieran Walsh[2], Sinéad Hynes[2]
[1]University of Galway, [2]

Background: While Patient and Public Involvement (PPI) is increasingly promoted in dementia research, its integration into studies specifically aimed at supporting caregivers' well-being remains limited. The demanding nature of caregiving responsibilities often limits informal caregivers' opportunities to have their voices heard in research. For doctoral researchers, accessing and involving caregiver contributors can be particularly challenging. In response, this doctoral study provides insights and an example of how PPI was embedded across a multi-phase project developing an online psychosocial intervention for informal caregivers of people with dementia.

Methods: PPI was integrated across the research cycle, guided by the GRIPP2 checklist. Reflections were collected through meeting notes, email correspondence, and contributor feedback.

Results: PPI contributors— including family caregivers and people living with dementia—were involved in three core phases: (1) a systematic review assessing the effectiveness of online psychosocial interventions, (2) a qualitative study exploring caregivers' needs and preferences, and

(3) the planning of an online intervention. Contributors helped interpret review findings, identify priorities, co-design materials, assist with data collection, and contribute to dissemination.

Reflecting on the process, we identified a trajectory of evolving engagement and flexible collaboration. Balancing project timelines with contributors' time and capacity posed challenges. Practical involvement in this doctoral study was supported through inclusive communication, flexible engagement formats (e.g. group or one-to-one meetings, email, phone, or post), and tailored levels of engagement (e.g. consult, partnership) based on contributors' preferences and capacity.

Conclusion: This study contributes to the limited knowledge base on how meaningful and practical PPI can be embedded throughout a doctoral research project focused on dementia caregiving. Ongoing involvement was enabled through flexible engagement, trust-building, and clear communication. The study adds to broader efforts to promote inclusive caregiver-focused research and offers recommendations for doctoral researchers seeking to build and sustain effective PPI partnerships.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-10 - The MIND diet and cognitive performance: a modulating role of CVD risk

Megan Smith, John Gallacher, Sarah Bauermeister
University of Oxford, Department of Psychiatry

Background: The Mediterranean-Dietary Approaches to Stop Hypertension Diet Intervention for Neurodegenerative Delay (MIND) diet was created specifically for the optimisation of brain health. Adherence to the MIND diet has been associated with advantageous cognitive outcomes. The majority of MIND-cognition studies have follow-up durations below 10 years. Consequently, the long-term cognitive associations of consuming the MIND diet remains to be understood. Additionally, shared biological pathways between cardiovascular disorder (CVD), brain health and diet suggests the relationship between MIND diet adherence and cognitive performance is affected by the presence of CVD risk factors.

Methods: This is an observational analysis of 1,638 participants from the EPIC-Norfolk study. We used the MIND dietary index to score the participants adherence to the MIND diet pattern using data from the baseline FFQs. Confirmatory Factor Analysis was employed to establish a latent construct of general cognitive ability at two time points (12 years and 23 years post baseline). We applied a structural equation modelling (SEM) framework to explore how MIND diet adherence affects later life cognition. To assess whether CVD risk moderated this relationship we conducted multi-group SEM analysis with QRISK2 score as the grouping variable.

Results: The total sample SEM exploring MIND diet and later cognitive performance had good model fit and so did the SEM split by CVD risk. In the full sample, consumption of the MIND diet was associated with significantly better cognitive performance at both time points. Multi-group SEM identified a longitudinal modulating role of CVD risk. In those with lower risk of CVD, consuming the MIND diet had a significant beneficial effect on cognitive performance at 12 years later but not 23 years. Contrastingly, in those at higher risk of CVD, adherence to the MIND diet predicted better cognitive performance both 12 years and 23 years later.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-01 - Promoting a Brain-Healthy Lifestyle through Digital Tools: Evaluation of the Implementation of the pdp Braincoach App in Luxembourg

Nina Possemis[1], Margarita Reyes[2], Anne Kaysen[2], Amna Skrozic[2], Valerie Schröder[2], Dorothee Erz[2], João Loureiro[2], Kay Deckers[3], Sebastian Köhler[3], Joëlle Fritz[2], Rejko Krüger[2]
[1]Centre Hospitalier de Luxembourg / Programme Dementia Prevention, [2], [3]Maastricht University

Background: In October 2024, the "*pdp* Braincoach" application was launched in Luxembourg as part of the "Programme Dementia Prevention (*pdp*)" to promote brain-healthy lifestyle habits and raise awareness of modifiable risk and protective factors for cognitive decline, particularly among middle-aged adults. Originally developed by the Alzheimer Centrum Limburg at Maastricht University, the application was specifically adapted for Luxembourg and is currently offered in three languages (German, French, and English). The application offers personalized tips, daily reminders, quizzes, and challenges, after users fill in the short LIfestyle for BRAin health (LIBRA) questionnaire to assess individual brain health risk profiles.

Methods: We analyzed anonymized data collected between October 2024 and April 2025. Key metrics included number of downloads, registration rate and number of improvement/maintain suggestions regarding specific

risk/protective factors from the application. Descriptive statistics and trend analyses were conducted.

Results: By April 2025, the app had been downloaded and used by 4,026 individuals, with 45% completing registration and continuing usage. The mean age of users was 57.1 years (SD = 8.5), with 63% identifying as female. The majority of users reported having an academic education with a mean education year of 14.9 years. Among the modifiable risk factors identified via the short LIBRA questionnaire, the most frequently flagged were nutrition (81%), mental stimulation (70%), and physical activity (60%) of which 37% needed to improve in all 3 categories. Less commonly reported were low mood (7%) and smoking (9%).

Conclusion: Preliminary findings indicate promising uptake and engagement with the "*pdp* Braincoach" application in Luxembourg. The high prevalence of the application suggesting nutrition, mental stimulation, and physical activity as key areas for improvement highlights potential targets for future public health strategies, as well as multidomain interventions. Ongoing user data monitoring and content updates will be essential to optimize user experience and long-term engagement.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-11 - Does Musical Experience Influence Executive Function Ability? A Large-Scale Empirical Study

Ryan Gray[1], Michael Craig[2], Michaela Dewar[3], Alan J. Gow[3]
[1]Heriot-Watt University, Dementia UK, [2]Northumbria University, Heriot-Watt University, [3]Heriot-Watt University

Musical training is a complex activity that integrates motor, sensory and cognitive functions. Research demonstrates that engagement in this activity may benefit higher-order cognitive functions, such as executive function (EF) and processing speed in older populations. However, grouping criteria for musicians in cross-sectional work often miss potentially important nuances in participants' musical experience. Thus, it remains unclear which aspects of musical experience are associated with cognitive abilities in later life.

The current study therefore examined whether and how musical experience is associated with EF ability, while considering participants' varying degrees of musical experience. Four thousand four hundred and thirty-nine healthy adults aged between 18-90 (M = 61.54) years of age took part. They were recruited via a range of methods, including platforms such as Join Dementia Research. Participants provided information about gender, age, and total years of education before completing the Edinburgh Lifetime Musical Experience Questionnaire (ELMEQ). EF was assessed across several domains, including working memory, inhibition and cognitive flexibility.

Associations between musical experience and EF were examined through Structural Equation Models (SEM). Cognitive measures were used to construct a single cognitive domain, EF. Musical experience was included in the model as four latent variables: instrument experience, singing experience, perceived musicality, and music listening. Age, gender, and years of education were included as covariates. There was a positive relationship between instrument experience only and EF performance ($\beta = 0.089$, $p < 0.001$). Age $\beta = -0.003$, $p < 0.001$) and years of education ($\beta = 0.003$, $p < 0.001$) were also significantly related to EF.

Results suggest that instrument experience may be associated with benefits to EF. As EF is critical for managing daily life activities, this positive relationship suggests that regular instrument practice could be a viable strategy for maintaining cognitive function in older age.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-12 - An Investigation into the Role of Lifestyle Factors in SuperAgers using UK Biobank

Philippa Watson[1], Ivan Koychev[2], John Gallacher[2], Sarah Bauermeister[2]
[1]Department of Psychiatry, University of Oxford, [2]University of Oxford

Background: Cognitive abilities typically decline with age, but a small group of outlier individuals, termed "SuperAgers," maintain performance comparable to much younger adults. The factors enabling this resilience remain unclear, though it is hypothesised that protective mechanisms against cognitive decline may play a role.

Methods: This study leverages data from UK Biobank with SuperAgers defined as those 65+ years at wave 3 who scored above the mean of 37-45 year olds (middle-aged adults) on a test of numerical memory performance at wave 3 and who performed within one standard deviation of the mean for fluid intelligence at wave 3. Structural equation modelling will be used to examine associations between lifestyle factors (e.g., mental health, biomedical factors, social engagement, and physical activity) in SuperAgers versus cognitively normal agers (CN's).

Results: The study included 19,557 participants (13,088 SuperAgers; 6,469 CN's). SuperAgers showed significantly lower physical activity (t = 7.56, p < .001), higher likelihood of smoking (χ^2 = 188.45, p = .003), greater alcohol intake (t = -17.76, p < .001), worse MIND diet adherence (t = 6.12, p < .001), more social visits (t = -9.72, p < .001), and lower anxiety (t = 11.40, p < .001)

and depression (t = 9.32, p < .001). No differences were found in BMI, hypertension, medications, social activity, or sleep (p > .05). Additional analyses are ongoing and will be completed by the conference date.

Conclusions: This study highlights modifiable lifestyle factors linked to preserved cognitive function in aging, offering insights for interventions to preserve cognitive function during older age.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-05 - Risk perception and knowledge of risk factors for dementia: a systematic review and meta-analysis

Muhammed Lamin Sambou[1], Jolanda H.M. Dobbe[2], Lidia R. Arends[1], Arfan Ikram[1], Ellen M.A. Smets[2], Wichor Bramer[1], Jeremy Labrecque[1], Leonie N.C. Visser[2], Frank J. Wolters[1]
[1]Erasmus MC, [2]Amsterdam UMC

Background: The proportion of people with dementia has increased over time. Recent evidence highlights the potential for prevention, emphasizing the importance of awareness among citizens regarding risk and protective factors. Therefore, we performed a systematic review of current evidence on public knowledge of risk and protective factors, and risk perception, for dementia.

Methods: We searched MEDLINE ALL, Embase, Web of Science, the Cochrane Central Register of Controlled Trials, and PsychINFO for English articles, including original empirical data. Two researchers independently conducted the screening, data extraction, and quality appraisal. Meta-regression analyses were performed for knowledge of risk and protective factors, with eight predictors: age, gender, population, education, continent, year of publication, measurement method, and quality appraisal. For the qualitative studies, we employed narrative synthesis. Lastly, mean levels of risk perception, and methodological characteristics of these articles, were evaluated.

Results: We included 160 eligible articles (knowledge: 111 quantitative and 23 qualitative; 48 risk perception). Most of the quantitative studies (n =105, 94.6%) assessed knowledge of dementia risk and protective factors passively, through prompted questionnaires. Knowledge of modifiable risk factors was

approximately 10% lower than that of non-modifiable factors (e.g. age and heredity). Of the modifiable risk factors, the highest percentage of knowledge was found for social and psychological factors (66.4%), and the lowest for cardiometabolic (37.1%), and environmental factors (35.7%). Meta-regression revealed some differences in knowledge across populations and geographical locations. The qualitative articles also revealed limited awareness of risk and protective factors for dementia. Risk perception was measured inconsistently across studies, and a limited number of articles compared participants' perceived and objective risk.

Conclusion: Our findings indicate that knowledge of risk and protective factors for dementia remains limited. Meta-regression results emphasize room for improvement, particularly regarding cardiometabolic and environmental risk factors.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-06 - Social support, loneliness and their associations with cognitive performance in older adults at risk of cognitive decline: Baseline findings from the FINGER-NL trial.

Lion Soons[1], Kay Deckers[2], Sietske Sikkes[2], Nynke Smidt[2], Rianne de Heus[2], Rebecca Otte[2], Marian de van der Schueren[2], Marissa Zwan[2], Sebastian Köhler[2]
[1]Maastricht University, [2]

Background: Social support and loneliness are key targets for cognitive health, yet they are distinct constructs and can exist independently of each other. This study investigated their associations with cognitive performance in older adults at risk of cognitive decline, their independence from each other and other modifiable dementia risk factors, and potential sociodemographic differences.

Methods: We used cross-sectional data of 1186 participants (mean age 67.6 (SD 4.6), 63.7% female) from the Dutch, multicenter, randomized controlled lifestyle intervention FINGER-NL. Social support and loneliness were measured using the Lubben Social Network Scale and De Jong Gierveld Loneliness Scale, respectively. Cognitive performance was assessed with a composite score of z-scores from tests of memory, processing speed, and executive function/attention. Multiple linear regression analyses, adjusted for age, sex, study site, educational level, household income, other modifiable dementia risk factors (LIBRA), and marital status, examined associations of social support, loneliness and cognitive performance. Interaction analyses and stratified analyses were used to explore potential differences across sociodemographic groups.

Results: Lower social support was modestly associated with worse cognitive performance after adjusting for sociodemographics and study site (B=-0.01, 95% CI -0.02 to -0.00, P=0.046), but this association disappeared after accounting for LIBRA. Loneliness was not associated with cognitive performance, nor was there an interaction with social support. Subgroup analyses revealed that lower social support and higher levels of loneliness were associated with worse cognitive performance in the younger age group (60-67 years based on median split), and lower social support was also associated with worse cognitive performance in the lowest income tertile.

Conclusion: Social support and loneliness were not generally associated with cognitive performance in later life independent from other dementia risk factors. However, they may play a role in specific subgroups, including younger late-life and individuals with lower household income. These subgroup differences warrant further investigation.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-03 - Impressive Results from FINGER Group Activities in Northern Finland

Kati Göös, Minna Kaltio, Marika Kulppi
Suomenselän Muisti ry

Introduction: The group activities following the FINGER model, coordinated by the the MemoryHealth Northern Finland 2023–2025 project, started in Northern Finland in 2024 at six pilot locations. The activities were carried out with professionals and volunteers from welfare areas and municipalities. The groups met for a year, a total of 37–38 times. The program included an initial and final consultation with a healthcare professional, health and wellness measurements, five nutrition group sessions, 20 exercise group sessions, and 10 cognitive training group sessions.

Target Group: The activities involved 53 individuals, with an average age of 70, who were at risk of developing memory disorders. A quarter of the participants were men. Three participants dropped out.

Methods: Standardized tests and self-assessment questionnaires were used at the beginning and end of the activities; these included the THL memory disorder risk test, participation indicator, SPPB test, and questionnaires.

Results: The memory disorder risk scores of the participants (N=39) decreased by 66%. Improvements in physical functioning were mainly seen in getting up from a chair and balance. The overall average of the participation indicator

increased from 81 to 88. The proportion of those experiencing loneliness decreased from 19% to 8%.

92% of the participants made some permanent lifestyle change. The proportion of those who rated their health as fair or poor decreased from 72% to 32%.

92% felt that the group's support helped them make lifestyle changes, and 89% felt that the group activities promoted social well-being. The NPS score was 95.

Final results (N=49) will be available in May 2025.

Conclusions: Participation in FINGER group activities helped make lifestyle changes, improve the experience of participation, reduce the experience of loneliness, and lower the risk of developing memory disorders.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-07 - Self-reported sleep, cardiometabolic health and cognitive function in Dutch older adults at risk for cognitive decline participating in the FINGER-NL trial

Rachel Heutz[1], Rianne de Heus[2], Kay Deckers[3], Sebastian Köhler[3], Wiesje van der Flier[3], Nynke Smidt[3], Yannick Vermeiren[3], Jurgen Claassen[3], Joukje Oosterman[3]
[1]Radboud University Medical Center (Radboudumc), [2]Radboud University Medical Center, [3]

Background: Suboptimal sleep is recognized as a potential modifiable risk factor for cognitive decline and dementia, possibly through its impact on cardiometabolic risk factors. This study aimed to investigate the relationship of self-reported sleep with cardiometabolic health and cognitive function in older adults at risk of dementia.

Methods: We used cross-sectional data of the FINGER-NL trial (N=1210), a multi-centre, randomized, controlled multidomain lifestyle intervention in older adults (aged 60-79). Average total sleep time (TST, hours), sleep regularity (intra-individual standard deviation of TST, minutes) and wake after sleep onset (WASO, minutes) were derived from a self-reported 7-day sleep diary. Cardiometabolic health was assessed with the metabolic syndrome severity score (MetSSS). Cognitive function was measured with a neuropsychological test battery (NTB). Associations of sleep with MetSSS, and sleep with NTB score were examined with multiple linear regression including a quadratic term for

TST due to potential non-linearity, interaction terms with sex and adjusted for age, study-site, and education.

Results: A total of 1088 participants (mean age 67.6, 64.1% female) with complete data were included. Compared to men, women recorded shorter TST (-0.28, 95%CI= -0.39 to -0.17), increased sleep irregularity (9.9, 95%CI=6.8 to 12.9), and longer WASO (10.5, 95%CI=7.4 to 13.7). Both regularity and WASO showed no association (p>0.05) with either the MetSSS or the NTB score (B-values range: 0.000-0.003). The quadratic term for TST was significantly associated with the NTB score (B=-0.058, 95%CI -0.10 to -0.015), but not with the MetSSS (B=-0.008, 95%=-0.075-0.059). All interaction terms were nonsignificant.

Conclusion: This study identified an inverted U-shaped relationship between sleep duration and cognitive function in Dutch older adults at risk for cognitive decline. There was no evidence linking self-reported sleep measures to cardiometabolic health. Longitudinal studies are necessary to clarify the interaction between sleep, cardiometabolic health and cognition, with implications for dementia prevention strategies.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-02 - Associations of neighborhood walkability and access to green spaces with cognitive decline and incident dementia - 25-year follow-up of the Maastricht Aging Study

Jens Soeterboek, Kay Deckers, Sebastian Köhler
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Background: Walkable neighborhoods and green spaces are associated with improved metabolic, cardiovascular, and mental health outcomes. Emerging evidence also suggests associations with cognitive functioning and dementia risk. This study examines whether green space density and walkability are associated with cognitive decline and incident dementia, independent of key demographic, socioeconomic, and health-related risk factors.

Methods: Data from 1,738 participants (aged 24–82 years) of the Maastricht Aging Study (MAAS) were assessed on cognitive functioning (memory, information processing speed, executive functioning and attention) at baseline, 6, 12, and 25 years. Residential postcodes were linked to geospatial data from the Geoscience and Health Cohort Consortium (GECCO). Green space density and a standardized Walkability Index were calculated for 250m, 500m, 1000m, and 1650m radii. Linear mixed models were used to examine associations with cognitive functioning adjusted for age, sex, education, modifiable dementia risk factors and air pollution. Cox regression will examine incident dementia risk.

Results: At basline, higher green space density was associated with better memory performance at larger radii (1000m: β= 0.025, p = 0.042; 1650m: β = 0.031, p = 0.019). Higher Walkability Index scores were associated with faster

information processing speed at baseline across all radii (250m: β = 0.049, p = 0.021; 500m: β = 0.046, p = 0.018; 1000m: β = 0.049, p = 0.017; 1650m: β = 0.051, p = 0.014). Longitudinal analyses are ongoing to determine associations with cognitive decline and dementia incidence.

Discussion/Conclusion: Baseline findings indicate that neighborhood green space and walkability are differentially associated with cognitive domains, independent of individual modifiable dementia risk factors. Associations with larger green buffers may suggest greater exposure to restorative environments, while walkability could support cognitive functioning through physical and social activity. These findings may have implications for urban planning and public health strategies for dementia prevention.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-08 - Improving awareness and knowledge about dementia risk reduction in the general population: a Dutch public awareness campaign

Niels Janssen, Dominique Paauw, Lieke Bakker, Irene Heger, Kay Deckers, Sebastian Köhler
Maastricht University

Background: Around 45% of dementia cases is likely attributable to modifiable risk factors, such as hypertension or physical inactivity. Increasing awareness on the potential of dementia risk reduction on a population level is crucial. Herein, people with low socioeconomic status or migration background are often underrepresented. A dedicated public awareness campaign is currently being conducted in the Netherlands as part of the Netherlands Dementia Prevention Initiative (NDPI). This abstract focuses on the results regarding levels of awareness measured before the start of the campaign.

Methods: The campaign is currently being conducted in the regions of South Limburg and Groningen and two local districts, characterized by low-socioeconomic position or migration background. The local campaigns will be implemented using a participatory, bottom-up approach. Various activities are planned, including the use of mass media and public events. Online surveys and street interviews were conducted in both regions (n=1550 and n=483) and districts (n=113 and n=329) to examine awareness about dementia risk being modifiable and knowledge regarding individual risk factors.

Results: Initial results of measurements before the start of the campaign show that between 49% and 72% of all respondents (i.e., two regions and two

districts) are aware of the potential of risk reduction. Of all statements on risk and protective factors, maintaining cognitive activity ('stimulating your brain reduces dementia risk') was identified most often in three samples, ranging between 88% and 91%. The risk factors chronic kidney disease and hearing impairment were least identified.

Conclusions: Educating the general population by raising awareness on protective and risk factors for brain health is essential. Maximizing reach and engagement of underrepresented groups is invaluable for developing interventions that help minimizing social inequalities in brain health and promote an inclusive dementia risk reduction strategy.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-09 - Digitally supported lifestyle program to promote brain health among older adults - the LETHE pilot trial: Results of a randomized controlled trial

Helena Untersteiner[1], Anna Rosenberg[2], Anna Giulia Guazzarini[3], Konsta Valkonen[2], Alara Abaci[4], Markus Bödenler[5], Jeroen Bruinsma[6], Ana Diaz[7], Hannes Hilberger[5], Vasileios Loukas[8], Miia Kivipelto[4], Sten Hanke[5], Francesca Mangialsche[4], Patrizia Mecocci[3], Tiia Ngandu[2], Elisabeth Stögmann[1]
[1]Medical University of Vienna, [2]Population Health Unit, Finnish Institute for Health and Welfare, [3]Department of Medicine and Surgery, Section of Gerontology and Geriatrics, University of Perugia, [4]Division of Clinical Geriatrics, Center for Alzheimer Research, Department of Neurobiology, Care Sciences and Society, Karolinska Institutet, [5]eHealth Institute, FH JOANNEUM University of Applied Sciences, [6]Department of Health Promotion, Care and Public Health Research Institute, Maastricht University, [7]Alzheimer Europe, [8]Unit of Medical Technology and Intelligent Information Systems, Department of Materials Science and Engineering, University of Ioannina

Background: The Finnish Geriatric Intervention Study to Prevent Cognitive Impairment and Disability (FINGER) trial demonstrated benefits on cognition resulting from a multidomain lifestyle intervention in a cognitively unimpaired population at risk of dementia. Digital tools may facilitate personalized

interventions, support self-management, and streamline digital biomarker collection. The aim of the LETHE trial is to test the feasibility of a digitally supported FINGER intervention.

Methods: The two-year multinational randomized controlled LETHE trial recruited older participants with an increased dementia risk but without a cognitive deficit. The recruitment goal was 160. Randomization took place in a 1:1 ratio. The intervention-group received a digitally supported lifestyle intervention in the domains of diet, physical activity, cognitive activity, cardiovascular risk management, sleep/relaxation, and social engagement. Digital elements were delivered via the LETHE App. The control-group received static lifestyle recommendations through a simplified version of the app. Follow-up visits took place at months 6, 12, and 24. The main outcomes of the study are feasibility and change in dementia risk measured using validated scores. Linear mixed models will be used to compare intervention effects between the two study-groups.

Results: Overall, 156 participants were included in the trial (mean age: 68.8 years [SD: 4.5], female: 101 [64.7%]). The retention rate is high; 5 (3.2%) participants dropped out (intervention-group: 3/78 [3.8%], control-group: 2/78 [2.6%]), one participant was lost to follow-up. On average, the LETHE app was used by 50.5% (SD: 7.5) of the intervention-group participants and 27.5% (SD: 6.7) of the control-group participants daily during the first six months. Further adherence data and results on dementia risk scores will be available for presentation at the conference.

Conclusion: Digital tools have the potential to enable resource-efficient and scalable lifestyle interventions. Preliminary results of our trial show high acceptance among older adults without dementia.

Trial Registration: ClinicalTrials.gov (NCT05565170)

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

From research to communities - Brain health and prevention

07/10/2025 - 14:00-15:15 - QOP4. Brain health and prevention

QOP4-04 - Longitudinal Lifestyle Profiles and Their Impact on Cognitive Health and Dementia Risk: Evidence from a Population-Based Sample of Older Adults

Irene Brianzoni, Michele Rossi, Mauro Colombo, Antonio Guaita, Elena Rolandi
Golgi-Cenci Foundation

Background: With the global population aging rapidly, understanding how changes in health-related behaviors are related to cognitive health is crucial. This study aimed to identify distinct profile of changes in six key lifestyle behaviors—physical activity, diet, smoking, alcohol consumption, cognitive activity, and social engagement—and assess their impact on cognitive health and dementia risk. A secondary aim was to determine the unique contribution of each health-related behavior on cognitive outcome.

Methods: This retrospective study included a sample of 966 older adults (70-75 years at baseline) from the InveCe.Ab population-based cohort, without dementia at baseline and performing at least three out of five multidimensional assessments over 12 years. Cognitive health was evaluated using the Mini-Mental State Examination (MMSE). A multivariate longitudinal K-means clustering approach grouped participants based on the longitudinal patterns of the six lifestyle habits. Linear mixed-effects and Cox models assessed the association of clusters with MMSE and dementia risk, adjusting for age, sex, education, and ApoE4 status.

Results: Three longitudinal profiles of changes in health-related behavior were identified. Cluster B (n=390, 40%), represented the healthiest lifestyle pattern

and showed better cognitive trajectories compared to Clusters A (n=531, 55%, β = -0.16, p < .001) and C (n=45, 5%, β = -0.23, p < .001). Among the health-behaviors considered, physical activity, social engagement and cognitive activity were independently associated with better cognitive outcome across the whole sample. Over the follow-up, 159 participants (16.5%) developed dementia. Compared to Cluster B, Cluster A had a 1.7-fold higher dementia risk, while cluster C showed a non-significant increase in risk, with a wide confidence interval.

Conclusions: Maintained engagement in healthier lifestyle patterns, during aging, led measurable cognitive benefits and may reduce dementia risk. These findings emphasize the importance of multifaceted community-level lifestyle interventions in preserving cognitive health in aging.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-01 - Meaningful Moments of Connection: how people living with dementia and their carers living at home understand, interpret and experience everyday aesthetics

Sarah Fox, John Keady, James Thompson
The University of Manchester

Yuriko Saito suggests that, unlike aesthetics in fine art or natural beauty, everyday aesthetics encompasses a rich array of everyday experiences. The aesthetic elements of our everyday lives also exert an impact on our emotional state, sense of identity and wellbeing. For example, a familiar scent or a warm smile from a stranger may precipitate a sense of safety and comfort, while the sight of rubbish fly-tipped is more likely to elicit a negative emotional response. These responses are unique and vary between individuals, based on the individual's personal history and preferences.

Our work, conducted in the Northwest of England between September 2023 and January 2024, explores how people affected by dementia living at home understand, interpret and experience everyday aesthetics in their day-to-day lives. We worked with nine households, comprising ten family carers and seven people living with dementia, including four households from underrepresented communities. Participants shared their self-identified meaningful everyday moments, reflective of their personal understanding and interpretation of everyday aesthetics. Data collection incorporated a range of creative, multisensory, self-initiated methods, alongside elicited interviews. Data were analysed using reflexive thematic analysis.

Our findings identified six discrete but interlinked themes, reflective of a range of everyday aesthetic, intersubjective, physical and psychological experiences. These were: Connection with others; 2. Connection with materiality; 3. Connection with self-image; 4. Connection with pride and societal value; 5. Connection with enjoyable activities; and 6. Connection with the lived environment. These aesthetic experiences supported personhood and identity for the person living with dementia and will be described in this presentation, drawing on a range of participant data. We suggest that these findings point towards a novel psychotherapeutic approach which focuses on understanding the aesthetic needs of individuals living with dementia and draws on these to create environments and experiences supportive of wellbeing, personhood and identity.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-02 - How person-centered care changes perspectives on relationship-work and potentiality of people living with dementia

Mai McLeod Winther[1], Julie Sørensen[1], Helle Hjørnholm Volhøj[2]
[1]Health and Care, Aarhus Municipality (Sundhed og Omsorg, Aarhus Kommune), [2]SOSU Ostjylland (SOSU Østjylland)

Human first is the goal and foundation of the strategy when Aarhus Municipality, Denmark's second-largest, educate 2,300 leaders and employees across professions in person-centered care — and continuously embed it in daily practice in our nursing homes and home care.

We wish to share this experience because we believe it represents a highly relevant perspective on the future of dementia care approaches.

VIVE (The Danish Center for Social Science Research) (2023) has described how care-professionals perceive relationship-work as a core task while also experiencing a lack of shared professional language for it. Grounded in neuro-pedagogy, we have found that person-centered care provides this common language for relational competence and psychosocial well-being.

In this project, we have gained experience in anchoring person-centered care as a philosophy at both strategic level and in everyday practice while also researching this in collaboration with Aalborg University. This change of culture of care amongst care-professionals on people with dementia requires fundamental prioritization -- to change daily routines to support using the new 'language' and the systematic approach that person-centered care represents.

By changing the perspective of care and using the approach, it enforces the potentiality of helping people with dementia.

However, evaluations show that the investment pays off on important levels: 1)Residents receive the support they need, enhancing their well-being while it also prevents apathy, agitation, and aggression and reduces the use of antipsychotic medication. 2)Relatives endorse the approach, increasing their sense of security. 3)Care-professionals strengthen their skills in observing, interpreting, and responding to what residents communicate through their behavior. This fosters job satisfaction and serves as a crucial counterbalance to the risk of compassion fatigue — because they succeed in a complex task.

We invite you to share your perspectives on our experiences on implementing person-centered care and also on the use of digital and hybrid solutions.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-04 - Working together for better dementia care and support: The Academic Workplace Post-diagnostic care and support in dementia

Sietske Sikkes[1], Charlotte Schmidt[2], Marjolein Wolf[3], Channah Osinga[3], David Neal[4], Rikke Komen[5], Franka Meiland[4], Anne Marie Vaalburg[6], Evelien Lemstra[4], Rose-Marie Dröes[4], Robbert Gobbens[6]
[1]VU University, [2]Kennemerhart, [3]Vrije Universiteit, [4]Amsterdam UMC, [5]Stichting Mantelzorger en Dementie, [6]Hogeschool InHolland

Introduction: Following a dementia diagnosis, people living with dementia (PwD), their family and caregivers often encounter fragmented care and support. The Academic Workplace Post-diagnostic care and support in dementia (AWPCSD) was established in 2022 to bridge and promote exchange between research, practice, education and welfare. The AWPCSD aims to improve the support, care and quality of life of people living with dementia and their caregivers, and to improve the knowledge exchange between researchers, welfare and health care professionals. Here, we highlight several projects from the AWPCSD.

Methods: Key initiatives of the AWHDD include (I) **Meeting Centers**, for which an online pioneer course was developed and a guidance for new meeting centers was updated and made available on the AWPCSD and Meeting Centers website, (II) **DemenTalent,** an initiative enabling PwD to contribute to society as volunteers, for which recommendations for further implementation were

formulated based on a nationwide survey, (III) **FindMyApps**: an online selection tool to find 'dementia friendly' apps, (IV) E-learning **STAR online** was adapted in a co-creation process with vocational secondary care students and adapted for informal caregivers and those with a migration background; (V) a nationwide **platform for Meetings Centers** was established, enabling knowledge dissemination and guidance for new and existing Meeting Centers. Completed projects include 'Known in the Nursing home', a photo-activity for people with moderate to severe dementia in the nursing home.

Results: These projects have led to practical tools, improved implementation of existing tools, better professional-patient communication tools, and targeted training tools for health care professionals, leading to greater alignment of care post-diagnosis. Inclusion of relevant stakeholders in the context of the AWPCSD, in the process towards implementation has enhanced knowledge transfer and sustainability.

Conclusion: The AWPCSD illustrates the impact of fostering and formalizing interdisciplinary academic-practice partnerships to contribute to improved, sustainable, person-centered dementia care.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-05 - Breaking Barriers in Dementia Care: A Sailing-Based Intervention Improves Cognitive, Functional, and Emotional Well-Being

Francesca Morganti[1], Marco Gagliani[2], Paolo Cornaglia Ferraris[2]
[1]Università di Bergamo, [2]Tender to Nave Italia Foundation

When first diagnosed, people with dementia are viewed as unable to carry out many of their daily activities. For individuals in a mild or moderate stage, this attitude constitutes a risk factor for disease progression, and it is imperative to prioritize the maintenance of a high level of autonomy to mitigating the onset of cognitive and functional decline.

The aim of this study was to introduce a psycho-educational program that can lead people with dementia towards a new empowerment in the trajectory of ageing with the disease. Twenty-four people diagnosed with mild-to-moderate Alzheimer's dementia (average Age 84.3; sd 7.4/Females 15 - Males 9; average MMSE 22,4; sd 4,6) were introduced to the Outdoor Training' program ideated by Tender to Nave Italia Foundation. The persons were embarked for 1 week in the brig Nave Italia without family members or caregivers. They were requested to participate in maritime activities with professional sailors, assuming diverse roles on board. To verify the benefits obtained from the week-long sailing, the project encompasses a comprehensive assessment of the cognitive, motor, and functional domains in different phases: the pre-boarding phase and the post-boarding phase. The findings indicate that there was significative impact on cognitive (MMSE), functional (IADL and ADL), emotive (GDS) and Quality of life (WHOQoL) when comparing the pre- and post-boarding phases. These results align with the necessity to incorporate functional activities and reorganize daily

autonomy into the rehabilitation pathways of individuals with dementia, in conjunction with cognitive training. This approach aligns with the Dementia Friendly initiative, which aims to enhance the quality of life for individuals living with dementia. Notably, this initiative has facilitated the cohabitation of individuals with dementia with a crew of professional sailors, thereby breaking down the conventional barriers between patients and healthcare providers.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-06 - Co-development of core competences for working therapeutically with families affected by dementia

Alys Griffiths[1], Divine Charura[2], Yelena Mikhaylova-O'Connell[3], Sophie Jeffery[4], Cara Gates[1], Esther Whittlesea Reed[5], Warren Donnellan[3], Jennifer O'Donnell[6], Emily Shoesmith[7], Heather Wilkinson[8]
[1]University of Sheffield, [2]York St John University, [3]University of Liverpool, [4]Greater Manchester Mental Health NHS Trust, [5]PPI Representative, [6]BACP, [7]University of York, [8]University of Edinburgh

Background: Current competence frameworks for therapists offer little guidance on delivering psychological therapies to people with dementia and their families, and this is not often prioritised within curricula. We aimed to develop core competences to guide practitioners working with these families.

Methods: We used a participatory approach that centred the voices of people with dementia and their families. We brought together data from 50 interviews with individuals with dementia, relatives, and therapists, followed by three collaborative workshops using the World Café method - which aims to invoke a café atmosphere - to explore in depth the questions that matter to families affected by dementia. We incorporated a range of inclusive methods to foster creativity, including LegoSeriousPlay, drawing, writing and speaking.

Results: Thirty-five people participated in the workshops. Through the World Café discussions we found that a more humanistic approach should be adopted, being more sensitive to dementia and the challenges associated with the diagnosis, and

considering feelings of loss and grief. We developed an initial set of core competences, which were refined with people with dementia and therapists. These focused on four areas; (1) knowledge of dementia and how this may impact communication and therapeutic experiences, (2) therapeutic skills and techniques for working with people with dementia, (3) specific considerations required when developing and maintaining therapeutic relationships, and (4) broad competences around scope of practice. The competences are separated by three levels; generic competences (for all people working therapeutically), specialist competences (for all people working therapeutically with people with dementia) and leading, (for people who are supervising or managing people working therapeutically, or who lead, deliver or commission services).

Discussion: The development of these competences offer a clear framework for improving delivery of psychotherapy to families affected by dementia. We will test implementation of core competences within practice and embed in curricula.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-07 - TaIlored ManagEment of Sleep (TIMES) for people with dementia or mild cognitive impairment – A Cluster Randomised Feasibility Trial

Jayden van Horik[1], Louise Allan[1], Aidin Aryankhesal[2], Niall Broomfield[2], Andrea Hilton[2], Anne Killett[2], Mizanur Khondoker[2], Fiona Warren[2], Gill Livingston[2], Yoon Loke[2], Ian Maidment[2], Antonieta Medina-Lara[2], Lee Shepstone[2], Joanne Reeve[2], Geoff Wong[2], Chris Fox[2]
[1]University of Exeter, [2]

People Living With Dementia (PLWD) or Mild Cognitive Impairment (MCI), often experience sleep disturbances, which can impact their daily living, increase carer burden, and potentially accelerate the decline of their independence. The cause of these sleep issues is often multifactorial. Consequently, effective management of sleep in PLWD/MCI within primary care settings remains challenging. Sleep disturbances are often not recognised by PLWD/MCI or families, leading to delayed, or a lack of, management. If recognised, long-term pharmacological approaches, such as hypnotics, are inappropriate and associated with significant adverse events in this population, and access to effective non-pharmacological interventions are limited or untested.

To address these limitations, we co-designed a tailored intervention for managing sleep (TIMES) with Patient and Public Involvement (PPI) groups and health and social care professionals. TIMES supports GPs and other primary

care staff to provide person-centred care for PLWD/MCI and their carers, by addressing the multifactorial aspects of sleep disturbance.

We delivered the TIMES intervention as a cluster-randomised feasibility trial, in 10 general practices in England, recruiting 23 patient-carer dyads. We will present key findings on: (i) barriers and enablers to successful recruitment and retention of patient-carer dyads; (ii) intervention fidelity and acceptability; (iii) preliminary outcomes of the TIMES intervention on patient sleep, quality of life, costs and resource utilisation, including medication, and primary care staff confidence in managing sleep disturbances in PLWD/MCI.

We will discuss the implications of our findings for improving sleep management for PLWD/MCI within primary care settings. Our findings will help PLWD/MCI, their carers, and clinicians, identify issues associated with sleep disturbance, and support tailored strategies that optimise sleep, potentially resulting in improved wellbeing, prolonged independence and preventative care. This study will also inform the design of a subsequent full-scale randomised controlled trial of the TIMES intervention.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-08 - Post-Diagnostic Dementia Support within the ReCOVERY College Model: A Realist Evaluation- DiSCOVERY Programme

Chris Fox[1], Juni West[2], Bonnie Teague[3], Corinna Hackmann[3], Geoff Wong[4], Linda Birt[4], Fiona Poland[5], Emma Wolverson[6], Mel Handley[7], Esme Moniz-Cook[8]
[1]University of exeter, [2]NSFT/NHS, [3]NSFT-NHS, [4]University of Oxford, [5]University of East Anglia, [6]Dementia UK and University of West London, [7]University of Hertfordshire, [8]University of Hull

Background: Worldwide, 55 million people live with dementia, predicted to reach 78 million by 2030. Dementia is the most feared health condition for older adults and incurs considerable personal and financial impact on individuals, families and society, with an annual global cost of US$1313.4 billion. Post-diagnostic support for individuals living with dementia is important but currently exhibits significant heterogeneity. Often, the emphasis of such support lies in strategies aimed at preserving existing cognitive abilities or disseminating information about the condition and its management, neglecting personal 'recovery' (psychological adaptation and living well). Recovery Colleges, co-produced with individuals with dementia, are a promising alternative, offering person-centered support. However,

effectiveness, and the role of mechanisms and contextual factors remain unclear. This study examined what works, how, for whom, and in what circumstances within Recovery College courses for people with dementia, addressing critical knowledge gaps in this emerging area of support.

Method: A realist evaluation across four English mental health services incorporated interviews, ethnographic observations, and documentary analysis from five courses.

Results: Observation data from five courses (case studies) and interviews with 13 tutors (including 3 people with dementia) and 32 course attendees (8 people with dementia) were analysed. Four overarching causal explanations (i.e. Context-Mechanism-Outcome Configurations - with 26 granular CMOCs) related to staging a course/implementation were found. These were: 1) the necessity of shared co-production values among staff and peer tutors; 2) the importance of a trusted person endorsing a course to encourage attendance; 3) course delivery emphasizing problem-solving, stigma reduction, and hopeful futures; and 4) challenges in evaluating impact.

Conclusion: The DiSCOVERY study employed mixed-methods to create a framework for establishing and sustaining co-produced, peer-led Recovery College dementia courses focused on promoting positive living and hope. This framework, derived from five national case studies, offers valuable insights for dementia-specific Recovery Colleges globally.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-09 - How does video feedback intervention work for people with dementia and challenging behaviour, for whom and under which circumstances? A realist interview study

Stephanie Timmermans[1], Annette Plouvier[1], Anne Kolmans[1], Mandy Wijnen[1], Anke Persoon[1], Annemiek Bielderman[1], Cécile Boot[2], Debby Gerritsen[1]
[1]Radboudumc, [2]Amsterdamumc

Background: Challenging behavior of people living with dementia is associated with negative effects for the person themself, family, and nursing staff. Video feedback intervention seems a promising tool to use in nursing homes in cases of challenging behavior. In the Netherlands, a video feedback intervention "VIO" – in which the care team reflectively watches video footage, is asked stimulating questions by the VIO-counsellor, and practices with assignments – is used. This study aims to explain how VIO works, for whom, and under which circumstances.

Methods: A purposive sample of eight VIO-counsellors and three care team members was interviewed in this realist interview study, conducted in the Netherlands in 2022. Consequently, the client panel of the University Knowledge network of Older adult care Nijmegen (UKON) was consulted on the results.

Results: We found that VIO can improve (non)verbal communication with the person with dementia because team members become aware of their contribution to the interaction with the person with dementia. The impact of VIO is determined by safety and trust within the care team, a team member with an

exemplary role, trust between the VIO-counsellor and care team, organizational restraints such as lack of (permanent) staff, sick leave, and lack of managerial support. The role of family appeared limited.

Conclusions: The design of VIO aligns with the way in which the care team learns. The intended outcomes of improved (non)verbal communication and decreased challenging behavior can be achieved when organizational and team conditions, and the VIO-counsellor's approach are satisfactory. Future research should focus on testing and refining the discovered lines of reasoning in practice. For daily practice, it is recommended to explore how to increase the role of family, and how to overcome negative expectations.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-11 - Peer Support as a Necessity: Addressing the Needs of Working-Age Family Carers of a Parent with Dementia

Ulla Kaikkonen
Memory Association of Oulu Region

Working-age family members caring for a parent with dementia face complex and demanding challenges. Often, they are juggling employment, raising children, and caregiving responsibilities simultaneously. This "sandwich generation" is particularly vulnerable to emotional exhaustion, social isolation, and feelings of inadequacy and guilt. Despite these pressures, peer support remains an underutilised resource, even though it can significantly enhance carers' well-being and coping capacity.

This presentation highlights the importance of peer support for working-age carers and their specific needs. Peer support offers a safe space to share emotions and exchange practical coping strategies. However, many carers do not receive adequate support due to time constraints, insufficiently targeted services, and limited access to relevant information, especially during the early stages following a parent's diagnosis, when support is most urgently needed.

Low-threshold peer support—delivered in person or online—can make a substantial difference. Early access to peer support can help carers adjust to their new life circumstances and reduce their burden, leading to better long-term outcomes. Personal accounts consistently highlight the value of peer support: carers feel less alone, more competent, and better prepared to

manage both the emotional and practical challenges of dementia care. They also report feeling seen and heard.

Expanding accessible, flexible peer support options is essential to ensure that the needs of working-age carers are recognised and addressed. Achieving this requires strong collaboration between health and social care services and organisations supporting family carers.

Peer support is not a luxury—it is a necessity for working-age carers. Investing in peer support means investing in the well-being of families, the resilience of caregivers, and the sustainability of dementia care systems.



35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Care approaches - Psychosocial interventions

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-12 - What works, for whom and in what contexts: the impact of dementia support workers in preventable high-cost care: the Dementia PersonAlised Care Team (D-PACT) study

Tomasina M Oh[1], Hannah Wheat[1], Sonia Dalkin[2], Angela Bate[2], Richard Byng[1]
[1]University of Plymouth, [2]Northumbria University

Context: Dementia is a growing public health challenge in the UK and worldwide. Around 77% of people with dementia have at least one other long-term condition, underscoring the need for personalised support. The Dementia PersonAlised Care Team (D-PACT) study was a longitudinal mixed-methods realist evaluation of dementia support workers (DSWs) embedded in primary care. Here we present findings from a realist-informed economic analysis examining how, in what circumstances and for whom DSWs helped reduce preventable and unwanted high-cost care, such as unplanned hospital or care home admissions.

Methods: A total of 126 participants with dementia and 121 carers were included in the study. Multiple types of high-volume qualitative data were collected, alongside resource use and timesheet data documenting all DSW activities. An exploratory realist-informed economic analysis helped refine an initial programme theory that personalised, continuous, and proactive DSW-led care (low-level planned care) may reduce expensive, unplanned high-level care.

Results: DSWs provided tailored support by fostering trust and understanding individual needs. Initially, this increased resource use, but enabled earlier intervention and disclosure of concerns, potentially reducing inappropriate

service use. Crucial factors included DSW access to medical records and the ability to alert GPs to escalating situations. Contexts where outcomes were not realised included systemic barriers such as overstretched services or poor communication with supported participants. Flexible support, with variable intensity rather than fixed-frequency meetings, led to differing resource use, with a mean contact frequency of 11.5 times per participant over 12 months.

Implications: This study enhances the understanding of realist-informed economic evaluation in dementia care, offering a nuanced perspective on resource implications in complex interventions. By focusing on context-specific factors affecting resource use, it provides valuable insights for future intervention design and dementia care resource allocation.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

Abstracts for keynote speakers and plenary sessions (INVITATION ONLY)

08/10/2025 - 10:30-11:45 - QOP5. Psychosocial interventions

QOP5-10 - Developing the In-Touch Logic Model: Charting the Implementation of a Person-Centred Palliative Care Intervention in Care Homes for Residents with Advanced Dementia

Elaine Lehane[1], Noeleen Brady[2], Suzanne Timmons[2], Irene Hartigan[2], Catherine Walshe[2], Kevin Brazil[2], Nancy Preston[2], Jenny van der Steen[2], Silvia Gonella[2], Paola Di Giulio[2], Sandra Martins Pereira[2], Sharon Kaasalainen[2], Cathy Payne[2], Katarzyna Szczerbińska[2], Martin Loucka[2], Nicola Cornally[2]
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The In-Touch programme aims to advance psychosocial, person-centred palliative care for people with advanced dementia living in care homes. Addressing recognised gaps in care, the programme combines two evidence-based components: Namaste Care, supporting quality of life in the present, and the Family Carer Decision Support tool, facilitating future care planning.

We describe the development and refinement of the In-Touch Logic Model, designed to articulate the programme's core components, mechanisms of action, intervention assumptions, implementation strategies, and anticipated outcomes. Guided by the Wisconsin Logic Model framework, development drew on three key data sources. First, a review of theoretical and empirical literature shaped the overall structure of the Logic Model, informing assumptions, mechanisms of change, implementation strategies, and external factors. Second, an online

questionnaire completed by 13 members of the international research team, representing 10 countries, provided detailed insights into the programme's inputs, activities, outputs, and anticipated outcomes. Finally, an online focus group involving five care partner representatives across participating countries offered real-life perspectives to ensure the model remains grounded in everyday care experiences.

Two rounds of feedback from researchers and care partners led to the refinement of the In-Touch Logic Model. The resulting model captures the programme's underlying theory, 6 core intervention components, 8 intervention assumptions, and 5 implementation strategies. It will underpin future adaptation and testing across diverse care home settings in a multi-country research programme.

This structured, collaborative approach demonstrates how early co-design efforts can strengthen intervention interpretation, implementation and evaluation, ensuring they are responsive to the needs of people living with advanced dementia and those supporting them.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-02 - 'Pampering weekend' for children of a parent with young-onset dementia

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Alzheimer Liga Vlaanderen

Background and aims: Since 2021, Alzheimer's Association Flanders has organized a Summer Camp for children of a parent with young-onset dementia in Houthulst, West Flanders. In 2024 the weekend gets a new name, chosen by the target group: 'pampering weekend'. Th target group: school-going children of a parent with young-onset dementia aged between 8 and 25 years. Their parent who does not have dementia can also join us. The goal of the pampering weekend is to provide a haven for young people struggling with questions about how to cope with the changes their parents are undergoing due to young-onset dementia.

Methods: Workshops, activities, and in-depth conversations help them not only understand themselves better but also find their place within a community of peers. The young participants and their parents will connect with peers, receive information about young-onset dementia, and gain numerous tips and insights to help them manage their daily lives.

Results: Participant quotes: "Here, we can just 'be' without having to explain anything. We understand each other without many words because we all go through the same experiences. Dementia affects us too, but it's not always easy

to talk about it with others. Here, we can," many young people agreed in unison. During the summer camp, heart-warming moments were shared, unique stories exchanged, and valuable friendships forged.

Discussion: Despite the heart-warming stories and the enthusiasm of the participants, as well as the growing recognition of the weekend, it remains challenging to reach families with a parent with young-onset dementia or to convince them to overcome the barrier to participate.

An exponential growth in the number of participants and activities is a promising vision for the future, along with expanding our services to include the 'older' group of children with a parent with young-onset dementia.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-10 - Supportive Care Needs of People with Comorbid Cancer and Dementia and their Caregivers: A Qualitative Meta-Synthesis

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The identification of supportive care needs (SCNs) for people with comorbid cancer and dementia and their caregivers, and the barriers/facilitators to those needs being met has been identified as an important area for future research. The objective of this paper was to systematically review the research on the SCNs of people with comorbid cancer and dementia (PWCD) and their caregivers and identify the barriers and facilitators to care needs being met.

Method: Systematic searches were performed using relevant databases; CINAHL, Medline, PsychINFO, Embase and Web of Science, and included a mixture of controlled vocabulary and free text terms. This study employed thematic synthesis to analyse extracted data.

Results: A total of 3,095 articles were identified from databases, following screening, a total of 11 articles being included and synthesised. SCNs for PWCD included the adoption of dementia-friendly care, continuity of care, and tailored communication strategies. SCNs for caregivers included effective coping strategies, and access to cancer-dementia specific information. Barriers to these needs being met included a lack of dementia education for healthcare staff, stigma surrounding dementia, and a lack of cancer-dementia specific help resources for caregivers. Facilitators to these needs being met included

healthcare professionals getting to know the PWCD, multidisciplinary teams, and a person-centred approach for PWCD.

Conclusion: These findings highlight a need for more research regarding this comorbidity and the SCNs of PWCD and their caregivers, particularly in countries outside the U.K and a need for more cancer-dementia specific services and information.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-11 - Family Interventions iN Dementia Mental health Environments (FIND ME): Caregiver experiences of dementia in-patient units post-discharge

Juliet Gillam[1], Prof Emma Wolverson[2], Dr Rosie Dunn[3], Prof Katie Featherstone[2], The Dementia Inpatient Experience Group[4]
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Background: Caregivers play a vital role in supporting people living with dementia, particularly around admission to dementia in-patient units (DIU); also known as mental health or psychiatric wards. Their involvement can improve social and clinical outcomes such as care quality, reduced length of stay, and lower relapse and readmission rates. Despite this, caregivers both nationally and internationally report feeling excluded from care decisions and unsupported by DIUs.

Aim: To explore experiences of caregivers involved in care of people living with dementia who have been discharged from DIUs, and to identify opportunities to improve caregiver support and involvement.

Methods: In-depth interviews were conducted with 24 caregivers of people living with dementia who had been discharged from a DIU within the previous three years. Participants were recruited from three

geographically diverse areas in the United Kingdom, selected to reflect varied aging populations with significant health and social care needs. Data were analysed thematically to identify key experiences.

Results: Caregiver experience of DIUs varied. Whilst there was evidence of staff involving caregivers in shared decision-making and the delivery of person-centred care, many reported minimal communication from staff and a perception of being excluded. In some cases, a lack of caregiver support exacerbated feelings of distress, both whilst the person with dementia was on the ward and following discharge. Caregivers valued accessible education about the ward and the admission/discharge process, ongoing emotional and informational support and improved communication to facilitate a smooth transition.

Conclusions: Admission to a DIU can be an acutely distressing time for both a person with dementia and their caregiver, yet caregivers often feel excluded and unsupported at a time of crisis. To improve outcomes, strategies for shared decision-making, and ongoing caregiver support should be co-produced with caregivers with lived experience, and implemented as routine practice in DIUs.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-12 - Adult children providing care for parents living with dementia: An examination of who "self-sacrifices" for the sake of family caregiving, and why

Heather Campbell-Enns
Canadian Mennonite University

Objective: Adult children are often primary caregivers for parents living with dementia. Dementia care is a unique family caregiving context due to the variation of symptoms and the hallmarks of the later stages of dementia that impact the parent-child relationship (i.e., changes in memory, communication, behaviour, mood). Adult child caregivers report the rewards of caregiving, and the stresses associated with the self-sacrifice required. Self-sacrifice is a darker aspect of caregiving seldom discussed, particularly in terms of which family members self-sacrifice, and why. The objective of this paper is to answer the question, "Who self-sacrifices for dementia care, and why?"

Method: Definitions of self-sacrifice are examined and a conceptual integration of three structural theories occurs to explain adult child self-sacrifice in the context of dementia care. Specific theories/perspectives provide concepts for analysis, including family systems theory (e.g., family interdependence), care-focused feminist theory(ies) (e.g., power), and the life course perspective (e.g., cumulative disadvantages).

Results: A theoretical framework results to describe who is likely to self-sacrifice to provide care for a parent with dementia results. An explanation of why these individuals enter unpaid family care is included along with discussion on inequities observed and implications for psychosocial and policy improvements.

Conclusions: While adult children have varied motivations to provide unpaid carer for a parent with dementia, this paper highlights inequities that lead some adult children to self-sacrifice for caregiving. Introducing an integrated theoretical framework to describe self-sacrifice by adult children in the care for older parents has positive implications for practice and policy. The framework can be applied to practice to enhance psychosocial support to family carers and it can be used to enhance policy development to support family carers who may be inequitably self-sacrificing for family care.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-04 - Navigating Dementia Services: A Global Review of Informal Caregiver Perspectives

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York St. John University

Background: Dementia impacts millions worldwide, with increasing prevalence due to aging populations. Informal caregivers – often unpaid family or friends - provide essential support but face significant challenges due to fragmented services and inadequate resources. This global review offers a cross-cultural perspective of caregiver experiences to inform improvements in dementia services.

Methods: Findings from 30 studies exploring the experiences of informal caregivers were examined using Thomas and Harden's thematic synthesis approach to identify key patterns and insights. Studies were selected through a comprehensive search of MEDLINE, PsycINFO, and CINAHL databases. The search was not restricted by country/region however only included studies published in English. Included studies were critically appraised for quality, validity, and relevance. This review was pre-registered on the International Prospective Register of Systematic Reviews (PROSPERO).

Results: Four major themes were conceptualised:

1. **The Impact of Navigating Complex and Confusing Service Delivery:** Caregivers struggled with navigating poorly coordinated services, highlighting the need for improved communication and a relational approach to care.
2. **Services Causing Harm:** Inadequate services led to emotional distress, emphasizing the need for more effective and compassionate support.
3. **Thinking About and Planning for an Unclear Future:** Many caregivers faced anxiety and uncertainty due to insufficient professional guidance on future care planning.
4. **The Centrality and Importance of Valuing Difference, Diversity, and Culture:** Cultural and linguistic differences created significant obstacles in accessing services, underscoring the need for culturally sensitive care.

Discussion: This review highlights critical gaps in dementia services in communication, coordination, and future planning. Notably, some services not only fail to support but actively cause harm, further increasing caregiver distress. Despite policies promoting caregiver support, implementation remains inconsistent. Dementia services must prioritize caregiver needs through person-centred, culturally sensitive, and coordinated care. Urgent policy and practice changes are needed to address these gaps and better support the vital role of informal caregivers.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-05 - Ethical Challenges and Dilemmas in Home-Based Dementia Care in Türkiye: Perspectives of Family Caregivers

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Aim: This study explores the ethical challenges and dilemmas faced by family caregivers providing home-based dementia care in Türkiye, focusing on their experiences with formal and informal care services. The study uses an interpretive approach to understand caregivers' lived experiences and decision-making processes.

Methods: Data were collected through face-to-face, in-depth interviews with 12 family caregivers (6 daughters, 4 sons, 1 husband, and 1 sister) using a semi-structured interview guide (Kallio et al., 2016). The interviews explored domains related to dementia care experiences and ethics. Data were analyzed using Interpretative Phenomenological Analysis (IPA) according to Smith et al. (2022).

Findings: Four major themes emerged after analyzing the data:

(1) Relatives' Thoughts on Formal Care: Caregivers expressed dissatisfaction with the quality, accessibility, and personalization of formal services but maintained expectations for more comprehensive, empathetic, and specialized dementia care.

(2) Reflections on Informal Care: Caregiving experiences were influenced by personal traits like resilience, empathy, cultural norms, and family dynamics. Emotional bonds, moral duty, religious belief, and societal expectations were key motivators.

(3) Care Needs and Challenges: Caregivers faced systemic issues such as bureaucratic obstacles, lack of integrated services, and insufficient professional support, alongside personal challenges like exhaustion, burnout, financial strain, and social isolation.

(4) Ethical Issues and Dilemmas: Ethical concerns included breaches of patient dignity, autonomy, and consent in formal care, as well as neglect, caregiver burden, and lack of accountability in informal care. Caregivers frequently faced dilemmas balancing their well-being with the needs of the person with dementia.

Conclusion: The study highlights the urgent need for systemic reforms, improved caregiver support, and culturally sensitive ethical guidelines in dementia care in Türkiye.

Keywords: Dementia, Ethical Challenges, Ethical Dilemmas, Family Caregivers

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

---

QOP6-08 - The experiences of dementia in farming communities

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Background: Despite the growing interest in improving support and reducing inequalities for people living with dementia in rural areas, research evidence relating to the experiences of people living with dementia in farming communities is scarce. Farming communities experience significant rates of dementia, and therefore understanding the support needs of this population is vital. In response, we conducted a scoping review of the published literature exploring the experiences of dementia in farming communities.

Method: The review followed Arksey and O'Malley's (2005) six step framework and adhered to the PRISMA extension for scoping reviews (PRISMA-ScR). Five databases were searched (ProQuest, CINAHL, PsycINFO, Web of Science, and MEDLINE) for peer-reviewed articles, and a general google search was conducted for grey literature.

Results: Eighteen articles were included in the review. Thematic analysis generated thirteen sub-themes that are presented within two overarching themes: 'challenges' and 'fostering resilience'. Stakeholder engagement with representatives from eight organisations that support farmers was organised to discuss themes and gain additional insights. Findings indicate a unique set of challenges faced by farming communities in relation to dementia, that are in addition to those faced by people living rurally in general. Importantly, this

work also highlights opportunities for fostering resilience in people living with dementia and their families in farming communities.

Conclusions: This work reveals a combination of factors that influence access to dementia care and support in farming contexts. Addressing these challenges requires targeted interventions and a commitment to tailoring support to the unique strengths, assets, and needs of farming populations. Our findings are being used as evidence to guide the development of future research plans for supporting the unique needs of farming populations.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

---

QOP6-03 - Crossing the Line: Providing personal care in the context of families affected by dementia

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The Association for Dementia Studies at the University of Worcester was granted 18-month funding by the UK National Institute for Health and Care Research to conduct the research study, Crossing the Line. The study commenced in December 2022, with the aim to gain a deep understanding of the experiences of family carers relating to their provision of care to people living with dementia and hear their often-hidden voice.

The challenges around personal care are often a tipping point for the person living with dementia to move into a care home. Personal care includes helping with going to the toilet, washing, bathing, dressing, mouth-care, shaving, haircare, foot and nail-care. Through initial research, it was shown that little was known about it in the context of dementia and family care.

The findings from the study enabled the development of accessible, co-produced personal care resources and education around personal care for family carers. The project has a strong patient and public involvement aspect running throughout and a range of stakeholder perspectives, including from family carers, who informed the development of the research.

A UK-wide survey exploring the insights of 300 family carers about their experiences of delivering personal care for someone with dementia, their coping mechanisms, and the impact it may have on their wellbeing was conducted. This informed the topic guide for interviews conducted with 30 family carers. In addition to statistical analysis of survey findings, thematic and Interpretive Phenomenological Analysis was used to make sense of qualitative data.

There will be discussion around future funding priorities including measuring the impact i.e. who is accessing the resources, how they are accessing them and what difference it is making to the way care and support is provided.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

---

QOP6-06 - Finding hope and connection amidst grief and transition: A successful co-produced & co-facilitated support group for spousal dementia carers in Ireland

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There are currently over 64,000 people living with dementia (PLwD) in Ireland (HSE, 2025), set to rise to over 150,000 by the year 2045. The transition to long-term care is identified as the most emotionally turbulent time for spousal dementia carers, marked by existential conflict and ambiguous loss (Brooks, et al, 2022; Duggleby, et al., 2011; Holton, et al., 2023).

Currently, there is little research into spousal dementia carer support groups for this difficult transition period, and no identified research studies that highlight the positive effects of co-production and co-facilitation in such groups. The Carers' Transition Group (CTG), a psychosocial and psychoeducational support group, supports spousal dementia carers to process their grief, whilst educating them about the final stages of dementia and what to expect as their caring role evolves. The group promotes self-care and helps members find purpose after caregiving. The group is comprised of spousal carers of PLwD who are currently patients of a mental health service for older adults, either residing in or transitioning to LTC. To accurately reflect the needs of all group members, an assessment both pre- and post- group is completed utilising the Carer Support Needs Assessment Tool (CSNAT).

The CTG is also co-produced together with both current and past members, utilising tools such as the CSNAT and the group evaluation form, as well as informal interviews to inform group content and function. The co-facilitator, a former group member, through their lived experience, further enhances resource identification and helps group members connect through this emotional journey. Our findings underscore the need for psychosocial and psychoeducational interventions for this population that provide flexible and hybrid support options throughout the caring journey. Our research indicates an overall positive user experience, with carers expressing that sharing emotions and experiences, and feeling understood are the most beneficial elements.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-01 - The emotional impact of crisis situations on formal and informal caregivers of people with dementia: a qualitative study.

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Introduction: People with dementia are at increased risk of care crises: situations that suddenly seem unmanageable at home, which can arise from a range of health-related problems and personal circumstances. However, little is known about the emotional impact these crisis situations on (in)formal caregivers.

Aim: To identify the emotions experienced by caregivers during crises involving people with dementia and the factors influencing these emotions.

Method: This qualitative study, conducted in an urban area of the Netherlands, reports on semi-structured interviews with key stakeholders in a crisis concerning persons with dementia: formal and informal caregivers. Participants included 17 formal caregivers (including general practitioners, specialists in elderly care, district nurses, and case managers) and 5 informal caregivers. The data were analyzed using inductive thematic analysis.

Results: Caregivers experience a wide range of emotions during crises, ranging from satisfaction to frustration and regret. Factors that influence these emotions can be summarized into three interrelated themes: 1) Holding on, handing over, 2) Collaboration and coordination and 3) Care burden and

efficiency. During crisis situations, caregivers face the tension between holding on and relinquishing responsibility, while also confronting the deeper challenge of letting go: accepting cognitive decline and loss. This process is further complicated when roles and responsibilities among professionals are unclear, as several participants reported that lack of collaboration led to disrupted continuity of care. Additionally, caregivers experienced a high care burden due to inefficiencies in the care process, which added to their emotional exhaustion.

Conclusion: Crisis situations of people with dementia lead to significant emotional impact among caregivers, primarily due to the tension between holding on and letting go, lack of collaboration, and high care burden. Future research should focus on reducing caregiver burden by strengthening support for both formal and informal caregivers, enhancing collaboration among caregivers, and ensuring continuity in crisis care.

35th Alzheimer Europe Conference

06/10/2025 to 08/10/2025

People - Family carers of people with dementia

08/10/2025 - 14:00-15:15 - QOP6. Carers of people with dementia

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QOP6-07 - Experiences of informal carers supporting people living with dementia from a distance: A systematic scoping review

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Distance caring is an understudied field, and the role of distance carers supporting people living with dementia has not been the focus of an evidence review. This paper aims to report their experiences, define 'distance caring' in this context, and summarise the factors that characterise negative and positive experiences.

The protocol for this evidence review was developed collaboratively with an advisory board comprising individuals living alone with dementia, distance carers, specialist dementia nurses, and researchers. A systematic scoping review was identified as the most appropriate method for reviewing the evidence base of this field. Four electronic databases were searched using terms and criteria guided by combining concepts of relevant literature for informal caregiving for people living with dementia, and distance caregiving for other health populations.

Searches yielded 603 unique records of which 12 met the inclusion/exclusion criteria for exploring the experiences of informal carers supporting people living with dementia from a distance. The majority of included studies were qualitative

in design. Five emergent themes relevant to the research question were identified:

(1) emotional and physical health;

(2) practical challenges;

(3) communication and information access;

(4) cultural context;

(5) technology;

Distance carers of people living with dementia experience stress, guilt, anxiety and a profound sense of loss. The separation from the care recipient can increase feelings of helplessness as carers struggle to coordinate care, whilst managing their own personal and professional lives. Cultural factors can influence distant caregiving practices, determining how families approach and balance the responsibility of providing care.

Technological support such as remote monitoring are available, but their effectiveness is yet to be evaluated. The evidence base for distance care of people living with dementia is small, warranting further research that reports the views of more people and more diverse populations both providing and receiving care.