Royal United Hospitals Bath
NHS Foundation Trust

# Dementia
# Current Awareness Bulletin

March 2021

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**Title: Could robotic animals become part of NHS dementia care provision?**

**Citation:** Journal of Dementia Care - 19 February 2021

A new generation of robotic animals could soon be offering support in dementia care as US company Ageless Innovation launches its products in the UK next month. According to the i-news website, the company has ambitions to work with the NHS and sees its robotic pets as safer and more predictable alternatives to living animals. In the vanguard of the new product range is a battery powered cocker spaniel, which is due to go on sale for £129 on 15 March. A 2019 study by Exeter University found that robotic animals could reduce loneliness and agitation in care home residents, while another study reported a reduction in the frequency at which medication was prescribed for anxiety. The spaniel robot can respond to human voices, make dog-like sounds in response to touching and hugging, and has a simulated heartbeat. Ageless Innovation told i-news that the robots were available in parts of the US on health insurance. "If you live in Minnesota and fit into either the categories of experiencing chronic depression, which is loneliness or isolation, or Alzheimer's and dementia, it's a fully covered supplemental benefit, and our goal would be to follow that in the UK," said chief executive Ted Fischer. A study to be published in the March/April issue of JDC finds that for most residents robotic animals are "a source of comfort, an opportunity for social engagement and a trigger for shared memories."

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**Title: Managing volunteers who support patients with dementia or cognitive impairment on acute hospital wards: the NURTURe model.**

**Citation:** Nursing management (Harrow, London, England : 1994); Feb 2021

**Author(s):** Charalambous, Liz

**Abstract:** Volunteers are widely used to support patients with dementia or cognitive impairment on acute hospital wards. However, it appears that traditional volunteer management models do not fully address the challenges posed by managing volunteers in that setting. In a study of the use of volunteers in the care of people with dementia and cognitive impairment on acute hospital wards, interviews with a range of stakeholders revealed challenges regarding the environment, role and image of volunteers. Based on the study findings, an alternative model for managing volunteers on acute hospital wards was developed. This article describes the study and discusses the development of this alternative approach, the NURTURe model**.**

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**Title: Placing assistive technology and telecare in everyday practices of people with dementia and their caregivers: findings from an embedded ethnography of a national dementia trial.**

**Citation:** BMC geriatrics; Feb 2021; vol. 21 (no. 1); p. 121

**Author(s):** Lariviere, Matthew; Poland, Fiona; Woolham, John; Newman, Stanton; Fox, Chris

**Objective:** Policy makers and care providers see assistive technology and telecare as potential products to support people with dementia to live independently in their homes and

communities. Previous research rarely examined how people with dementia and their caregivers actually use such technology. The study examined how and why people living with dementia and their caregivers used assistive technology and telecare in their own homes.

**Methods:** This study used an ethnographic design embedded within the NIHR-funded Assistive Technology and Telecare to maintain Independent Living At home for people with dementia (ATTILA) randomised controlled trial. We collected 208 h of observational data on situated practices of ten people with dementia and their ten caregivers. We used this data to construct extended cases to explain how technologies supported people with dementia in home and community settings.

**Results**: We identified three themes: placing technology in care, which illustrates how people with dementia and caregivers 'fit' technology into their homes and routines; replacing care with technology, which shows how caregivers replaced normal care practices with ones mediated through technologies; and technology displacing care and everyday life, which highlights how technologies disrupted the everyday lives of people with dementia.

**Discussion**: This study exemplifies unintended and unanticipated consequences for assistive technology and telecare uptake in 'real world' community-based dementia care. It underlines the need to identify and map the context of technological provision over time within the changing lives of people with dementia and their caregivers.

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## Title: The language of behaviour changes in dementia: A mixed methods survey exploring the perspectives of people with dementia.

**Citation:** Journal of advanced nursing; Feb 2021

**Author(s):** Wolverson, Emma; Dunn, Rosie; Moniz-Cook, Esme; Gove, Dianne; Diaz-Ponce, Ana

**Objectives:** The aim of this study was to explore the opinions of people with dementia, about the language used to describe changes in behaviour associated with dementia.

**Design**: This study adopted a human rights approach in a mixed methods convergent parallel synthesis design.

**Methods:** Online and paper-based questionnaire data were collected between November 2019 and March 2020. A combination of convenience and purposive sampling was used to invite people with dementia to participate.

**Results:** In total, 54 people completed the survey. There was no clear consensus on a preferred term, but 28.3% preferred the term 'unmet needs' for describing changes in behaviour associated with dementia. Qualitative data revealed important nuances and challenges for researchers and practitioners in relation to terminology for this paradigm. Participants felt that the language we use to talk about changes in behaviour could influence how people with dementia are viewed and treated and how people feel about themselves.

**Conclusion:** The majority of participants were familiar with a range of terminology. There was no universal agreement on terminology, but there was an overall preference for terms that reflect the unmet needs likely to underlie perceived changes in behaviour.

**Impact:** People with dementia raised concerns about the language used to describe changes in behaviour that can occur in dementia. There is scope for improvements in the language used for this paradigm in both research and practice. Following a diagnosis of dementia, clinicians need to take the time to explore an individual's preferences and understandings. They can then share their own understanding about the potential for changed behaviour and if relevant, how any negative impact of this may be minimized.

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**Title: Tele-Rehabilitation for People with Dementia during the COVID-19 Pandemic: A Case-Study from England.**

**Citation:** International journal of environmental research and public health; Feb 2021; vol. 18 (no. 4)

**Author(s):** Di Lorito, Claudio; Duff, Carol; Rogers, Carol; Tuxworth, Jane; Bell, Jocelyn; Fothergill, Rachael; Wilkinson, Lindsey; Bosco, Alessandro; Howe, Louise; O'Brien, Rebecca; Godfrey, Maureen; Dunlop, Marianne; van der Wardt, Veronika; Booth, Vicky; Logan, Pip; Cowley, Alison; Harwood, Rowan H

**Introduction:** The Promoting Activity, Independence and Stability in Early Dementia (PrAISED) is delivering an exercise programme for people with dementia. The Lincolnshire partnership National Health Service (NHS) foundation Trust successfully delivered PrAISED through a video-calling platform during the Coronavirus Disease 2019 (COVID-19) pandemic.

**Methods:** This qualitative case-study aimed to identify participants that video delivery worked for, to highlight its benefits and its challenges. Interviews were conducted between May and August 2020 with five participants with dementia and their caregivers (n = 10), as well as five therapists from the Lincolnshire partnership NHS foundation Trust. The interviews were analysed through thematic analysis.

**Results**: Video delivery worked best when participants had a supporting caregiver and when therapists showed enthusiasm and had an established rapport with the client. Benefits included time efficiency of sessions, enhancing participants' motivation, caregivers' dementia awareness, and therapists' creativity. Limitations included users' poor IT skills and resources.

**Discussion:** The COVID-19 pandemic required innovative ways of delivering rehabilitation. This study supports that people with dementia can use tele-rehabilitation, but success is reliant on having a caregiver and an enthusiastic and known therapist.

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**Title: Frailty and neuropathology in relation to dementia status: the Cambridge City over-75s Cohort study.**

**Citation:** International psychogeriatrics; Feb 2021 ; p. 1-9

**Author(s):** Wallace, Lindsay; Hunter, Sally; Theou, Olga; Fleming, Jane; Rockwood, Kenneth; Brayne, Carol

**Objective:** To examine the relative contributions of frailty and neuropathology to dementia expression in a population-based cohort study.

**Design:** Cross-sectional analysis of observational data.

**Setting**: Population-representative clinicopathological cohort study.

**Participants**: Adults aged 75+ recruited from general practice registries in Cambridge, UK, in 1985.

**Measurements**: A 39-item frailty index and 15-item neuropathological index were used to operationalize frailty and neuropathology, respectively. Dementia status was ascertained by clinical consensus at time of death. Relationships were evaluated using logistic regression models in participants with autopsy records (n = 183). Model fit was assessed using change in deviance. Population attributable fraction for frailty was evaluated in relation to dementia incidence in a representative sample of the survey participants (n = 542).

**Results:** Participants with autopsy were 92.3 ± 4.6 years at time of death, and mostly women (70%). Average frailty index value at last survey before death was 0.34 ± 0.16. People with dementia (63% of the sample) were frailer, had lower MMSE scores, and a higher burden of neuropathology. Frailty and neuropathological burden were significantly and independently associated with dementia status, without interaction; frailty explained an additional 3% of the variance in the model. Assuming a causal relationship and based on population-attributable fraction analyses, preventing severe frailty (Frailty Index ≥ 0.40) could have avoided 14.2% of dementia cases in this population-based cohort.

**Conclusions:** In the very old, frailty contributes to the risk for dementia beyond its relationship with the burden of traditional dementia neuropathologies. Reducing frailty could have important implications for controlling the burden of dementia. Future research on frailty interventions should include dementia risk as a key outcome, public health interventions and policy decisions should consider frailty as a key risk factor for dementia, and biomedical research should focus on elucidating shared mechanisms of frailty and dementia development.

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## Title: COVID-19 and dementia: Analyses of risk, disparity, and outcomes from electronic health records in the US.

**Citation:** Alzheimer's & dementia : the journal of the Alzheimer's Association; Feb 2021

**Author(s):** Wang, QuanQiu; Davis, Pamela B; Gurney, Mark E; Xu, Rong

**Introduction:** At present, there is limited data on the risks, disparity, and outcomes for COVID-19 in patients with dementia in the United States.

**Methods:** This is a retrospective case-control analysis of patient electronic health records (EHRs) of 61.9 million adult and senior patients (age ≥ 18 years) in the United States up to August 21, 2020.

**Results:** Patients with dementia were at increased risk for COVID-19 compared to patients without dementia (adjusted odds ratio [AOR]: 2.00 [95% confidence interval (CI), 1.94-2.06], P < .001), with the strongest effect for vascular dementia (AOR: 3.17 [95% CI, 2.97-3.37], P < .001), followed by presenile dementia (AOR: 2.62 [95% CI, 2.28-3.00], P < .001), Alzheimer's disease (AOR: 1.86 [95% CI, 1.77-1.96], P < .001), senile dementia (AOR: 1.99 [95% CI, 1.86-2.13], P < .001) and post-traumatic dementia (AOR: 1.67 [95% CI, 1.51-1.86] P < .001). Blacks with dementia had higher risk of COVID-19 than Whites (AOR: 2.86 [95% CI, 2.67-3.06], P < .001). The 6-month mortality and hospitalization risks in patients with dementia and COVID-19 were 20.99% and 59.26%, respectively.

**Discussion:** These findings highlight the need to protect patients with dementia as part of the strategy to control the COVID-19 pandemic.

## Title: A dementia care training using mobile e-learning with mentoring support for home care workers: a controlled study.

**Citation:** BMC geriatrics; Feb 2021; vol. 21 (no. 1); p. 126

**Author(s):** Su, Hsin-Feng; Koo, Malcolm; Lee, Wen-Li; Sung, Huei-Chuan; Lee, Ru-Ping; Liu, Wen-I

**Background:** Caring of older adults with dementia at home can be challenging for home care workers. There is a need to develop suitable training for home care workers to improve the quality of dementia care. We evaluated a 12-week dementia care training including mobile e-learning, social networking, and mentoring support group meetings on the dementia care knowledge, attitude, and competence of home care workers.

**Methods:** This controlled study involved 140 home care workers from two home care agencies, which were selected from 12 home care agencies in eastern Taiwan. The two home care agencies were randomly allocated either the intervention group or the control group. The intervention group received mobile e-learning, mentor-led online social support networking, and monthly face-to-face mentoring support group meetings. Participants in the control group received 8-h conventional lectures. The primary outcomes were knowledge, attitude, and competence in dementia care. Questionnaires consisting of the Dementia Knowledge Assessment Scale, Approaches to Dementia Questionnaire, and Sense of Competence in Dementia Care Staff scale were administered to the participants at three time points (baseline, end of the 12-week intervention, and 12 weeks after the end of the intervention).

**Results:** Generalized estimating equation analyses showed that the intervention significantly improved the knowledge, attitude, and competence of home care workers on dementia care. The effects remained significant even 12 weeks after the end of the intervention.

**Conclusions:** A 12-week dementia care training program consisting of mobile e-learning, social networking, and face-to-face mentoring support group meetings were found to a feasible approach in improving the knowledge, attitude, and competence of home care workers. Mobile e-learning and online environment provides a platform that is self-directed, flexible, accessible, and cost-effective for training home care workers. The findings provide a call to action for nurse educators and policy makers to re-design existing dementia care training for home care workers to meet the critical home care needs of a growing dementia population.TRIAL

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## Title: Knowledge Exchanges and Decision-Making Within Hospital Dementia Care Triads: An Ethnographic Study.

**Citation:** The Gerontologist; Feb 2021

**Author(s):** Kelley, Rachael; Godfrey, Mary; Young, John

**Objectives:** Important decisions about the future care of people living with dementia are routinely made in hospitals. Very little is known about how the care needs of hospitalized people with dementia are understood, or how the perspectives of the person, families, and staff intersect to inform decision-making. This study explores how the care needs of people with dementia are understood by the person, their family, and hospital staff (the care triad), and how these perspectives shape decision-making.

**Research design and methods:** Ethnographic data were collected from 2 care-of-older-people general hospital wards via observations, conversations, and interviews with people with dementia, families, and staff. In total, 400 hr of observation and 46 interviews were conducted across two 7- to 9-month periods.

**Results:** The person's care needs were often understood differently between and within arms of the care triad. A lack of consistent engagement with families and people with dementia reduced opportunities to recognize and integrate this range of views, leading to delays or difficulties in decision-making. People with dementia, particularly those lacking capacity, were most likely to have their perspectives overlooked.

**Discussion and implications:** Early engagement with people with dementia and their families is required to ensure that all perspectives on the person's current and future care needs are understood and represented during decision-making. Particular attention should be paid to involving people living with dementia in discussions and decisions about their care, and to the assessment and involvement of people who may lack capacity.

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## Title: Instruments to Assess Social Functioning in Individuals with Dementia: A Systematic Review.

**Citation:** Journal of Alzheimer's disease : JAD; Feb 2021

**Author(s):** Grothe, Jessica; Schomerus, Georg; Dietzel, Jens; Riedel-Heller, Steffi; Röhr, Susanne

**Objective:** Social functioning is an important parameter for the early detection and diagnosis of dementia, as well as the description of its course and the assessment of intervention effects. Therefore, valid and reliable instruments to measure social functioning in individuals with dementia are needed. We aimed to provide an overview of such instruments including information on feasibility and psychometric properties.

**Methods:** The review is informed by the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines. Relevant literature was identified using a pre-specified search string in the databases MEDLINE, PsycINFO, and Web of Science. Information on the characteristics, feasibility, and psychometric properties of the identified instruments were extracted, summarized, and discussed.

**Results:** Out of 5,307 articles, 8 were selected to be included in the study, describing a total of three instruments for measuring social functioning in individuals with dementia: the Nurses' Observation Scale for Geriatric Patients (NOSGER; dimension "social behavior"), the Socioemotional Dysfunction Scale (SDS), and the Social Functioning in Dementia Scale (SF-DEM). The validity of all the three instruments was overall acceptable. Reliability was high for the NOSGER scale "social behavior" and the SF-DEM. Information on the usability of the instruments tended to be scarce.

**Conclusion:** There are a few valid and reliable instruments to assess social functioning in individuals with dementia. Further considerations could comprise their feasibility with regard to measuring changes in social functioning over time, in additional target groups, e.g., different types and stages of dementia, and adaptions to different languages and cultural backgrounds.

## Title: The components of personal passports for people living with dementia in an acute healthcare setting: An integrative review.

**Citation:** Journal of clinical nursing; Feb 2021

**Author(s):** Beattie, Fiona; Kerr, Lisa; Larkin, John; Cawley, Des

**Objective:** To explore the components of personal passports for people living with dementia in an acute healthcare setting BACKGROUND: Globally, supporting people with dementia poses a prominent health and social care challenge. Importance for people with dementia in an acute healthcare setting includes social relationships and communication with healthcare staff. A personal passport is an international initiative designed to support the personhood of the person living with dementia.

**Methods:** This integrative review is based on the methodology of Whittmore and Knafl (2005). The Preferred Reporting for Systematic Reviews and Meta-Analyses (PRISMA) guidelines and checklist were adhered to. A database search of PubMed, MEDLINE, CINHAL, Scopus and EBSCO databases were systematically searched.

**Results**: This integrative review identified nine research studies on the components of personal passports that met the inclusion and exclusion criteria. A constant comparative method of data analysis identified five key pivotal themes: person-centredness, communication, family/carer involvement, education and leadership.

**Conclusion:** The use of personal passports supports the provision of person-centred care for people living with dementia through enhancing the wellbeing of both the person and their families/caregivers. Relevance to clinical practice Personal passports are an important document and should be determined by the person with dementia, their care needs and the caregiver's role in meeting these needs.

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## Title: Family Caregiver Needs and Preferences for Virtual Training to Manage Behavioral and Psychological Symptoms of Dementia: Interview Study.

**Citation:** JMIR aging; Feb 2021; vol. 4 (no. 1); p. e24965

**Author(s):** Ramirez, Magaly; Duran, Miriana C; Pabiniak, Chester J; Hansen, Kelly E; Kelley, Ann; Ralston, James D; McCurry, Susan M; Teri, Linda; Penfold, Robert B

**Background:** Behavioral and psychological symptoms of dementia (BPSD) are associated with increased stress, burden, and depression among family caregivers of people with dementia. STAR-Caregivers Virtual Training and Follow-up (STAR-VTF) is adapted from an evidence-based, in-person program that trains family caregivers to manage BPSD. We used a human-centered design approach to obtain feedback from family caregivers about STAR-VTF. The program will be evaluated using a pragmatic randomized trial.

**Objective:** The objective of the study was to understand the needs of family caregivers for improving BPSD management and the extent to which caregivers perceived that STAR-VTF could address those needs.

**Methods**: Between July and September 2019, we conducted 15 semistructured interviews with family caregivers of people with dementia who receive care at Kaiser Permanente Washington in the Seattle metropolitan area. We identified participants from electronic health records, primarily based on a prescription for antipsychotic medication for the person with dementia (a proxy for caregivers dealing with BPSD). We showed caregivers low-fidelity prototypes of STAR-VTF online self-directed materials and verbally described potential design elements. We obtained caregiver feedback on these elements, focusing on their needs and preferences and perceived barriers to using STAR-VTF. We used a hybrid approach of inductive and deductive coding and aggregated codes to develop themes.

**Results:** The idea of a virtual training program for learning to manage BPSD appealed to caregivers. They said health care providers did not provide adequate education in the early disease stages about the personality and behavior symptoms that can affect people with dementia. Caregivers found it unexpected and frustrating when the person with dementia began experiencing BPSD, symptoms they felt unprepared to manage. Accordingly, caregivers expressed a strong desire for the health care organization to offer programs such as STAR-VTF much sooner. Caregivers had already put considerable effort into problem solving challenging behaviors. They anticipated deriving less value from STAR-VTF at that point. Nonetheless, many were interested in the virtual aspect of the training due to the convenience of receiving help from home and the perception that help from a virtual program would be timelier than traditional service modalities (eg, face to face). Given caregivers' limited time, they suggested dividing the STAR-VTF content into chunks to review as time permitted. Caregivers were interested in having a STAR-VTF provider for additional support in managing challenging behaviors. Caregivers reported a preference for having the same coach for the program duration.

**Conclusions:** Caregivers we interviewed would likely accept a virtual training program such as STAR-VTF to obtain information about BPSD and receive help managing it. Family caregivers anticipated deriving more value if STAR-VTF was offered earlier in the disease course.

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## Title: Impact of dementia literacy interventions for non-health-professionals: systematic review and meta-analysis.

**Citation:** Aging & mental health; Feb 2021 ; p. 1-15

**Author(s):** Nguyen, Hoang; Phan, Hoang T; Terry, Daniel; Doherty, Kathleen; McInerney, Fran

**Objectives:** To assess evidence regarding the effects of interventions aimed at improving dementia literacy for different groups of non-health-professionals.

**Methods:** A systematic search for relevant interventions was conducted using a range of online databases (e.g. CINAHL, Embase, Medline, ProQuest, and PsycINFO) and hand-searching of reference lists. Eligible interventions were identified based on predefined inclusion/exclusion criteria and methodological quality criteria. Meta analyses were performed using a random-effects model.

**Results:** The final review included 14 interventions, which were either randomised controlled trials or non-randomised controlled trials. The interventions had varied contents, approaches, settings, and outcome measures. Evidence of improved dementia literacy in various aspects was found, and the intervention effects were strongest on knowledge of dementia.

**Discussion:** There is evidence for the positive impact of dementia literacy interventions on different groups of non-health-professionals. Best practices in intervention contents, approaches, and outcome measures should be examined to guide future interventions.

## Title: Impacts of Low-cost Robotic Pets for Older Adults and People with Dementia: Scoping Review.

**Citation:** JMIR rehabilitation and assistive technologies; Feb 2021; vol. 8 (no. 1); p. e25340

**Author(s):** Koh, Wei Qi; Ang, Faith Xin Hui; Casey, Dympna

**Background:** Older adults and people with dementia are particularly vulnerable to social isolation. Social robots, including robotic pets, are promising technological interventions that can benefit the psychosocial health of older adults and people with dementia. However, issues such as high costs can lead to a lack of equal access and concerns about infection control. Although there are previous reviews on the use of robotic pets for older adults and people with dementia, none have included or had a focus on low-cost and familiarly and realistically designed pet robots.

**Objective:** The aim of this review is to synthesize evidence on the delivery and impact of low-cost, familiarly and realistically designed interactive robotic pets for older adults and people with dementia.

**Methods:** The Arksey and O'Malley framework was used to guide this review. First, the research question was identified. Second, searches were conducted on five electronic databases and Google Scholar. Studies were selected using a two-phase screening process, where two reviewers independently screened and extracted data using a standardized data extraction form. Finally, the results were discussed, categorized, and presented narratively.

**Results:** A total of 9 studies were included in the review. Positive impacts related to several psychosocial domains, including mood and affect, communication and social interaction, companionship, and other well-being outcomes. Issues and concerns associated with its use included misperceptions of the robotic pets as a live animal, ethical issues of attachment, negative reactions by users, and other pragmatic concerns such as hygiene and cost.

**Conclusions:** Overall, the findings resonate with previous studies that investigated the effectiveness of other social robots, demonstrating the promise of these low-cost robotic pets in addressing the psychosocial needs of older adults and people with dementia. The affordability of these robotic pets appeared to influence the practicalities of real-world use, such as intervention delivery and infection control, which are especially relevant in light of COVID-19. Moving forward, studies should also consider comparing the effects of these low-cost robots with other robotic pets.

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## Title: In-home dementia caregiving is associated with greater psychological burden and poorer mental health than out-of-home caregiving: a cross-sectional study.

**Citation:** Aging & mental health; Feb 2021 ; p. 1-7

**Author(s):** Brini, S; Hodkinson, A; Davies, A; Hirani, S; Gathercole, R; Howard, R; Newman, S P

**Objective:** Caregivers who live with a person with dementia who receives care, compared with those who live elsewhere, are often considered to experience greater levels of psychological and affective burden. The evidence for this is, however, only limited to studies employing small sample sizes and that failed to examine caregivers' psychological wellbeing. We address these issues in a large cohort of dementia caregivers.

**Methods**: We conducted a cross-sectional study comparing caregivers living with a dementia care recipient (n = 240) to caregivers living elsewhere (n = 255) on caregivers' burden, anxiety, and depression.

**Results:** We found that caregivers living with the care recipient relative to those living elsewhere showed significantly greater burden and depression, but we found no group difference in anxiety.

**Conclusions:** Our study adds to the evidence by showing that cohabiting with a care recipient with dementia is associated with greater burden and poorer psychological wellbeing. Strategies aiming to improve caregivers' burden and psychological wellbeing should take account of caregivers' living arrangements.

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**Title: Doing their damnedest to seek change: How group identity helps people with dementia confront public stigma and maintain purpose.**

**Citation:** Dementia (London, England); Feb 2021 ; p. 1471301221997307

**Author(s):** Hagan, Robert J; Campbell, Sarah

**Abstract:** Dominant messages about the capabilities of those with dementia post-diagnosis are often dehumanising and focused on mental declines. Additionally, carers for those with dementia are more likely to be involved in consultations and enquiries about the condition. This study helps to challenge stigmatising cultural messages by reporting upon the experiences of 13 adults diagnosed with early-stage dementia and how their involvement with empowerment groups in Northern Ireland has led to their involvement in consultations with policy makers and educational opportunities with the wider public. The study finds that this not only helps in challenging stereotypical ideas about dementia, as well as informing others, but also gives a sense of purpose to adults in their post-diagnosis lives. It is further noted that group identity helps give confidence and amplifies the voice of those who take part, allowing members to adopt a shared narrative and learn from each other

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**Title: Expressions of masculine identity through sports-based reminiscence: An ethnographic study with community-dwelling men with dementia.**

**Citation:** Dementia (London, England); Feb 2021 ; p. 1471301220987386

**Author(s):** Sass, Cara; Surr, Claire; Lozano-Sufrategui, Lorena

**Objective:** Despite increasing numbers of men living in isolation with dementia in the community, uptake of supportive interventions remains low. This may be because of limited availability of activities suited to men's interests. One organisation reporting higher attendance from men is Sporting Memories, offering inclusive sports-based reminiscence and physical activities for men living with dementia. This study aimed to explore the impact of the Sporting Memories intervention on men living with dementia.

**Method:** This study was an ethnography employing techniques of participant observation, informal conversations and semi-structured interviews with group participants. Data were woven into a series of narratives using creative non-fiction, to bring life to the first-hand accounts of participants and experiences within a typical group setting.

**Findings:** The groups provided an environment for men with dementia to explore, reflect upon and reinforce their masculine identities through the subject of sport. Physical activities further facilitated this embodied demonstration for some, although this was not a feature of all sessions.

**Conclusions:** The content of Sporting Memories group sessions provides a vehicle for men to retain an important aspect of personhood. They also hold the potential to present opportunities for men to feel a sense of value by contributing to sessions in varied ways. Facilitators and volunteers require support and training to ensure this benefit is maintained.

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**Title: Smarthealth technology study protocol to improve relationships between older adults with dementia and family caregivers.**

**Citation:** Journal of advanced nursing; Feb 2021

**Author(s):** Rose, Karen M; Coop Gordon, Kristina; Schlegel, Emma C; Mccall, Matthew; Gao, Ye; Ma, Meiyi; Lenger, Katherine A; Ko, Eunjung; Wright, Kathy D; Wang, Hongning; Stankovic, John

**Objective:** The aim of this study is to develop a Smarthealth system of monitoring, modelling, and interactive recommendation solutions (for caregivers) for in-home dementia patient care that focuses on caregiver-patient relationships.

**Design:** This descriptive study employs a single-group, non-randomized trial to examine functionality, effectiveness, feasibility, and acceptability of the novel Smarthealth system.

**Methods:** Thirty persons with Alzheimer's Disease or related dementia and their family caregivers (N = 30 dyads) will receive and install Smarthealth technology in their home. There will be a 1-month observation phase for collecting baseline mood states and a 2-month implementation phase when caregivers will receive stress management techniques for each detected, negative mood state. Caregivers will report technique implementation and usefulness, sent via Ecological Momentary Assessment system to the study-provided smartphone. Caregivers will provide daily, self-reported mood and health ratings. Instruments measuring caregiver assessment of disruptive behaviours and their effect on caregivers; caregiver depressive symptoms, anxiety and stress; caregiver strain; and family functioning will be completed at baseline and 3 months. The study received funding in 2018 and ethics board approval in 2019.

**Discussion:** This study will develop and test novel in-home technology to improve family caregiving relationships. Results from this study will help develop and improve the Smarthealth recommendation system and determine its usefulness, feasibility, and acceptability for persons with dementia and their family caregiver.

**Impact:** The Smarthealth technology discussed will provide in-home stress reduction resources at a time when older adults may be experiencing increasingly high rates of isolation and anxiety and caregiver dyads may be experiencing high levels of relationship strain.

**Title: Use of the Long-Term Conditions Questionnaire (LTCQ) for monitoring health-related quality of life in people affected by cognitive impairment including dementia: pilot study in UK memory clinic services.**

**Citation:** Quality of life research : an international journal of quality of life aspects of treatment, care and rehabilitation; Feb 2021

**Author(s):** Potter, Caroline M; Peters, Michele; Cundell, Maureen; McShane, Rupert; Fitzpatrick, Ray

**Objective:** The aim of this study was to validate the Long-Term Conditions Questionnaire (LTCQ) among patients using memory clinic services in England. LTCQ is a short self-administered measure of 'living well with long-term conditions' that has not been previously tested in patients with cognitive impairment.

**Methods:** The mixed-methods study included cognitive interviews to test the comprehensibility and content validity of LTCQ from the patient's perspective, followed by a pilot survey to test the measure's internal consistency, construct validity, structural validity, and responsiveness. Participants were recruited through memory clinics following a diagnosis of mild cognitive impairment or dementia.

**Results:** Interview respondents (n = 12) all found LTCQ's content relevant, with only minor formatting modifications required. Among survey respondents (n = 105), most patients (86%) were able to self-report answers to LTCQ. High multimorbidity among the sample was associated with reduced LTCQ and EQ-5D scores. Internal consistency of LTCQ was high (Cronbach's α = 0.93), no floor or ceiling effects were observed, and missing data levels were low. Factor analysis results further supported LTCQ's structural validity, and predicted positive correlation with EQ-5D indicated construct validity. Score changes observed in a four-month follow-up survey (n = 61) are suggestive of LTCQ's responsiveness.

**Conclusion**: LTCQ is a valid means of assessing health-related quality of life for people living with cognitive impairment (including dementia) in the early period of support following diagnosis. Owing to high levels of multimorbidity in this patient population, LTCQ offers an advantage over dementia-specific measures in capturing the cumulative impact of all LTCs experienced by the patient.

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**Title: Pain in persons with dementia and the direct and indirect impacts on caregiver burden.**

**Citation:** Geriatric nursing (New York, N.Y.); Feb 2021; vol. 42 (no. 2); p. 366-371

**Author(s):** Regier, Natalie G; Taylor, Janiece L; Szanton, Sarah L; Parmelee, Patricia A; Perrin, Nancy; Liu, Minhui; Jenkins, Emerald; Hodgson, Nancy A; Gitlin, Laura N

**Objectives:** Unresolved pain is related to neuropsychiatric symptoms (NPS) in persons living with dementia (PLWD), and an increase in NPS is distressing for PLWD and their caregivers. Hence, we examined whether pain in PLWD was related to caregiver burden and whether caregiver upset with NPS mediated this relationship.

**Method:** We examined, cross-sectionally, the relationships among pain in PLWD, caregiver burden, and upset with NPS. Data from 272 PLWD and their caregivers who participated in the Advancing Caregiver Training (ACT) trial were analyzed using structural equation modeling (SEM).

**Results:** Model fit was satisfactory, and caregiver upset with NPS fully mediated the association between pain in PLWD and caregiver burden.

**Conclusion:** Caregiver upset with NPS helps explain the relationship between pain in PLWD and burden in their caregivers. Pain and NPS are amenable to modification, as is caregiver burden, suggesting great opportunity to impact the lives of PLWD and their caregivers.

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**Title: Development and validation of a delirium risk assessment tool in older patients admitted to the Emergency Department Observation Unit.**

**Citation:** Aging clinical and experimental research; Feb 2021

**Author(s):** Zucchelli, A; Apuzzo, R; Paolillo, C; Prestipino, V; De Bianchi, S; Romanelli, G; Padovani, A; Marengoni, A; Bellelli, G

**Objective:** Delirium is frequent though undetected in older patients admitted to the Emergency Department (ED). This study aims to develop and validate a delirium risk assessment tool for older persons admitted to the ED Observation Unit (OU).

**Methods:** We used data from two samples of 65 + year-old patients, one admitted to the ED of Brescia Hospital (n = 257) and one to the ED of Desio Hospital (n = 107), Italy. Data from Brescia were used as training sample, those collected in Desio as testing one. Delirium was assessed using the 4AT and patients' characteristic were retrieved from medical charts. Variables found to be associated with delirium in the training sample were tested for the creation of a delirium risk assessment tool. The resulting tool's performances were assessed in the testing subsample.

**Results**: Of all possible scores tested, the combination with the highest discriminative ability in the training sample included: age ≥ 75 years, dementia diagnosis, chronic use of neuroleptics, and hearing impairment. The delirium score exhibited an AUC of 0.874 and 0.893 in the training and testing samples, respectively. For a 1-point increase in the score, the odds of delirium increased more than twice in both samples.

**Discussion:** We propose a delirium risk assessing tool that includes variables that can be easily collected at ED admission and that can be calculated rapidly.

**Conclusion:** A risk assessment tool could help improving delirium detection in older persons referring to ED.

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**Title: Increasing awareness, sensitivity, and empathy for Alzheimer's dementia patients using simulation.**

**Citation:** Nurse Education Today; Mar 2021; vol. 98

**Author(s):** Campbell ; Lugger, Suzanne; Sigler, Gina S.; Turkelson, Carman

**Abstract:** Alzheimer's Disease (AD), a type of dementia that interferes with memory, thinking, and behavior is the most common type of dementia. As a result, it is a leading contributor to death and disability for those over the age of 65. Therefore, future nurses must have the knowledge and skills to manage patients with AD in any setting spanning the healthcare continuum. The goal of this project was to evaluate perceptions of awareness, knowledge and sensitivity of future nurses concerning AD patients before and after participation in a simulated virtual reality dementia experience. Design/Participants. A quasi-experimental repeated measure pre-post design was used with a convenience sample of 163 undergraduate baccalaureate nursing students from three different courses at large public university in the Midwest. Students were placed in teams of four to participate in a 45-minute interactive simulated virtual reality dementia experience. Each session started with a 15-minute team pre-briefing session, followed by a 10-minute individual simulation, which was then followed by a 30-minute team debriefing session facilitated by faculty using the Plus/ Delta debriefing technique. The Dementia Attitudes Scale (DAS), The Knowledge About Memory Loss and Care Test (KAML-C), and the Healthcare Tour Survey were administered pre/post participation. Qualitative data was also collected from student reflections. Statistically significant changes ($p < 0.001$) were noted in the pre/post DAS survey and the Healthcare Tour Survey. No significant change was noted on the KAML-C, although there was a trend towards improvement. No differences were noted between courses on any of the surveys. Using a virtual reality dementia experience proved to be a valuable strategy to increase student perceptions of awareness, knowledge, and sensitivity of AD. Further exploration is warranted to establish how these may be further facilitated to translate into improved care for those with AD.

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### Title: Effects of Simulation on Nursing Students' Dementia Knowledge and Empathy: A Mixed Method Study.

**Citation:** Issues in Mental Health Nursing; Mar 2021; vol. 42 (no. 3); p. 274-279

**Author(s):** Kimzey ; Patterson, Jodi; Mastel-Smith, Beth

**Abstract:** The experience of living with dementia is multifaceted while unique to the individual. Dementia education must empower nursing students to recognize the complexity of the experience while also emphasizing the need for person centered care. Participation in Dementia Live® provides nursing students a glimpse into the life of a person living with dementia incorporating common symptoms associated with dementia and time for reflection regarding the experience. The purpose of the study was to determine the effects of dementia simulation on nursing students' dementia knowledge and empathy for people living with dementia. This convergent mixed methods study involved a convenience sample of 65 undergraduate nursing students. A pretest/posttest design was used to collect quantitative data while thematic analysis of focus group discussions was used for qualitative data collection. Quantitative results reported a significant increase in empathy. Qualitative findings supported the quantitative findings with themes identifying four of the six components of empathy. This study adds to the understanding of teaching and learning about dementia care and highlights the contributions a seven-minute simulation made to improve empathy.

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### Title: Training hospital inpatient nursing to know (THINK) delirium: A nursing educational program.

**Citation:** Geriatric Nursing; Jan 2021; vol. 42 (no. 1); p. 16-20

**Author(s):** Solberg ; Campbell, Colleen S.; Jones, Kimberly; Vaughn, Ivana; Suryadevara, Uma; Fernandez, Carmen; Shorr, Ronald

**Abstract:** Delirium in the hospital is a medical emergency. Under-recognition and misunderstanding of delirium impacts nursing care. Nursing education in recognizing delirium is paramount to improving patient outcomes. We developed and implemented a delirium education program with three steps; 1) self-directed online module; 2) dementia simulation experience; and 3) a multi-station delirium skills fair. Conducted pre and post-tests after step 2, and a four-month follow-up survey. Interprofessional education about delirium with a standardized screening tool, documentation, and non-pharmacologic interventions improved knowledge of delirium and may have changed the culture surrounding delirium in the hospital. Recognition and documentation of delirium is a challenge in the hospital. Education programs lack standardized screening tools. The presence of dementia or depression contribute to poor recognition of delirium. Many front-line healthcare workers attribute delirium to dementia, often misidentifying or delaying a correct diagnosis and in turn, treatment. Unrecognized and untreated delirium is costly. Non-pharmacologic interventions improve patient outcomes and decrease costs. Without delirium education, nurses are vulnerable to injury and low job satisfaction when caring for delirious patients. We describe an education program improving recognition and attitudes towards patients experiencing delirium. An education program about screening, documenting, and treating delirium. A large Veterans Health System Hospital. Healthcare professionals(n = 389) participated in the education program. 355 Nurses and patient-care assistants took the pre and post-test, and 43 returned the post program follow-up survey. A delirium education program with three steps; 1) self-directed online module; 2) dementia simulation experience; and 3) a multi-station delirium skills fair. Pre and post-tests were conducted after step 2, as well as a four-month follow-up survey. Changes in attitude toward patients with cognitive impairment and their abilities. Self-assessment of attitudes toward patients with delirium. Statistically significant differences in pre and post-testing suggested increased understanding of the experience and abilities of people experiencing cognitive impairment. The four-month follow-up survey showed a continued understanding of the importance of recognizing, documenting, and treating delirium. Nursing Education about delirium that includes instruction on a standardized screening tool, documentation, and non-pharmacologic interventions improved knowledge and recognition of delirium and may have changed attitudes surrounding delirium in the hospital.

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**Title: Learning to communicate with people with dementia: Exploring the impact of a simulation session for medical students (Innovative practice).**

**Citation:** Dementia (14713012); Nov 2020; vol. 19 (no. 8); p. 2919-2927

**Author(s):** Winter ; Al-Jawad, Muna; Harris, Richard; Wright, Juliet

**Abstract:** There is a recognised need to improve undergraduate education within dementia care. UK medical schools provide dementia-specific teaching, but this has previously been found to focus more on student knowledge and skills rather than behaviours and attitudes and does not often involve the wider multidisciplinary team. A simulation day was established, based on communicating with a person with dementia in a number of scenarios. This article aims to identify if this method of teaching within dementia care is successful. It is a qualitative study and draws on data from postcourse questionnaire responses and field notes of the simulation day. The data offered rich insights into how the session allowed participants to be challenged and taken to their perceived thresholds of capability. It highlights that behaviours and skills can be learnt via simulation and leads to a transformative change in the language learners used, suggesting that learning may happen through threshold concepts.

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**Title: Impact of 'DEALTS2' education intervention on trainer dementia knowledge and confidence to utilise innovative training approaches: A national pre-test – post-test survey.**

**Citation:** Nurse Education Today; Feb 2021; vol. 97

**Author(s):** Heward ; Board, Michele; Spriggs, Ashley; Emerson, Laurie; Murphy, Jane

**Abstract:** Gaps in acute care staff knowledge, skills, and attitudes towards dementia exist. Innovative training approaches that improve the delivery of care for people with dementia are needed. We were commissioned by Health Education England to develop and evaluate a new dementia education intervention 'Dementia Education And Learning Through Simulation 2' (DEALTS2), a simulation toolkit to enhance delivery of dementia training nationally across England.

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**Title: Dementia stigma reduction (DESeRvE) through education and virtual contact in the general public: A multi-arm factorial randomised controlled trial.**

**Citation:** Dementia (London, England); Jan 2021 ; p. 1471301220987374

**Author(s):** Kim, Sarang; Richardson, Alice; Werner, Perla; Anstey, Kaarin J

**Objective:** To examine the efficacy of the Dementia Stigma Reduction (DESeRvE) programme, aimed at reducing the general public dementia-related stigma utilising 'education' and 'contact' approaches.

**Methods**: A total of 1024 Australians aged between 40 and 87 years ($M = 60.8$, $SD = 10.1$) participated in a factorial randomised controlled trial. This trial examined four conditions: online education programme (ED), contact through simulated contact with people with dementia and carers (CT), education and contact (ED+CT) and active control. Cognitive, emotional and behavioural aspects of dementia-related stigma were measured with a modified Attribution Questionnaire, and dementia knowledge was measured with the Dementia Knowledge Assessment Scale at the baseline, immediately and 12 weeks after the completion of the intervention.

**Results:** All four groups improved (reduction in scores) significantly from baseline to week 12 in dementia-related stigma, and the effects were stronger for those with higher baseline stigma scores. Intervention groups also improved significantly from baseline in dementia knowledge. Especially, the ED ($\beta = .85$, $SE = .07$; $p < .001$) and ED+CT ($\beta = .78$, $SE = .08$; $p < .001$) groups at immediate follow-up and CT ($\beta = .21$, $SE = .09$; $p < .05$) and ED+CT ($\beta = .32$, $SE = .09$; $p < .001$) at 12-week follow-up showed significant effects.

**Conclusions:** Findings suggest that DESeRvE can be a valuable tool to enhance public's dementia knowledge and reduce dementia-related stigma, especially for those with higher levels of stigma. Reduction in stigma, however, may take a longer time to achieve, whereas improvement in dementia knowledge is instant.

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### Title: Is Perception Reality? Using Person-in-Context Simulation to Promote Empathic Understanding of Dementia among Nurse Practitioner Students.

**Citation:** Nursing education perspectives; Feb 2021

**Author(s):** Harrington, Candace C; Neil, Janice A; Hardin, Sonya R; Roberson, Donna W

**Abstract:** This one-group nonexperimental pretest/posttest repeated-measures design plus interpretative phenomenological analysis explored nurse practitioner students' perceptions of dementia using virtual simulation. Perceptions of dementia and its associated challenges differed after the simulation. A critical theme that emerged was "developing empathic understanding"; the two subthemes were "mirroring dementia behaviors" and "provoking emotions." Virtual dementia simulation is an inexpensive, low-fidelity strategy to challenge assumptions and preconceived belief systems about dementia. Person-in-context experiential learning is valuable in nurse practitioner education for facilitating empathic understanding. Further research is needed to explore the correlation between empathic understanding and altruistic helping behaviors in professional practice.

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### Title: Discontinued dental care attendance among people with dementia: A register-based longitudinal study.

**Citation:** Gerodontology; Mar 2021; vol. 38 (no. 1); p. 57-65

**Author(s):** Lexomboon, Duangjai; Gavriilidou, Nivetha Natarajan; Höijer, Jonas; Skott, Pia; Religa, Dorota; Eriksdotter, Maria; Sandborgh-Englund, Gunilla

**Objective:** To investigate the factors that increase the risk of discontinuing dental care utilisation after dementia is diagnosed in a population in Stockholm County, Sweden.

**Background:** the progression of dementia results in a deteriorating ability to maintain good oral health, it is important to identify people at risk of discontinued dental care after being diagnosed with dementia.

**Materials and methods:** This study is a register-based longitudinal study. Data were extracted from the Swedish Dementia Registry (SveDem), the Swedish National Patient Register, the Dental Health Register and the Municipal Dental Care Register (Stockholm County Council). The data included people using both general public dental services and care-dependent individuals. Dental visits three years before and after dementia had been diagnosed were analysed.

**Results:** In total, 10 444 people were included in the analysis, of which 19% did not have dental visits recorded after they were diagnosed with dementia. A logistic regression model, adjusted for relevant factors, showed that the factors associated with a greater risk for discontinued dental attendance were fewer remaining teeth (OR = 0.96, 95% CI = 0.95, 0.97) and living alone compared to living with another adult (OR = 1.23, 95% CI = 1.05, 1.43). People with Parkinson's disease dementia had a lower risk (OR = 0.40, 95% CI = 0.19, 0.84) than people with Alzheimer's disease.

**Conclusion:** Patients, dental and healthcare personnel, and family members should all be aware of these risk factors so that appropriate support and oral care for people with dementia can be delivered.

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## Title: Dementia and outcomes from coronavirus disease 2019 (COVID-19) pneumonia: A systematic review and meta-analysis.

**Citation:** Archives of gerontology and geriatrics; 2021; vol. 93 ; p. 104299

**Author(s):** Hariyanto, Timotius Ivan; Putri, Cynthia; Arisa, Jessie; Situmeang, Rocksy Fransisca V; Kurniawan, Andree

**Objective:** The number of positive and death cases from coronavirus disease 2019 (COVID-19) is still increasing until now. One of the most prone individuals, even in normal situations is patients with dementia. Currently, no study provides clear evidence regarding the link between dementia and COVID-19. This study aims to analyze the relationship between dementia and poor outcomes of COVID-19 infection.

**Materials and methods:** We systematically searched the PubMed and Europe PMC database using specific keywords related to our aims until October 25th, 2020. All articles published on COVID-19 and dementia were retrieved. The quality of the study was assessed using the Newcastle Ottawa Scale (NOS) tool for observational studies. Statistical analysis was done using Review Manager 5.4 software.

**Results:** A total of 24 studies with 46,391 dementia patients were included in this meta-analysis. This meta-analysis showed that dementia was associated with composite poor outcome [RR 2.67 (95% CI 2.06 - 3.47), p < 0.00001, I2 = 99%, random-effect modeling] and its subgroup which comprised of risk of COVID-19 infection [RR 2.76 (95% CI 1.43 - 5.33), p = 0.003, I2 = 99%, random-effect modeling], severe COVID-19 [RR 2.63 (95% CI 1.41 - 4.90), p = 0.002, I2 = 89%, random-effect modeling], and mortality from COVID-19 infection [RR 2.62 (95% CI 2.04 - 3.36), p < 0.00001, I2 = 96%, random-effect modeling].

**Conclusions:** Extra care and close monitoring should then be provided to patients with dementia to minimize the risk of infections, preventing the development of severe and mortality outcomes.

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## Title: Exploring the needs of people with dementia living at home reported by people with dementia and informal caregivers: a systematic review and Meta-analysis.

**Citation:** Aging & mental health; Mar 2021; vol. 25 (no. 3); p. 397-407

**Author(s):** Curnow, Eleanor; Rush, Robert; Maciver, Donald; Górska, Sylwia; Forsyth, Kirsty

**Objectives:** To provide prevalence estimates of needs of people with dementia living at home, and to determine sources of variation associated with needs for this population.

**Method**: A systematic review and meta-analysis was performed searching CINAHL, MEDLINE, PsycINFO and ASSIA databases. Following quality checks, random effects meta-analysis produced prevalence estimates for needs reported by people with dementia and by their informal caregivers. Fixed effects models were undertaken to compare caregiver and person with dementia reported needs. Heterogeneity was explored through sensitivity analysis. The study protocol was registered with Prospero #CRD42017074119.

**Results:** Six retrieved studies published between 2005 and 2017 including 1011 people with dementia and 1188 caregivers were included in the analysis. All data were collected using Camberwell Assessment of Need for the Elderly. Prevalence estimates are provided for 24 needs reported by participants in The Netherlands, United Kingdom, Poland, Ireland, Germany, Norway, Portugal, Italy and Sweden. Most prevalent needs reported by people with dementia were Memory 0.713 [95% CI 0.627, 0.791]; Food 0.706 [95% CI 0.547, 0.842]; Household activities 0.677 [95% CI 0.613, 0.738]; and Money 0.566 [95% CI 0.416, 0.711]. Caregivers reported greater prevalence than people with dementia did for 22 of 24 needs, although the priority ranking of needs was similar. Exploration of heterogeneity revealed that people with young onset dementia were the major source of variation for 24 out of 48 analyses.

**Conclusion:** Increased understanding of prevalence of needs of people with dementia and associated heterogeneity can assist in planning services to meet those needs.

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## Title: Remote primary care consultations for people living with dementia during the COVID-19 pandemic: experiences of people living with dementia and their carers.

**Citation:** The British journal of general practice : the journal of the Royal College of General Practitioners; Feb 2021

**Author(s):** Tuijt, Remco; Rait, Greta; Frost, Rachael; Wilcock, Jane; Manthorpe, Jill; Walters, Kate

**Abstract:** COVID-19 has accelerated remote healthcare provision in primary care, with changes potentially permanent. The implementation of remote provision of healthcare needs to hear from vulnerable populations, such as people living with dementia. This study aims to understand the remote healthcare experiences of patients living with dementia and their family carers during the COVID-19 pandemic.

**Design and setting:** Qualitative interviews with community-based patients living with dementia and their carers during early months (May-August 2020) of the COVID-19 pandemic in England.

**Methods**: Semi-structured interviews were conducted remotely by telephone or video call with 30 patients living with dementia and 31 carers. Data were analysed using thematic analysis.

**Results:** Three main themes were derived relating to: 1) proactive care at the onset of COVID-19 restrictions, 2) avoidance of healthcare settings and services, and 3) difficulties with remote healthcare encounters. People living with dementia and their carers felt check-up calls were reassuring but limited in scope and content. Some avoided healthcare services, wishing to minimise COVID-19 risk, reduce NHS burden, or encountering technological barriers. Difficulties in remote consultations included lack of prompts to remember problems, dealing with new emerging problems, rescheduling/missed calls, and inclusion of the person with dementia's voice.

**Conclusion:** While remote consultations could be effective, pro-active calls could be more structured around needs, and consideration should be given to replace non-verbal prompts to describe problems, particularly for new health concerns. In continuing remote consultations, it is important to facilitate engagement with patients living with dementia and their carers to ensure best practice.

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**Title: Characteristics of Advance Care Planning Interventions Across Dementia Stages: A Systematic Review.**

**Citation:** Journal of nursing scholarship : an official publication of Sigma Theta Tau International Honor Society of Nursing; Mar 2021; vol. 53 (no. 2); p. 180-188

**Author(s):** Kim, Hyejin; Cho, Jeonghyun; Park, Won Seok; Kim, Sang Suk

**Objective:** Little is known regarding how advance care planning (ACP) interventions change with the progression of dementia. Thus, the primary purpose of this systematic review is to compare characteristics of ACP interventions across dementia stages. We also identify the role of nurses in implementing ACP interventions for persons with dementia and their surrogates.

**Design:** A systematic review of ACP intervention studies.

**Methods:** After searching PubMed, Web of Science, EMBASE, PsycArticles, the Cumulative Index to Nursing and Allied Health Literture (CINAHL), and Scopus, the final sample included 11 studies representing 10 interventions. We conducted a quality assessment and extracted data on dementia stage, intervention characteristics, and the role of nurses in the intervention. The extracted data were categorized according to stages of dementia, and analyzed to identify commonalities and differences between intervention characteristics.

**Findings:** Three ACP interventions focused on mild dementia and seven on advanced dementia. We observed four primary findings. First, we found a major difference in intervention recipients between the two dementia stages. Second, most ACP interventions included structured discussions regarding the person's life goals and values, goals of care, and preferences concerning future care via individual, face-to-face interactions. Third, ACP interventions designed to promote ongoing discussions and documentation were lacking. Finally, nurses played important roles in implementing ACP interventions.

**Conclusions:** The findings suggest more nurse-led, dementia-related ACP interventions. In addition, ACP interventions should promote ongoing discussions and documentation and target persons with dementia and their surrogates in various countries.

**Clinical relevance:** Many persons with dementia and their surrogates have limited knowledge about ACP; thus, more nurse-led ACP programs that reflect dementia stages may help them prepare for the situations in which persons with dementia lack decision-making capacity.

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**Title: Treatment pathway analysis of newly diagnosed dementia patients in four electronic health record databases in Europe.**

**Citation:** Social psychiatry and psychiatric epidemiology; Mar 2021; vol. 56 (no. 3); p. 409-416

**Author(s):** James, Glen; Collin, Estelle; Lawrance, Marcus; Mueller, Achim; Podhorna, Jana; Zaremba-Pechmann, Liliana; Rijnbeek, Peter; van der Lei, Johan; Avillach, Paul; Pedersen, Lars; Ansell, David; Pasqua, Alessandro; Mosseveld, Mees; Grosdidier, Solène;

Gungabissoon, Usha; Egger, Peter; Stewart, Robert; Celis-Morales, Carlos; Alexander, Myriam; Novak, Gerald; Gordon, Mark Forrest

**Objectives:** Real-world studies to describe the use of first, second and third line therapies for the management and symptomatic treatment of dementia are lacking. This retrospective cohort study describes the first-, second- and third-line therapies used for the management and symptomatic treatment of dementia, and in particular Alzheimer's Disease.

**Methods:** Medical records of patients with newly diagnosed dementia between 1997 and 2017 were collected using four databases from the UK, Denmark, Italy and the Netherlands.

**Results:** We identified 191,933 newly diagnosed dementia patients in the four databases between 1997 and 2017 with 39,836 (IPCI (NL): 3281, HSD (IT): 1601, AUH (DK): 4474, THIN (UK): 30,480) fulfilling the inclusion criteria, and of these, 21,131 had received a specific diagnosis of Alzheimer's disease. The most common first line therapy initiated within a year (± 365 days) of diagnosis were Acetylcholinesterase inhibitors, namely rivastigmine in IPCI, donepezil in HSD and the THIN and the N-methyl-D-aspartate blocker memantine in AUH.

**Conclusion:** We provide a real-world insight into the heterogeneous management and treatment pathways of newly diagnosed dementia patients and a subset of Alzheimer's Disease patients from across Europe.

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## Title: A description of the components of a specialist younger-onset dementia service: a potential model for a dementia-specific service for younger people.

**Citation:** Australasian psychiatry : bulletin of Royal Australian and New Zealand College of Psychiatrists; Feb 2021 ; p. 1039856221992643

**Author(s):** Loi, Samantha M; Walterfang, Mark; Kelso, Wendy; Bevilacqua, JoAnne; Mocellin, Ramon; Velakoulis, Dennis

**Objectives:** This narrative paper describes the influences behind the development of, and key components of a specialist younger-onset dementia service located in metropolitan Victoria, Australia.

**Conclusion:** The Melbourne Young-Onset Dementia Service was established in 2013 and provides diagnosis and ongoing care for people with younger-onset dementia and their families, through collaboration with other medical units, allied health and community services. It is potentially a model for other younger-onset dementia services nationally and internationally.

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## Title: A UK survey of COVID-19 related social support closures and their effects on older people, people with dementia, and carers.

**Citation:** International journal of geriatric psychiatry; Mar 2021; vol. 36 (no. 3); p. 393-402

**Author(s):** Giebel, Clarissa; Lord, Kathryn; Cooper, Claudia; Shenton, Justine; Cannon, Jacqueline; Pulford, Daniel; Shaw, Lisa; Gaughan, Anna; Tetlow, Hilary; Butchard, Sarah; Limbert, Stan; Callaghan, Steve; Whittington, Rosie; Rogers, Carol; Komuravelli, Aravind; Rajagopal, Manoj; Eley, Ruth; Watkins, Caroline; Downs, Murna; Reilly, Siobhan; Ward, Kym; Corcoran, Rhiannon; Bennett, Kate; Gabbay, Mark

**Objectives:** The aim of this national survey was to explore the impact of COVID-19 public health measures on access to social support services and the effects of closures of services on the mental well-being of older people and those affected by dementia.

**Methods:** A UK-wide online and telephone survey was conducted with older adults, people with dementia, and carers between April and May 2020. The survey captured demographic and postcode data, social support service usage before and after COVID-19 public health measures, current quality of life, depression, and anxiety. Multiple linear regression analysis was used to explore the relationship between social support service variations and anxiety and well-being.

**Results:** Five hundred and sixty-nine participants completed the survey (61 people with dementia, 285 unpaid carers, and 223 older adults). Paired samples t-tests and X2 -tests showed that the mean hour of weekly social support service usage and the number of people having accessed various services was significantly reduced post COVID-19. Multiple regression analyses showed that higher variations in social support service hours significantly predicted increased levels of anxiety in people with dementia and older adults, and lower levels of mental well-being in unpaid carers and older adults.

**Conclusions:** Being unable to access social support services due to COVID contributed to worse quality of life and anxiety in those affected by dementia and older adults across the UK. Social support services need to be enabled to continue providing support in adapted formats, especially in light of continued public health restrictions for the foreseeable future.

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## Title: Innovative methods for involving people with dementia and carers in the policymaking process.

**Citation:** Health expectations : an international journal of public participation in health care and health policy; Mar 2021

**Author(s):** Keogh, Fiona; Carney, Patricia; O'Shea, Eamon

**Objective:** There are few examples of public patient involvement in policymaking for groups whose ability to participate may be affected by a disability, particularly for people with dementia and their family carers. Principles of engagement and inclusion in democratic processes are as important for these groups as other citizens. We used two innovative methods to increase involvement of people with dementia and family carers in the policymaking process in Ireland, specifically in relation to impending legislation on home care.

**Method:** A Policy Café was co-produced with people with dementia using a World Café methodology. A Carer's Assembly was co-produced with caregivers of people with dementia using a citizen's assembly model.

**Results:** Ten people with dementia discussed policy developments they wanted to see implemented in relation to diagnosis and home care. Twenty-eight dementia caregivers prioritized four topics: home care; respite services; psychosocial supports; and financial supports. Film and illustrations were used to create accessible messages for policy-makers to inform their decision making.

**Discussion:** Involving people with dementia and carers in policy development requires time and creativity to facilitate and maximize their involvement. Co-production is essential to ensure the priorities of participants are identified, expressed and communicated effectively.

A cumulative sequence of events and messages can generate significant engagement with policy-makers. Policy-makers need to hear the direct and authentic voice of people with dementia and carers when faced with important policy decisions.

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**Title: The mortality burden in patients with hip fractures and dementia.**

**Citation:** European journal of trauma and emergency surgery : official publication of the European Trauma Society; Feb 2021

**Author(s):** Ioannidis, Ioannis; Mohammad Ismail, Ahmad; Forssten, Maximilian Peter; Ahl, Rebecka; Cao, Yang; Borg, Tomas; Mohseni, Shahin

**Objective:** Dementia is strongly associated with postoperative death in patients subjected to hip fracture surgery. Nevertheless, there is a distinct lack of research investigating the cause of postoperative mortality in patients with dementia. This study aims to investigate the distribution and the risk of cause-specific postoperative mortality in patients with dementia compared to the general hip fracture population.

**Methods:** All adults who underwent emergency hip fracture surgery in Sweden between 1/1/2008 and 31/12/2017 were considered for inclusion. Pathological, conservatively managed fractures, and reoperations were excluded. The database was retrieved by cross-referencing the Swedish National Quality Registry for Hip Fracture patients with the Swedish National Board of Health and Welfare quality registers. A Poisson regression model was used to determine the association between dementia and all-cause as well as cause-specific 30-day postoperative mortality.

**Results:** 134,915 cases met the inclusion criteria, of which 20% had dementia at the time of surgery. The adjusted risk of all-cause 30-day postoperative mortality was 67% higher in patients with dementia after hip fracture surgery compared to patients without dementia [adj. IRR (95% CI): 1.67 (1.60-1.75), $p < 0.001$]. The risk of cause-specific mortality was also higher in patients with dementia, with up to a sevenfold increase in the risk cerebrovascular mortality [adj. IRR (95% CI): 7.43 (4.99-11.07), $p < 0.001$].

**Conclusion:** Hip fracture patients with dementia have a higher risk of death in the first 30 days postoperatively, with a substantially higher risk of mortality due to cardiovascular, respiratory, and cerebrovascular events, compared to patients without dementia.

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**Title: Referral criteria to specialist palliative care for patients with dementia: A systematic review.**

**Citation:** Journal of the American Geriatrics Society; Mar 2021

**Author(s):** Mo, Li; Geng, Yimin; Chang, Yuchieh Kathryn; Philip, Jennifer; Collins, Anna; Hui, David

**Background:** Patients with dementia often have significant symptom burden and a progressive course of functional deterioration. Specialist palliative care referral may be helpful, but it is unclear who and when patients should be referred. We conducted a systematic review of the literature to examine referral criteria for palliative care among patients with dementia.

**Methods:** We searched Ovid MEDLINE, Ovid Embase, Ovid PsycInfo, Cochrane Library, PubMed, and CINAHL databases for articles from inception to December 3, 2019, related to specialist palliative care referral for dementia. Two investigators independently reviewed the citations for inclusion, extracted the referral criteria, and categorized them thematically.

**Results:** Of the 1788 citations, 59 articles were included in the final sample. We identified 13 categories of referral criteria, including 6 disease-based and 7 needs-based criteria. The most commonly discussed criterion was "dementia stage" (n = 43, 73%), followed by "new diagnosis of dementia" (n = 17, 29%), "medical complications of dementia" (n = 12, 20%), "prognosis" (n = 11, 19%), and "physical symptoms" (n = 11, 19%). Under dementia stage, 37/44 (84%) articles recommended a palliative care referral for advanced dementia. Pneumonia (n = 6, 10%), fall/fracture (n = 4, 7%), and decubitus ulcers (n = 4, 7%) were most commonly discussed complications to trigger a referral. Under prognosis, the time frame for referral varied from <2 years of life expectancy to <6 months. 3 (5%) of articles recommended "surprise question" as a potential trigger.

**Conclusions:** This systematic review highlighted the lack of consensus regarding referral criteria for palliative care in patients with dementia and the need to identify timely triggers to standardize referral.

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## Title: The effectiveness of interventions to improve pain assessment and management in people living with dementia: A systematic review and meta-analyses.

**Citation:** Journal of advanced nursing; Mar 2021; vol. 77 (no. 3); p. 1127-1140

**Author(s):** Tsai, Yvette I-Pei; Browne, Graeme; Inder, Kerry Jill

**Objectives:** To synthesize and evaluate the effectiveness of interventions for nurses to improve the assessment and management of pain in people living with dementia.

**Design:** Systematic review and meta-analyses of randomized controlled trials.

**Data sources:** CINAHL, Joanna Briggs Institute (JBI) EBP, Cochrane Library, PubMed, and Scopus databases were searched for all journal articles published between 2009 -2019.

**Review methods:** Papers were included under population intervention comparator outcome (PICO) framework for: (a) people living with dementia aged 65 years and over; (b) interventions developed for nurses or other health professionals; (c) comparison group of standard care or control; and (d) outcome that measures the intervention effects on nurses and people living with dementia. Independent reviewers undertook critical appraisal, data abstraction, and synthesis. Meta-analyses were performed to determine the effectiveness of interventions.

**Results:** Of 2099 titles and abstracts screened, six interventions with low-to-moderate risk of bias met inclusion criteria. Studies that implemented a routine pain assessment tool showed no effect on nurses' analgesic management. Studies that developed a comprehensive pain model involving multidisciplinary health professionals showed overall effects on pain assessment and management in dementia care. Physician involvement had an impact on analgesic management.

**Conclusion:** Comprehensive pain models improve nurses' pain assessment and management. A lack of balance between analgesia use and non-pharmacological pain management in dementia care is evident. Multidisciplinary health professionals' involvement is essential for effective intervention design for pain management in dementia.

**Impact:** Various pain assessment tools have been considered to assist identification and management of pain in people living with dementia. Nevertheless, challenges exist when caring for people living with dementia in pain. These findings support the development of a comprehensive pain model, which may be a more effective strategy than routine use of a pain tool alone for nurses to improve pain management in dementia care.

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**Title: Treatment of Seizures in Older Patients with Dementia.**

**Citation:** Drugs & aging; Mar 2021; vol. 38 (no. 3); p. 181-192

**Author(s):** Cretin, Benjamin

**Abstract:** The numbers of patients with dementia and patients with epilepsy are increasing in the global population. In fact, these two conditions are related, and it is estimated that at least 5-10% of seizures or epilepsy in older individuals (aged > 60 years) are caused by a neurodegenerative dementia. In the vast majority, one of the four following diseases is involved: Alzheimer's disease, Lewy body dementia, frontotemporal dementia, or vascular dementia. These diseases cause, not only seizures or epilepsy in affected patients, but cognitive, behavioral, and motor disorders as well. As a result, the challenges of treating seizures in older patients with neurodegenerative disease go beyond the usual limitations associated with this age group (i.e., lower fluid compartment, lower protein binding, increased risk of drug-drug interactions) by imposing other issues and pitfalls. In this setting, the drug-related potential aggravation of neurodegenerative symptoms must be taken into account. As cognition is particularly vulnerable, the prescription of antiseizure medications in dementia must consider the potential neurocognitive impact and limit it as much as possible. Consequently, the choice of a treatment for seizures in this age group is even more demanding than in younger patients, and therefore more restricted. Based on current but limited evidence, it appears that second-generation antiseizure medications are more likely to be appropriate for the management of older patients with epilepsy with neurodegenerative disease given their more favorable pharmacokinetic profiles. Nevertheless, even newer antiseizure medications are not devoid of any risks, which can however be anticipated and corrected.

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**Title: Cornell's Depression for Dementia Scale: A psychometric study among Norwegian nursing home residents.**

**Citation:** Archives of gerontology and geriatrics; 2021; vol. 93 ; p. 104325

**Author(s):** Stensvik, Geir-Tore; Helvik, Anne-Sofie; Nakrem, Sigrid; Haugan, Gørill

**Background:** Depression is common among residents in long term-care facilities. Therefore, access to a valid and reliable measure of depressive symptoms among nursing home (NH) residents is highly warranted.

**Aim:** The aim of this study was to test the psychometrical properties of the Norwegian version of the Cornell Scale for Depression in Dementia (CSDD).

**Method:** SA sample of 309 NH residents were assessed for depressive symptoms using the CSDD in 2015-2016. Data on CSDD were missing for 64 residents, giving an effective sample of 245 (79.3%). Principal component and confirmatory factor analysis were used.

**Results:** A five-dimensional solution yielded the best fit with the data ($\chi 2=174.927$, df=94, $\chi 2/df=1.86$, p=0.0001, RMSEA=0.058, p-value for test of close fit=0.152, CFI=0.94, TLI=0.92 and SRMR=0.056). As expected, higher depressive symptoms correlated positively with higher scores on the Minimum Data Set Depression Rating Scale (MDSDRS) and correlated negatively with Quality of life assessed with the Quality of Life in Late Stage-Dementia Scale.

**Limitations:** The excluded residents (n=64, 20.7%) had lower cognitive function, which may limit the generalizability of the study results.

**Conclusion:** This study suggests a five-dimensional solution of the CSDD scale. Sixteen of the 19 original items showed highly significant loadings, explaining a notable amount of the variation in the CSDD-construct. Further development and testing of a well-adapted scale assessing depression in the nursing home population with and without dementia is required.

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**Title: Use of participatory action research approach to develop a self-management resource for persons living with dementia.**

**Citation:** Dementia (London, England); Feb 2021 ; p. 1471301221997281

**Author(s):** Dupuis, Sherry; McAiney, Carrie; Loiselle, Lisa; Hounam, Brenda; Mann, Jim; Wiersma, Elaine C

**Abstract:** This article describes the use of a participatory action research (PAR) approach to developing a self-management resource for persons living with dementia and care partners. Despite growing evidence that persons with dementia are able to contribute in meaningful ways to decision-making about their care and life preferences, few opportunities exist for them to participate in the design of resources and services meant for them. There is also a need to support the self-management of persons living with dementia with the provision of accurate, high quality, user-friendly information. The Living Well with Dementia resource was developed through a partnership with persons with dementia, family members, Alzheimer Society representatives, primary care providers, and researchers. The methods used in the development of this resource are outlined in six steps employed in this process, from establishment of a PAR team to final resource creation. Informed by a whole systems approach, the resource brings together essential components of self-management into a comprehensive system of care and support for living. It empowers users to be active participants in the application of new knowledge to their lives. Better self-management has important implications for access to health care and quality of life for persons with dementia and care partners.

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**Title: 'Living Together With Dementia': preliminary results of a training programme for family caregivers.**

**Citation:** Scandinavian journal of caring sciences; Mar 2021; vol. 35 (no. 1); p. 86-95

**Author(s):** Sousa, Lia; Sequeira, Carlos; Ferré-Grau, Carme; Graça, Luís

**Abstract:** The aim of this article was to present the preliminary results of a training programme for family caregivers of people with dementia at an early to moderate stage living at home - 'Living Together With Dementia'. In this randomised controlled trial, 27 family

caregivers who met the inclusion criteria were recruited from the neurology outpatient consultation clinic of a hospital in the north of Portugal and randomised into two groups (control and experimental) between October 2015 and March 2016. The programme 'Living Together With Dementia' was applied to the participants of the experimental group. The strategies used, overload, difficulties and satisfaction of the caregivers were assessed at three different stages (at the beginning and end of the intervention, as well as at follow-up). For the data analysis, quantitative parametric measures were applied. The Health Ethical Commission of the Hospital Centre approved the study, and its protocol and Helsinki Declaration ethical principles were considered throughout the process. In the final assessment, an improvement in the overload and difficulties was confirmed, as was an increase in the caregivers' satisfaction level and an improvement in coping/problem-solving strategies. In the follow-up stage, the results tended to revert towards those of the initial assessment. The programme 'Living Together With Dementia' appeared to be a major contribution enabling family caregivers of people with dementia, although there is a need to develop an efficacy study using a more substantial sample. The programme contributed to a reduction in the overload and difficulties borne by the family caregivers of people with dementia at an early to moderate stage living at home and to increased caregiver satisfaction.

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**Title: Opening Minds through Art: A preliminary study evaluating the effects of a creative-expression program on persons living with dementia and their primary care partners.**

**Citation:** Scandinavian journal of caring sciences; Mar 2021; vol. 35 (no. 1); p. 86-95

**Author(s):** Levenberg, Kate; George, Daniel R; Lokon, Elizabeth

**Abstract:** For people living with dementia and their care partners, a decline in the ability to effectively communicate can cause significant distress. However, in recent decades, the arts have emerged as an effective care modality in fostering communication and expression for those with declining verbal skills and memory loss. Opening Minds through Art (OMA) is a national initiative that empowers people living with dementia by facilitating creative expression and social engagement through art-making in partnership with trained college student volunteers. Research has demonstrated that participation in the program benefits quality of life for those living with dementia and also improves student attitudes toward dementia. To date, however, no research has involved primary care partners. We implemented an OMA program at three residential care homes in State College, Pennsylvania, with residents cocreating artwork alongside primary care partners (i.e., a family member or primary medical personnel) over the course of four art-making sessions. We evaluated the effects of participation on quality of life and care partner burnout through pre-post use of "emotional thermometers" (measuring levels of distress, anxiety, depression, anger, and perceived quality of life), the National Institute of Health NIH emotional support scale, and the NIH caregiver assessment (care partner burnout). For people living with dementia, participation significantly increased perceived quality of life while decreasing distress, anxiety, depression, and anger ($p < .01$; $n = 12$) after each class; however, the intervention did not significantly impact perceived emotional support. For care partners, participation significantly lowered post-intervention measures of burnout and self-rated stress ($p < .01$; $n = 9$). This preliminary study suggests that a structured art-based activity appears to positively impact acute mood for patients and, importantly, decrease care partner burnout. Future research can bring more robust methods to bear in determining how to use

OMA and other arts interventions to optimize social support for people living with dementia and their care partners.

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## Title: The impact of lockdown during SARS-CoV-2 outbreak on behavioral and psychological symptoms of dementia.

**Citation:** Neurological sciences : official journal of the Italian Neurological Society and of the Italian Society of Clinical Neurophysiology; Mar 2021; vol. 42 (no. 3); p. 825-833

**Author(s):** Manini, Arianna; Brambilla, Michela; Maggiore, Laura; Pomati, Simone; Pantoni, Leonardo

**Objective:** During Covid-19 pandemic, the Italian government adopted restrictive limitations and declared a national lockdown on March 9, which lasted until May 4 and produced dramatic consequences on people's lives. The aim of our study was to assess the impact of prolonged lockdown on behavioral and psychological symptoms of dementia (BPSD).

**Methods:** Between April 30 and June 8, 2020, we interviewed with a telephone-based questionnaire the caregivers of the community-dwelling patients with dementia who had their follow-up visit scheduled from March 9 to May 15 and canceled due to lockdown. Among the information collected, patients' BPSDs were assessed by the Neuropsychiatric Inventory (NPI). Non-parametric tests to compare differences between NPI scores over time and logistic regression models to explore the impact of different factors on BPSD worsening were performed.

**Results:** A total of 109 visits were canceled and 94/109 caregivers completed the interview. Apathy, irritability, agitation and aggression, and depression were the most common neuropsychiatric symptoms experienced by patients both at baseline and during Covid-19 pandemic. Changes in total NPI and caregiver distress scores between baseline and during lockdown, although statistically significant, were overall modest. The logistic regression model failed to determine predictors of BPSD worsening during lockdown.

**Conclusion:** This is one of the first studies to investigate the presence of BPSD during SARS-CoV-2 outbreak and related nationwide lockdown, showing only slight, likely not clinically relevant, differences in BPSD burden, concerning mostly agitation and aggression, anxiety, apathy and indifference, and irritability.

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## Title: Advance care planning participation by people with dementia: a cross-sectional survey and medical record audit.

**Citation:** BMJ supportive & palliative care; Mar 2021

**Author(s):** Bryant, Jamie; Sellars, Marcus; Waller, Amy; Detering, Karen; Sinclair, Craig; Ruseckaite, Rasa; White, Ben; Nolte, Linda

**Objectives:** To describe among individuals with dementia: (1) self-reported awareness of, and engagement in, advance care planning; (2) presence of advance care planning documentation in the health record and (3) concordance between self-reported completion of advance care planning and presence of documentation in the health record.

**Methods:** An Australian prospective multicentre audit and cross-sectional survey. Individuals diagnosed with dementia who were able to speak English and were judged by a healthcare provider as having decision-making capacity were recruited from self-selected hospitals, residential aged care facilities and general practices across Australia.

**Results:** Fifty-two people with dementia completed surveys and were included. Overall, 59.6% of participants had heard about advance care planning and 55.8% had discussed advance care planning with someone, most often a family member (48.1%). While 38.5% of participants had appointed a medical substitute decision maker, only 26.9% reported that they had written down their values and preferences for future care. Concordance between self-reported completion of advance care planning and presence of documentation in the health record was low (56.8%, κ=0.139; 57.7%, κ=0.053).

**Conclusion:** Effective models that promote discussion, documentation and accessible storage of advance care planning documents for people with dementia are needed.

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**Title: Co-design of an mHealth application for family caregivers of people with dementia to address functional disability care needs.**

**Citation:** Informatics for health & social care; Mar 2021; vol. 46 (no. 1); p. 1-17

**Author(s):** Rathnayake, Sarath; Moyle, Wendy; Jones, Cindy; Calleja, Pauline

**Abstract:** The co-design of a mobile health (mHealth) application for family caregivers of people with dementia to address functional disability care needs is presented. Participants included family caregivers of people with dementia, aged care nurses, physicians, occupational therapists, and information technology (IT) experts. The co-design process involved two phases: (1) needs assessment phase (an online survey and in-depth interviews with family caregivers and expert consultation); and (2) development of an mHealth application (content and prototype development). Data triangulation from phase one informed the content of the application. Data triangulation resulted in three content modules: "an overview of dementia and care," "management of daily living activities," and "caregivers' health and well-being." The content was based on contemporary literature, and care guidelines with input from family caregivers and dementia care experts. IT engineers developed the mHealth application. In this study, an Android-based mHealth application was designed to address the functional care needs of family caregivers and the co-design process ensured the incorporation of end-users' real-world experiences and the opinions and expertise of key stakeholders in the development of the application prototype.It is to be noted that before releasing the application into the app store, testing its feasibility and effectiveness is essential.

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**Title: Development of an assessment scale for engagement in activities for patients with moderate to severe dementia.**

**Citation:** Psychogeriatrics : the official journal of the Japanese Psychogeriatric Society; Mar 2021

**Author(s):** Tanaka, Hiroyuki; Umeda, Ren; Shoumura, Yuko; Kurogi, Tatsunari; Nagata, Yuma; Ishimaru, Daiki; Yoshimitsu, Koji; Tabira, Takayuki; Ishii, Ryouhei; Nishikawa, Takashi

**Background:** Various types of therapy, including occupational therapy, are utilised for the treatment of moderate to severe dementia. In order to determine the optimal rehabilitation strategy for such patients and examine the treatment efficacy, an assessment scale for engagement in various group activities that can be easily applied in clinical situations is required. We herein report the development of the Assessment Scale for Engagement in Activities (ASEA) and its clinical utility.

**Methods:** The ASEA was developed by nine occupational therapists and a psychiatrist with experience in developing measures for dementia, in accordance with the COSMIN (COnsensus-based Standards for the selection of health status Measurement INstruments) checklist. This assessment comprises 10 items covering four domains: Engagement in the Activity, Interaction, Arousal, and Affect. Participants with moderate to severe dementia who resided in a psychiatric acute phase hospital in Japan were assessed in terms of engagement in activities using the ASEA and Todai-shiki Observational Rating Scale (TORS), and in terms of cognitive function using the Mini-Mental State Examination (MMSE). We examined the internal consistency, inter- and intra-rater reliability, content validity, and concurrent validity of the ASEA.

**Results:** Cronbach's alpha of the ASEA was 0.889. The overall inter-rater reliability was 0.937 (Spearman rank correlation, $P < 0.001$), and the intraclass correlation (ICC) for each item was 0.490-0.965 ($P < 0.018$-0.001). The overall test-retest reliability was 0.778 (Spearman's rank correlation, $P < 0.001$), and the ICC for each item was 0.498-0.863 ($P < 0.023$-0.001). The test-retest correlations were significant for almost all items, aside from 'Interaction with others' ($P = 0.051$). The concurrent validity, examined using the TORS and MMSE, was 0.920 and 0.304 (Spearman's rank correlation, $P < 0.001$-0.006).

**Conclusions:** The ASEA has confirmed reliability and validity, aside from 'Interaction with others' regarding test-retest reliability. Generally, this assessment tool has clinical utility and allows the evaluation of activity engagement among patients with moderate to severe dementia.

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**Title: Rehabilitation of persons with dementia: using technology to improve participation.**

**Citation:** Aging & mental health; Mar 2021; vol. 25 (no. 3); p. 543-550

**Author(s):** Zarit, Steven H; Chiusano, Carrie; Harrison, Aime S; Sewell, Lynne; Krause, Christopher; Liu, Yin

**Objectives:** The current study examined how a technology system, "It's Never 2 Late" (iN2L), may help augment traditional rehabilitation strategies for older adults with dementia by improving engagement in therapy sessions and achieving better functional outcomes.

**Methods:** The study used a two group quasi-experimental design. Older adults with dementia ($N = 96$) were recruited from two rehabilitation departments housed within residential care communities. Participants received daily occupational and physical therapy sessions using treatment as usual (TAU) at one site ($n = 49$) or treatment with iN2L ($n = 47$) at the other site. A goal attainment approach was used to assess functional outcomes. It was hypothesized that patients whose therapists used iN2L in treatment will show greater attainment of therapy goals and greater engagement during OT and PT sessions than patients receiving TAU. It was also hypothesized that levels and improvement in engagement will mediate the association of treatment type (iN2L or TAU) with greater goal attainment.

**Results:** Participants in the iN2L treatment had significantly higher goal attainment than TAU, significantly higher levels of engagement at baseline, and significantly steeper increases in engagement over the course of therapy. The effects of treatment on goal attainment was significantly mediated by increases in engagement.

**Conclusion:** Findings suggest that iN2L technology has the potential to increase treatment engagement and enhance rehabilitation outcomes among older adults with dementia.

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**Title: Staff's perspectives on the organization of homecare services to people with dementia-A qualitative study.**

**Citation:** Nursing open; Feb 2021

**Author(s):** Hoel, Kari-Anne; Rokstad, Anne Marie Mork; Feiring, Ingvild Hjorth; Lichtwarck, Bjørn; Selbaek, Geir; Bergh, Sverre

**Objectives:** The aim of the study was to explore the experiences of homecare staff about the impact of the organization of homecare services for people with dementia.

**Design:** This study has a qualitative, exploratory design based on a phenomenological-hermeneutic approach, using individual in-depth interviews with homecare staff to collect data.

**Methods:** A convenience sample of 14 homecare staff from five municipalities participated in the study. Main topics introduced: (a) how homecare services for people with dementia are organized and (b) challenges in respondents' everyday practice of caring for people with dementia. Interviews were conducted from October to December 2017.

**Results:** Three main themes were identified from the interviews. (a) Complexity and need for individualized facilitated homecare services; homecare services were described as complex in regard to both the patient and the service. The complexity of the service made it challenging to tailor the service to the individual patient. (b) The importance of trust and relationships; establishing trust in the relationship between the patient and the staff resulted in better-quality care. This was crucial for identifying the patient's need for help. (c) Organizational challenges; homecare services could be vulnerable to changes in the organization. Practical tasks and following the daily scheduled task list were often prioritized at the expense of an individually tailored service.

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**Title: Predicting Short-Term Risk of Falls in a High-Risk Group with Dementia.**

**Citation:** Journal of the American Medical Directors Association; Mar 2021; vol. 22 (no. 3); p. 689

**Author(s):** Mehdizadeh, Sina; Sabo, Andrea; Ng, Kimberley-Dale; Mansfield, Avril; Flint, Alastair J; Taati, Babak; Iaboni, Andrea

**Objectives:** To develop a prognostic model to predict the probability of a short-term fall (within the next 7 to 30 days) in older adults with dementia.

**Design:** Prospective observational study.

**Setting and participants:** Fifty-one individuals with dementia at high risk of falls from a specialized dementia inpatient unit.

**Methods:** Clinical and demographic measures were collected and a vision-based markerless motion capture was used to record the natural gait of participants over a 2-week baseline. Falls were tracked throughout the length of stay. Cox proportional hazard regression analysis was used to build a prognostic model to determine fall-free survival probabilities at 7 days and at 30 days. The model's discriminative ability was also internally validated.

**Results:** Fall history and gait stability (estimated margin of stability) were statistically significant predictors of time to fall and included in the final prognostic model. The model's predicted survival probabilities were close to observed values at both 7 and 30 days. The area under the receiver operating curve was 0.80 at 7 days, and 0.67 at 30 days and the model had a discrimination performance (the Harrel concordance index) of 0.71.

**Conclusions and implications:** Our short-term falls risk model had fair to good predictive and discrimination ability. Gait stability and recent fall history predicted an imminent fall in our population. This provides some preliminary evidence that the degree of gait instability may be measureable in natural everyday gait to allow dynamic falls risk monitoring. External validation of the model using a separate data set is needed to evaluate model's predictive performance.

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## Title: Meaningful Engagement Among Assisted Living Residents With Dementia: Successful Approaches.

**Citation:** Journal of applied gerontology : the official journal of the Southern Gerontological Society; Mar 2021 ; p. 733464821996866

**Author(s):** Kemp, Candace L; Bender, Alexis A; Ciofi, Joy; Craft Morgan, Jennifer; Burgess, Elisabeth O; Duong, Stephen; Epps, Fayron R; Hill, Andrea Michelle; Manley, Pamela R; Sease, Jasmine; Perkins, Molly M

**Abstract:** Meaningful engagement is an important dimension of quality of life and care for persons living with dementia, including the growing number who reside in assisted living communities. This report presents preliminary findings from an ongoing qualitative study aimed at identifying best care practices to create and maintain meaningful engagement among persons with dementia. Over a 1-year period, we conducted interviews, residents' record review, and participant observations in four diverse care communities. Our analysis identified four approaches that successfully promote meaningful engagement: (a) knowing the person, (b) connecting with and meeting people where they are, (c) being in the moment, and (d) viewing all encounters as opportunity. Incorporation of these approaches in care routines and adoption by all care partners can promote meaningful engagement, including during crises such as COVID-19.

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## Title: Services for people with young onset dementia: The 'Angela' project national UK survey of service use and satisfaction.

**Citation:** International journal of geriatric psychiatry; Mar 2021; vol. 36 (no. 3); p. 411-422

**Author(s):** Stamou, Vasileios; La Fontaine, Jenny; Gage, Heather; Jones, Bridget; Williams, Peter; O'Malley, Mary; Parkes, Jacqueline; Carter, Janet; Oyebode, Jan

**Objectives:** Young onset dementia is associated with distinctive support needs but existing research on service provision has been largely small scale and qualitative. Our objective was to explore service use, cost and satisfaction across the UK.

**Methods**: Information about socio-demographic characteristics, service use and satisfaction were gathered from people with young onset dementia (YOD) and/or a family member/supporter via a national survey.

**Results:** Two hundred and thirty-three responses were analysed. Diagnosis was most commonly received through a Memory Clinic or Neurology. The type of service delivering diagnosis impacted on post-diagnostic care. Those diagnosed in specialist YOD services were more likely to receive support within the first 6 weeks and receive ongoing care in the service where they were diagnosed. Ongoing care management arrangements varied but generally care was lacking. Around 42% reported no follow-up during 6-weeks after diagnosis; over a third reported seeing no health professional within the previous 3 months; just over a third had a key worker and just under a third had a care plan. Satisfaction and quality of care were highest in specialist services. Almost 60% of family members spent over 5 h per day caring; median costs of health and social care, 3 months, 2018, were £394 (interquartile range £389 to 640).

**Conclusion:** Variation across diagnostic and post-diagnostic care pathways for YOD leads to disparate experiences, with specialist young onset services being associated with better continuity, quality and satisfaction. More specialist services are needed so all with YOD can access age-appropriate care.

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**Title: Our Dementia Choir hits the right notes.**

**Citation:** Lancet Neurology; Mar 2021; vol. 20 (no. 3); p. 175-175

**Author(s):** Ranscombe, Peter

## Sources Used:

The following databases are used in the creation of this bulletin: Amed, British Nursing Index, Cinahl & Medline.

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