

Dementia Current Awareness Bulletin

September 2017

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Family caregivers' conceptualisation of quality end-of-life care for people with dementia: A qualitative study.

Citation: Palliative Medicine; Sep 2017; vol. 31 (no. 8); p. 726-733

Author(s): Davies, Nathan; Rait, Greta; Maio, Laura; Iliffe, Steve

Background: People with dementia have been described as the 'disadvantaged dying' with poor end-of-life care. Towards the end of life, people with dementia cannot report on the care they receive. It is therefore important to talk to caregivers; however, few have explored the views about end-of-life care from the caregivers' perspective. The majority of research on family caregivers has focussed on the burden and psychological impact of caring for a relative with dementia

Aim: This study aimed to explore the views of family caregivers about quality end-of-life care for people with dementia

Design: Qualitative study using in-depth interviews and analysed using thematic analysis.

Setting/participants: Purposive sampling from a third sector organisation's caregiver network was used to recruit 47 caregivers in England (2012-2013), consisting of (1) family caregivers of someone who had recently received a diagnosis of dementia, (2) family caregivers currently caring for someone with dementia and (3) bereaved family caregivers

Results: Three over-arching themes were derived from the interviewees' discourse, including maintaining the person within, fostering respect and dignity and showing compassion and kindness

Conclusion: End-of-life care for people with dementia does not differ from care throughout the dementia trajectory. Throughout the findings, there is an implicit underlying theme of conflict: conflict between family caregivers and an increasingly systematised service of care and conflict between family caregivers and professionals. This study has in particular demonstrated the importance of the psycho-social aspects of care, aligning with the holistic definition of palliative care.

Joining forces to prevent dementia: The International Research Network On Dementia Prevention (IRNDP).

Citation: International psychogeriatrics; Sep 2017 ; p. 1-4

Author(s): Anstey, Kaarin J; Peters, Ruth; Clare, Linda; Lautenschlager, Nicola T; Dodge, Hiroko H; Barnes, Deborah E; Shahar, Suzana; Brodaty, Henry; Rees, Glenn

Abstract: Dementia is a neurodegenerative disorder with global impact, with the largest proportion of cases occurring in low- and middle-income countries. It is estimated that there are 46.8 million cases globally with approximately 10 million new cases each year or a new case occurring every 3 sec (Prince et al., 2015). For comparison there are 36.7 million HIV cases with an estimated 2 million new cases each year (WHO, 2017). The rise in dementia prevalence is largely due to population ageing, with the oldest being at highest risk. To date there are no diseases modifying medications for Alzheimer's disease or the other causes of dementia. Academics and research groups are increasingly focused on prevention or delay of dementia (Brayne and Miller, 2017) and a number of organizations now prioritize dementia, indicating a strong and coherent international effort to address this problem. Examples include the World Health Organisation (WHO), which has established a Global Dementia Observatory; the World Dementia Council; the Organisation for Economic Co-operation and Development (OECD); the U.S. National Alzheimer's Project Act (NAPA); and the Global Council on Brain Health.

Patient Variables Associated with the Assignment of a Formal Dementia Diagnosis to Positively Screened Primary Care Patients.

Citation: Current Alzheimer research; Sep 2017

Author(s): Eichler, Tilly; Thyrian, Jochen René; Hertel, Johannes; Richter, Steffen; Michalowsky, Bernhard; Wucherer, Diana; Dreier, Adina; Kilimann, Ingo; Teipel, Stefan; Hoffmann, Wolfgang

Background: Main objective was to analyze the associations of patient variables (depression, quality of life, anti-dementia drug treatment, knowledge about dementia) with the assignment of a formal diagnosis of dementia to community-dwelling primary care patients who have screened positive for dementia.

Methods: DelpHi-MV (Dementia: life- and person-centered help in Mecklenburg-Western Pomerania) is a general practitioner based randomized controlled intervention trial. Present analyses are based on cross-sectional data of 319 positively screened patients (age 70+, living at home) who had not been formally diagnosed with dementia before the screening. The medical diagnoses (ICD-10) were retrieved from the patient's medical records. Depression (Geriatric Depression Scale; GDS), quality of life in Alzheimer's disease (QoL-AD), knowledge about dementia, and anti-dementia drug treatment were assessed after the screening test at the baseline examination.

Results: At the baseline examination, 171 out of 319 patients (54%) had been formally diagnosed with dementia after they have screened positive. Univariate comparisons showed no statistically significant differences between diagnosed and undiagnosed patients regarding depression (GDS \geq 6: 11% vs. 15%; $p=0.396$), quality of life (mean (SD): 2.8 (0.3) vs. 2.8 (0.4); $p=0.833$), and the knowledge about dementia (75% vs. 75%; $p>0.999$). Patients who had received a formal diagnosis were more often treated with anti-dementia drugs (20% vs. 11%; $p=0.040$). Multivariate analyses controlled for confounding variables confirmed these findings.

Conclusion: Present findings do not support concerns that the assignment of a formal dementia diagnosis after screening is associated with potential harms. If confirmed in a prospective study, our data would suggest that patients may benefit from being formally diagnosed regarding anti-dementia drug treatment.

Affective and emotional dysregulation as pre-dementia risk markers: exploring the mild behavioral impairment symptoms of depression, anxiety, irritability, and euphoria.

Citation: International psychogeriatrics; Sep 2017 ; p. 1-12

Author(s): Ismail, Zahinoor; Gatchel, Jennifer; Bateman, Daniel R; Barcelos-Ferreira, Ricardo; Chantillon, Marc; Jaeger, Judith; Donovan, Nancy J; Mortby, Moyra E

Background: Affective and emotional symptoms such as depression, anxiety, euphoria, and irritability are common neuropsychiatric symptoms (NPS) in pre-dementia and cognitively normal older adults. They comprise a domain of Mild Behavioral Impairment (MBI), which describes their emergence in later life as an at-risk state for cognitive decline and dementia, and as a potential manifestation of prodromal dementia. This selective scoping review explores the epidemiology and neurobiological links between affective and emotional symptoms, and incident cognitive decline, focusing on recent literature in this expanding field of research.

Methods: Existing literature in prodromal and dementia states was reviewed, focusing on epidemiology, and neurobiology. Search terms included: "mild cognitive impairment," "dementia," "prodromal dementia," "preclinical dementia," "Alzheimer's," "depression," "dysphoria," "mania," "euphoria," "bipolar disorder," and "irritability."

Results: Affective and emotional dysregulation are common in preclinical and prodromal dementia syndromes, often being harbingers of neurodegenerative change and progressive cognitive decline. Nosological constraints in distinguishing between pre-existing psychiatric symptomatology and later life

acquired NPS limit historical data utility, but emerging research emphasizes the importance of addressing time frames between symptom onset and cognitive decline, and age of symptom onset.

Conclusion: Affective symptoms are of prognostic utility, but interventions to prevent dementia syndromes are limited. Trials need to assess interventions targeting known dementia pathology, toward novel pathology, as well as using psychiatric medications. Research focusing explicitly on later life onset symptomatology will improve our understanding of the neurobiology of NPS and neurodegeneration, enrich the study sample, and inform observational and clinical trial design for prevention and treatment strategies.

Consensus statement of the international summit on intellectual disability and Dementia related to post-diagnostic support.

Citation: Aging & mental health; Sep 2017 ; p. 1-10

Author(s): Dodd, Karen; Watchman, Karen; Janicki, Matthew P; Coppus, Antonia; Gaertner, Claudia; Fortea, Juan; Santos, Flavia H; Keller, Seth M; Strydom, Andre

Objectives: Post diagnostic support (PDS) has varied definitions within mainstream dementia services and different health and social care organizations, encompassing a range of supports that are offered to adults once diagnosed with dementia until death.

Method: An international summit on intellectual disability and dementia held in Glasgow, Scotland in 2016 identified how PDS applies to adults with an intellectual disability and dementia. The Summit proposed a model that encompassed seven focal areas: post-diagnostic counseling; psychological and medical surveillance; periodic reviews and adjustments to the dementia care plan; early identification of behaviour and psychological symptoms; reviews of care practices and supports for advanced dementia and end of life; supports to carers/ support staff; and evaluation of quality of life. It also explored current practices in providing PDS in intellectual disability services.

Results: The Summit concluded that although there is limited research evidence for pharmacological or non-pharmacological interventions for people with intellectual disability and dementia, viable resources and guidelines describe practical approaches drawn from clinical practice. Post diagnostic support is essential, and the model components in place for the general population, and proposed here for use within the intellectual disability field, need to be individualized and adapted to the person's needs as dementia progresses.

Conclusions: Recommendations for future research include examining the prevalence and nature of behavioral and psychological symptoms (BPSD) in adults with an intellectual disability who develop dementia, the effectiveness of different non-pharmacological interventions, the interaction between pharmacological and non-pharmacological interventions, and the utility of different models of support.

Identifying palliative care needs in people with dementia.

Citation: Current opinion in supportive and palliative care; Sep 2017

Author(s): Lloyd-Williams, Mari; Mogan, Caroline; Denning, Karen Harrison

Purpose Of Review: Dementia is now recognized as a progressive life-limiting illness where many patients can benefit from access to palliative care.

Recent Findings: The present review has focused on three areas namely, advanced care planning in supporting palliative care for dementia, hospice provision for people with dementia and provision of care within family home. In advanced care planning, there is little research on systematically developed and implemented advance care planning interventions or whether they achieve desired outcomes for end-of-life care. There is limited research on hospice-based care for patients with dementia and most studies are U.S. based. Equally studies exploring how family carers can be supported and facilitated to care at home for the

person with dementia to the end of life are exploratory rather than determining what factors may be important.

Summary: There are relatively few studies, especially quantitative studies or intervention studies being carried out to determine most effective means of providing palliative care for people with dementia, particularly with respect to advanced care planning, the provision of hospice-based care and support at home. Despite increased public awareness of dementia as a terminal illness, more research is required to support patients with dementia and their families at the end of life.

Perceptions and development needs of assistant practitioners supporting individuals with dementia.

Citation: British journal of nursing (Mark Allen Publishing); Sep 2017; vol. 26 (no. 16); p. 918-923

Author(s): Hardie, Debra; Smith, Joanne

Abstract: In the UK there are an estimated 850 000 people living with dementia. The condition costs the NHS £26 billion each year and it is estimated that this amount will treble over the next 30 years. Thus, there is a need for health and social care staff to be increasingly competent in the delivery of care to those living with dementia. The education of staff will improve knowledge and build capability to support and care for individuals with dementia. This research involved 44 assistant practitioners who shared opinions about their preparation for practice in dementia care. Focus groups and questionnaires were used to collect data that were then thematically analysed. The research also considered the assistant practitioner role in relation to workforce development. Key themes were 'training, awareness and knowledge associated with dementia care' and 'the perceptions of the assistant practitioner regarding confidence to support individuals with dementia'. There was role and responsibility protection from staff, for example, doctors and nurses were reluctant to delegate duties to the assistant practitioner. Participants' commentary indicated, however, that they were competent to support service users with dementia, although there were gaps in their experiences. The case study demonstrated the positive achievement of partnership working between a higher education institution and the workplace, which supported the assistant practitioners' learning and development.

The management of sleep disorders in dementia: an update.

Citation: Current opinion in psychiatry; Sep 2017

Author(s): Kinnunen, Kirsi M; Vikhanova, Anastasia; Livingston, Gill

Purpose Of Review: Sleep disorders in dementia cause distress and may lead to families being unable to care for someone with dementia at home. Recent Cochrane reviews found no interventions of proven effectiveness. There was no effect of light therapy and moderate evidence that melatonin was ineffective both given without knowledge of the patient's circadian rhythm. The current article updates this review by considering newer publications on interventions for sleep disorders or abnormalities of the sleep-wake cycle in people with dementia living in the community.

Recent Findings: We searched electronically for new primary research, reviews and meta-analyses and identified 258 articles published between 15/12/2015 and 14/06/2017 on sleep and dementia; 43 of them on nonpharmacological or pharmacological treatments. Fifteen articles reported on the management of sleep disturbances in people with dementia, living at home. Those using pharmacological treatments (melatonin, psychotropic medications, donepezil, memantine) encompassed a meta-analysis, two double-blind RCTs, two uncontrolled trials, two population-based studies, and one case report. The studies of behavioural interventions comprised five uncontrolled trials, one case series, and one qualitative study. We also included three recent reviews on the management of sleep disturbances in Alzheimer's disease; pharmacotherapies for sleep disturbances in dementia, and dementia prevention, intervention and care.

None of these found a treatment that showed definitive effectiveness, although there is preliminary work about nonpharmacological interventions, which can be built on.

Summary: Clinically effective, safe treatment of sleep disturbances in dementia remains an unresolved challenge. Given the importance of sleep and the many consequences of its disruption, well designed controlled trials are needed to determine acceptable and cost-effective treatment strategies that work for sleep disturbances. This is an open access article distributed under the Creative Commons Attribution License 4.0 (CCBY), which permits unrestricted use, distribution, and reproduction in any medium, provided the original work is properly cited. <http://creativecommons.org/licenses/by/4.0>.

Supporting spirituality in the care of older people living with dementia: a hermeneutic phenomenological inquiry into nurses' experiences.

Citation: Scandinavian journal of caring sciences; Sep 2017

Author(s): Toivonen, Kristiina; Charalambous, Andreas; Suhonen, Riitta

Background: Spirituality is defined as a search for answers to existential questions about the meaning of life and the individual's relationship with the sacred or transcendent. This relationship may or may not involve affiliation with a specific religion. Studies on spirituality have focused on palliative care, and there are limited studies into the spirituality in the care of older people with dementia.

Aim: To describe the experiences of nurses supporting spirituality in the care of older people living with dementia.

Method: This study, informed by Heideggerian hermeneutic phenomenology, was conducted in 2014/15. Data were collected by interviewing a purposive sample of 17 nurses.

Results: Supporting the spirituality of older people with dementia was seen as understanding their spirituality within a framework of person-centeredness and individuality. The participants came to understand the spiritual needs of older people with dementia through both verbal and nonverbal expression and by learning about older people's individual spiritual backgrounds. Meeting spiritual needs meant approaching the person with dementia as a valuable human as well as paying attention, to and supporting, his/her personal philosophy of life within nursing care.

Conclusion: Learning and developing an understanding of the spiritual needs of older people with dementia is challenging. The nurses offered person-centred, spiritual care, to people with dementia from a variety of perspectives, which is important in the provision of comprehensive care. There is a need to find usable tools to help nurses to learn and understand the individual spiritual needs of older people with dementia and to explore how these older adults experience having their spirituality supported within their nursing care.

The Clock Drawing Test: A Reasonable Instrument to Assess Probable Dementia in Primary Care?

Citation: Current Alzheimer research; Sep 2017

Author(s): Reiner, Katinka; Eichler, Tilly; Hertel, Johannes; Hoffmann, Wolfgang; Thyrian, Jochen René

Objective: The primary aim of the study was to determine accuracy, sensitivity and specificity of the Clock Drawing Test (CDT) in detecting probable dementia as compared to the multi-domain dementia screening test DemTect.

Methods: The sample was derived from the general practitioner (GP)-based, cluster-randomized controlled intervention trial DelPHi-MV (Dementia: life- and person-centered help in Mecklenburg-Western Pomerania). Selected from 6.440 patients systematically screened for dementia in primary care, we examined three groups (a,b,c) where the CDT (as index test) as well as the DemTect (as reference standard) were available. After excluding cases with missing values, we included a sample of n=462 with "probable dementia", n=586 with "mild cognitive impairment" and n=553 with "no cognitive impairment"

matched for age and gender. We analyzed the accuracy of the CDT in identifying people with probable dementia by the DemTect and report sensitivity, and specificity for the CDT. We further analyzed age and gender differences associated with the groups.

Results: In comparison to the DemTect the CDT identified more than twice as many of the screened patients as cognitively impaired (63.1% in the CDT vs. 28.9% in the DemTect). The sensitivity and specificity for the CDT were 84.4% and 45.6% respectively. We found considerable age and gender differences for the performance of the CDT. Higher age ($p < 0.001$) and female sex ($p < 0.001$) were associated with incorrect clock drawings.

Conclusion: The CDT shows a considerably high rate of false positive screening outcomes compared to the DemTect and disadvantages older people and women. Thus, in contrary to previous findings our results indicate that the CDT should not be used as exclusive instrument to screen for probable dementia in primary care.

Why does Finland have the highest dementia mortality rate? Environmental factors may be generalizable.

Citation: Brain research; Sep 2017; vol. 1671 ; p. 14-17

Author(s): Eiser, Arnold R

Abstract: Finland has the highest death rate from dementia in the world and its environmental features can be instructive in understanding hidden causes of dementia. Environmental factors there include: 1) a climate that is both very cold and humid resulting in housing frequently harboring molds that are capable of producing a neurotoxic mycotoxin 2) the Gulf of Finland as well as Finnish lakes harbor cyanobacteria that produce the neurotoxin, beta-N-methyl amino-L-alanine, known to cause dementia and related disorders 3) the aforementioned toxins can be potentiated by the presence of mercury and methyl mercury which can be found in Finnish waters 4) soil in Finland is naturally low in selenium and selenium deficiency may reduce the quantity and effectiveness of glutathione's ability to protect against neurotoxins. A high rate of fatal dementia could be the consequence of these environmental factors. Studies that can support or disprove this hypothesis are suggested. Such environmental toxins are likely to promote Alzheimer's disease elsewhere in the world where such a combination of neurotoxins may also occur.

Meeting psychosocial needs for persons with dementia in home care services - a qualitative study of different perceptions and practices among health care providers.

Citation: BMC geriatrics; Sep 2017; vol. 17 (no. 1); p. 211

Author(s): Hansen, Anette; Hauge, Solveig; Bergland, Ådel

Background: The majority of persons with dementia are home-dwelling. To enable these persons to stay in their own homes as long as possible, a holistic, individual and flexible care is recommended. Despite a requirement for meeting psychological, social and physical needs, home care services seem to focus on patients' physical needs. Accordingly, the aim of this study was to explore how the psychosocial needs of home-dwelling, older persons with dementia were perceived, emphasized and met by home care services.

Methods: A descriptive, qualitative approach was used. Data were collected through semi-structured focus group interviews with 24 health care providers in home care services from four municipalities. Data were analysed using systematic text condensation.

Results: This study showed major differences in how health care providers perceived the psychosocial needs of older home-dwelling persons with dementia and how they perceived their responsibilities for meeting those psychosocial needs. The differences in the health care providers' perceptions seemed to significantly influence the provided care. Three co-existing logics of care were identified: the physical need-oriented logic, the renouncement logic and the integrated logic.

Conclusions: The differences in how health care providers perceived the psychosocial needs of persons with dementia and their responsibilities for meeting those needs, influenced how the psychosocial needs were met. These differences indicates a need for a clarification of how psychosocial needs should be conceptualized and who should be responsible for meeting these needs. Further, increased competence and increased consciousness of psychosocial needs and how those needs can be met, are essential for delivering high-quality holistic care that enables persons with dementia to live in their own home for as long as possible.

The Edinburgh Feeding Evaluation in Dementia Scale: A Longitudinal Study in Nursing Home Residents.

Citation: Dementia and geriatric cognitive disorders; Sep 2017; vol. 44 (no. 3-4); p. 196-202

Author(s): Watson, Roger; Bagnasco, Annamaria; Catania, Gianluca; Aleo, Giuseppe; Zanini, Milko; Sasso, Loredana

Aims/Background: The Edinburgh Feeding Evaluation in Dementia (EdFED) scale has been shown to have good psychometric properties using a range of methods including Mokken scaling. We aimed to study the Italian version of the EdFED using Mokken scaling.

Methods: Data were gathered at 7 time points from 401 nursing home residents affected by dementia in the course of a 6-month intervention study using analysis of variance, Mokken scaling, and person-item fit statistics.

Results: The properties of the EdFED-I scale were stable over the course of the study with 4 items showing invariant item ordering at all time points. Some items behaved differently at different levels of difficulty in the scale and also depending on the mean level of feeding difficulty. The test information function showed a dip in the mid-range of difficulty scores.

Systematic review investigating multi-disciplinary team approaches to screening and early diagnosis of dementia in primary care - what are the positive and negative effects and who should deliver it?

Citation: Current Alzheimer research; Sep 2017

Author(s): Smith, Toby; Cross, Jane; Poland, Fiona; Brookes, Abbey; Maidment, Ian; Penhale, Bridget; Laidlaw, Ken; Fox, Chris

Background: Primary care services frequently provide the initial contact between people with dementia and health service providers. Early diagnosis and screening programmes have been suggested as a possible strategy to improve the identification of such individuals and treatment and planning health and social care support.

Objective: To determine what early diagnostic and screening programmes have been adopted in primary care practice, to explore who should deliver these and to determine the possible positive and negative effects of an early diagnostic and screening programme for people with dementia in primary care.

Methods: A systematic review of the literature was undertaken using published and unpublished research databases. All papers answering our research objectives were included. A narrative analysis of the literature was undertaken, with the CASP tools used appropriately to assess study quality.

Results: Thirty-three papers were identified of moderate to high quality. The limited therapeutic options for those diagnosed with dementia means that even if such a programme were instigated, the clinical value remains questionable. Furthermore accuracy of the diagnosis remains difficult to assess due to poor evidence and this raises questions regarding whether people could be over- or under-diagnosed. Given the negative social and psychological consequences of such a diagnosis, this could be devastating for individuals.

Conclusions: Early diagnostic and screening programmes have not been widely adopted into primary care. Until there is rigorous evidence assessing the clinical and cost-effectiveness of such programmes, there remains insufficient evidence to support the adoption of these programmes in practice.

Staff awareness of food and fluid care needs for older people with dementia in residential care: a qualitative study.

Citation: Journal of clinical nursing; Sep 2017

Author(s): Lea, Emma J; Goldberg, Lynette R; Price, Andrea D; Tierney, Laura T; McInerney, Fran

Aims And Objectives: To examine awareness of aged care home staff regarding daily food and fluid care needs of older people with dementia.

Background: Older people in residential care frequently are malnourished and many have dementia. Staff knowledge of the food and fluid needs of people with dementia is limited. Qualitative research on this topic is scarce but can provide insight into how nutrition and hydration care may be improved.

Design: Qualitative, interview-based study.

Methods: Eleven staff in a range of positions at one care home were interviewed regarding their perceptions of current and potential food/fluid care practices. Transcripts were coded and analysed thematically.

Results: Key food and fluid issues reported by these staff members were weight loss and malnutrition, chewing and swallowing difficulties (dysphagia), and inadequate hydration. Staff identified a number of current care practices that they felt to be effective in facilitating older people's food and fluid intake including responsiveness to their needs. Staff suggestions to facilitate food and fluid intake centred on improved composition and timing of meals, enhanced physical and social eating environment, and increased hydration opportunities. Staff commented on factors that may prevent changes to care practices, particularly the part-time workforce, and proposed changes to overcome such barriers.

Conclusions: Staff were aware of key food and fluid issues experienced by the older people in their care and of a range of beneficial care practices, but lacked knowledge of many promising care practices and/or how to implement such practices.

Relevance To Clinical Practice: Staff need to be supported to build on their existing knowledge around effective food and fluid care practices. The numerous ideas staff expressed for changing care practices can be leveraged by facilitating staff networking to work and learn together to implement evidence-based change. This article is protected by copyright. All rights reserved.

Involving institutionalised people with dementia in their care-planning meetings: lessons learnt by the staff.

Citation: Scandinavian journal of caring sciences; Sep 2017

Author(s): Villar, Feliciano; Celdrán, Montserrat; Vila-Miravent, Josep; Serrat, Rodrigo

Background: Applying a person-centred care (PCC) approach is an aspiration for many services attending people with dementia (PwD). However, the implementation and assessment of PCC practices represent a challenge to health professionals.

Aim: To evaluate the impact on staff of a programme aiming to involve people with dementia (PwD) in their individualised care-planning (ICP) meetings in long-term residential settings; specifically, to explore the lessons that staff perceived they had learned from the experience.

Methods: Twenty-one staff members working in residential facilities for older people were interviewed after the programme. Responses to two questions ('Do you think that your work has been affected in any way by

the attendance of PwD at ICP meetings?' and 'Have you learnt something new as a result of these meetings?') were submitted to thematic analysis.

Results: Eighteen of the 21 participants identified at least one lesson they had learned from the experience. The lessons could be grouped under three main headings: (i) an increase in their understanding of PwD, (ii) questioning of their own care practices, and (iii) an improvement in teamwork.

Conclusion: The involvement of PwD in ICP meetings had a positive impact on staff. They stated that the experience encouraged them to develop PCC-compatible attitudes and modify the way they treat PwD, thus improving the quality of care they deliver. The experience also seemed to empower staff (particularly the lesser trained members) and increase the cohesion of working teams.

Care staff and the creative arts: exploring the context of involving care personnel in arts interventions.

Citation: International psychogeriatrics; Sep 2017 ; p. 1-13

Author(s): Broome, Emma; Denning, Tom; Schneider, Justine; Brooker, Dawn

Background: Arts-based interventions play an important role in the care of people with dementia. Yet, creative arts are seldom implemented as a tool to enhance the care and wellbeing of people with dementia.

Methods: We examined the involvement of care staff in creative arts activities in residential care. Aspects of involvement that appear to influence outcomes in people with dementia were identified and analyzed. A broad systematic literature search of MedLine, EMBASE, PsychInfo, CINAHL, ASSIA, SCOPUS, and Web of Science led to the identification of 14 papers. The studies identified through the search process were examined in terms of intervention, context, mechanism and outcome, and the relationships between these aspects.

Results: Training sessions were identified as an opportunity to educate care personnel on useful techniques that are relevant to daily care practice. Evidence from the literature suggests that creative arts programs play a significant role in the way staff and residents interact and as a result influence the care practice of staff. Under certain conditions creative arts programs, that involve and engage staff, facilitate enhanced interactions and improve care strategies, which leads to the recognition and validation of personhood in residents with dementia.

Conclusions: These findings provide a basis for illustrating which elements of care staff involvement in creative arts programs could be implemented in residential care contexts in order to have the upmost benefit.

Outdoor spaces improve dementia care.

Citation: Nursing standard (Royal College of Nursing (Great Britain) : 1987); Sep 2017; vol. 32 (no. 2); p. 24-26

Author(s): Trueland, Jennifer

Abstract: Rachel Potter saw many examples of great practice when she visited residential homes as part of her research into their physical environment. But none sticks in her memory quite as much as the giant rabbits, which were kept as pets at one care home.

People who face the bereavement of a partner with dementia have poorer mental health than those whose partners are dying from other diseases.

Author(s): Meichsner, Franziska; Wilz, Gabriele

Source: Evidence-based nursing; Sep 2017

The mourning process of older people with dementia who lost their spouse

Author(s): Watanabe, Akiko; Suwa, Sayuri

Source: Journal of Advanced Nursing; Sep 2017; vol. 73 (no. 9); p. 2143

Aims: To explore the mourning process of people with dementia who have lost their spouse, using family caregivers' and professionals' perspectives and to devise grief care for people with dementia.

Background: There have been studies on the loss of one's spouse; however, little is known about widows and widowers with dementia as they may find it hard to tell their perception and feelings to others accurately because of cognitive impairment.

Design: Qualitative descriptive study using semi-structured interviews.

Method: Seven family caregivers and six professional caregivers from day care centres were interviewed between June and September 2015. Qualitative content analysis was used to identify mourning behaviours of people with dementia.

Results: In the mourning process of people with dementia, different behaviours were found according to dementia stages and different circumstances. In FAST2, they could remember their spouse's death. In FAST4 -6, it took 1 year to be able to perceive their spouse's death and more time to store it. In FAST 7, people with dementia did not discern his spouse's death throughout the process. Furthermore, it was revealed that people with dementia followed a different mourning process from conventional ones.

Conclusion: In the care of widows and widowers with dementia it is crucial to adjust circumstances to allow people with dementia to guess reality. Further studies are needed to clarify differences between the mourning process of people with dementia and that of intact older people to develop a grief model and educational programmes.

Think outside: positive risk-taking with people living with dementia

Citation: Working With Older People; 2017; vol. 21 (no. 3); p. 157-166

Author(s): Mapes, Neil

Purpose: The purpose of this paper is to share findings from the evaluation of dementia adventure (DA) holidays provided in 2016 and drawing on these data, to share reflections on positive risk-taking, which are inherent in outdoor activities, and consider the implications for research and practice with people with dementia.

Design/methodology/approach: Data are drawn from the 2016 internal evaluation report, using mixed methods design, of DA holidays independently reviewed by Dr Ruth Bartlett at the University of Southampton.

Findings: DA holidays are leading to a range of social, emotional and physical well-being outcomes, as well as wider benefits for the community of people with dementia, their family and carers.

Practical implications: Drawing on what positive risk-taking means for individuals, families and organisations, top ten considerations for positive risk taking outdoor activities are presented.

Originality/value: The number of organisations providing adventure experiences and holidays for people with dementia in the UK remains very low with just a handful of organisations. The impact and evaluation of these holidays is just emerging and whilst compelling needs replication, with larger sample sizes supported by clinical and scientific expertise to deepen our understanding of the impact of positive risk-taking outdoor activities. Additionally, there is a need for thinking and acting differently summarised by the phrase "THINK OUTSIDE" in developing a wide range of nature based positive risk-taking activities with people with dementia.

Nursing home manager's knowledge, attitudes and beliefs about advance care planning for people with dementia in long-term care settings: a cross-sectional survey

Citation: Journal of Clinical Nursing; Sep 2017; vol. 26 (no. 17-18); p. 2633

Author(s): Beck, Esther-Ruth; McIlpatrick, Sonja; Hasson, Felicity; Leavey, Gerry

Aims and objectives: To examine nursing home managers' knowledge, attitudes, beliefs and current practice regarding advance care planning for people with dementia in long-term care settings informed by the theory of planned behaviour.

Background: Internationally, advance care planning is advocated for people with dementia. However, evidence suggests that discussions with people with dementia are rare, particularly in long-term care settings. Whilst nursing home managers can be considered central to implementation in this setting, there is a dearth of research that has examined their perspective. This study reports on their role with regard to advance care planning and the perceived factors which influence this.

Design: A cross-sectional postal survey was carried out as part of a larger scale sequential explanatory mixed-methods study between January-March 2015. Setting and participants Nursing home managers in a region in the UK (n = 178).

Results: A response rate of 66% (n = 116) was achieved. Nursing home managers demonstrated a lack of knowledge of advance care planning, with negative attitudes underpinned by concerns regarding the capacity and lack of perceived benefits to the person with dementia. Currently, they do not view advance care planning as part of their role, with lack of ownership impacting upon current practice behaviours.

Conclusions: Whilst nursing home managers recognise the potential benefits of advance care planning, barriers and challenges create a reluctance to facilitate. Targeted training to address the knowledge deficit is required, with the wider components of advance care planning promoted. There is a need for greater role clarification to ensure nurses in long-term care settings identify with the process in the future. A gap between rhetoric and reality of implementation is evident; therefore, long-term care settings must critically examine system, organisational and individual factors for failure to implement advance care planning for people with dementia.

Relevance to Clinical Practice: Increased cognisance of the context in which advance care planning takes place is vital for improved implementation in this context. In addition strong nursing leadership is imperative to facilitate initiation, engagement and re-evaluation of the process of advance care planning.

'There's a Catch-22' - The complexities of pain management for people with advanced dementia nearing the end of life: A qualitative exploration of physicians' perspectives

Citation: Palliative Medicine; Sep 2017; vol. 31 (no. 8); p. 734

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Background: Pain management is a cornerstone of palliative care. The clinical issues encountered by physicians when managing pain in patients dying with advanced dementia, and how these may impact on prescribing and treatment, are unknown.

Aim: To explore physicians' experiences of pain management for patients nearing the end of life, the impact of these on prescribing and treatment approaches, and the methods employed to overcome these challenges.

Design: Qualitative, semi-structured interview study exploring barriers to and facilitators of pain management, prescribing and treatment decisions, and training needs. Thematic analysis was used to elicit key themes.

Setting/participants: A total of 23 physicians, responsible for treating patients with advanced dementia approaching the end of life, were recruited from primary care (n = 9), psychiatry (n = 7) and hospice care (n = 7).

Results: Six themes emerged: diagnosing pain, complex prescribing and treatment approaches, side effects and adverse events, route of administration, importance of sharing knowledge and training needs. Knowledge exchange was often practised through liaison with physicians from other specialities. Cross-speciality mentoring and the creation of knowledge networks were believed to improve pain management in this patient population.

Conclusion: Pain management in end-stage dementia is complex, requiring cross-population of knowledge between palliative care specialists and non-specialists, in addition to collateral information provided by other health professionals and patients' families. Regular, cost- and time-effective mentoring and ongoing professional development are perceived to be essential in empowering physicians to meet clinical challenges in this area.

Assistive Technology Addressing Safety Issues in Dementia: A Scoping Review

Citation: The American Journal of Occupational Therapy; 2017; vol. 71 (no. 5); p. 1-10

Author(s): Gagnon-Roy, Mireille; Bourget, Annick; Stocco, Stéphanie; Courchesne, Annie-Claude Lemieux; Kuhne, Nicolas; Provencher, Véronique

Abstract: The number of people age 65 yr and older with a diagnosis of Alzheimer's disease or other forms of dementia in the United States was estimated to be 5.2 million in 2016, and it is expected to nearly triple by 2050 (Hebert, Weuve, Scherr, & Evans, 2013). Because many older adults choose to age at home, a large proportion of people with dementia are living in the community despite increasing disabilities, generally with help from family members and health professionals (Gould et al., 2015). [...]modifications to the environment and occupations are often made by family caregivers to improve safety and reduce their stress (e.g., remove sharp knives, limit use of the oven, prevent exiting; Walker et al., 2006), but these modifications may restrict their relative's autonomy. Managing risks and balancing risk reduction with encouraging an active lifestyle are major challenges for caregivers and professionals (Clarke, Wilkinson, Keady, & Gibb, 2011; Rosenberg, Kottorp, & Nygård, 2012). [...]none of the studies reviewed (Bharucha et al., 2009; Carswell et al., 2009; Landau & Werner, 2012) identified which factors to consider when selecting appropriate and adapted IATs. [...]in this study, we aimed to synthesize current knowledge in the existing literature on (1) types and characteristics of IATs used to address safety issues in dementia while enhancing participation in meaningful activities, including advantages and disadvantages pertaining to their use, and (2) factors to consider in the choice of IATs with this population. [...]research should focus on how to improve the flexibility of IATs to ensure the "justright" fit over the years while enhancing greater participation and independence in meaningful activities.

Woodland Wellbeing: a pilot for people with dementia

Citation: Working With Older People; 2017; vol. 21 (no. 3); p. 178-185

Author(s): Gibson, Elanor; Ramsden, Nicola; Tomlinson, Rachel; Jones, Charlie

Purpose: The purpose of this paper is to understand whether a woodland-based intervention might offer something helpful and engaging for people affected by dementia. In total, 18 people came to Woodland Wellbeing groups over summer and autumn in 2016.

Design/Methodology/Approach: The authors made observations during the groups, kept some notes and conducted some interviews around three months after people had participated in Woodland Wellbeing.

Findings: Feedback from participants indicated themes around connection with nature and to one another; the joy in new learning and activities; and the inspirational impact of feeling part of nature.

Originality/Value: This paper adds to the growing literature on natural approaches in supporting the wellbeing of people affected by dementia, and highlights the value of partnership working.

Animal-Assisted Therapies and Dementia: A Systematic Mapping Review Using the Lived Environment Life Quality (LELQ) Model

Citation: The American Journal of Occupational Therapy; 2017; vol. 71 (no. 5); p. 1-10

Author(s): Wood, Wendy; Fields, Beth; Rose, Michelle; McLure, Merinda

Abstract: [...]there is extensive interdisciplinary consensus that the everyday environments of people with dementia profoundly influence their QOL, and there is interdisciplinary support for nonpharmacological environment-based interventions to enhance QOL (Padilla, 2011b; Sloane et al., 2005; Small et al., 1997). Altogether, the model serves as a guide to client-centered environmental interventions that aim to optimize occupational engagement, functional abilities, and wellbeing. Because occupation is central to the LELQ Model's conceptualization of occupational profile, environmental press, and life quality, the model also promotes practices that are occupation focused, as defined by Fisher (2014). [...]the first and second authors created a synthesis table in which they mapped extracted information onto relevant domains and subdomains of the LELQ Model. [...]although all participants in the included studies lived in a nursing home or assisted living facility, participants in 1 study received AAT in an adult day care program (Kanamori et al., 2001).

Sources Used:

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

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