

Dementia - Alzheimer's - Old Age Psychiatry October 2019

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Kind regards

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Dementia-friendly communities

Recently published research, informed by Age UK's Dementia-Friendly Programme, found that the views held by staff and volunteers can [influence the types of services available to people living with dementia](#). **Source:** Age UK

Annual Quality Outcomes Framework (QOF) report for England published

[Figures have been released](#) by NHS Digital which show the recorded prevalence of 21 conditions, including asthma, hypertension, dementia, diabetes, and depression. **Source:** NHS Digital

New local guidance published to support the needs of older people

The Old Age Faculty [launches guidance](#) to help local areas plan and deliver specialist services, led by old age psychiatrists, to meet the needs of older people.

Source: Royal College of Psychiatrists

NHS Choices

[Dementia guide](#)

This site offers information for people with dementia and their families and friends. It aims to raise awareness of dementia, as well as help people create networks and better understand the impact of the condition.

Useful Links

<https://www.alzheimers.org.uk/>

[Social Care Institute for Excellence \(SCIE\) Dementia Gateway](#)

[Gov.Uk : Dementia](#)

[Fab NHS Stuff – dementia](#)

[National Elf Service – The Mental Elf , Dementia](#)

[Dementia Evidence Toolkit](#)

<https://www.bmj.com/search/advanced/dementia>



For references where there is a link to the full text, you may need to use your NHS Athens username & password to access <https://openathens.nice.org.uk/>

Developing the advanced nurse practitioner role in a memory service

Richard Clibbens Angela Depledge Steve Hemingway

British Journal of Nursing Volume 28, Issue 19 24 Oct 2019

<https://doi.org/10.12968/bjon.2019.28.19.1251>

Abstract

This article describes how one NHS trust in northern England developed the advanced nurse practitioner (ANP) role within its memory services. It discusses how ANP roles were developed and implemented across four localities of a large NHS trust that provides a number of locally based memory services to improve the diagnostic pathway for people referred to the service and their carers. Advanced practice is considered more broadly followed by a review of the literature related to the role of the ANP and non-medical prescriber in mental health and, more specifically, memory assessment and diagnostic services. Challenges to gaining the requisite competency to work as an ANP are discussed. The need for a clear agreed strategy to ensure practitioner competence and effective governance for the introduction of these roles is described. It is argued that using this model allowed for mental health nurses within memory services to make a major contribution to the transformation of such services and receive recognition for the expansion of their role and appropriate remuneration linked to national NHS employment role profiles. The potential benefit of the ANP role more broadly in mental health services is discussed, together

with factors that may have previously hindered their contribution to the transformation of services. The strategic development and planning process that led to implementing the ANP role within memory services is presented, together with a description of how the relevant higher level clinical skills required for the roles were achieved and formally accredited.

[Enhancing the care environment for people living with dementia](#)

Alan Glasper

British Journal of Nursing Volume 28, Issue 18 09 Oct 2019

Abstract

Emeritus Professor Alan Glasper, from the University of Southampton, discusses aspects of a recently published briefing paper report on dementia from the House of Commons Library

[British Journal of Healthcare Assistants Vol. 13, No. 10](#)

Dementia 4. Lewy body dementia: diagnosis, treatment and medical management

Linda Nazarko

Published Online: 10 Oct 2019 <https://doi.org/10.12968/bjha.2019.13.10.474>

In the UK, an estimated 954 000 people have dementia. Lewy body dementia (LBD) can be difficult to diagnose and estimates of its prevalence in the UK range from 38 000–100 000 (Prince et al, 2014:14, 16; Table 4, 2019 estimates; NHS, 2019). This article, the fourth in a series, explains about the pathophysiology and clinical features of LBD, how it is diagnosed, treated and managed

[British Journal of Healthcare Assistants Vol. 13, No. 10 Health Matters](#)

On your bike! Transforming the lives of elderly and dementia patients

Anthony Bonnici

Published Online: 10 Oct 2019 <https://doi.org/10.12968/bjha.2019.13.10.518>

Residents at a Westminster City Council care home have embarked on a round-the-world cycle race— although none will leave their lounge. People living at Norton House near Victoria Station have been given a new state-of-the-art bike—a so called ‘dementia bike’— to participate in the Road World for Seniors challenge against seniors from across the world.

[Attitudes to dementia: calling neuroscience nurses to action](#)

Karen Harrison Denning

British Journal of Neuroscience Nursing Volume 15, Issue 5 02 Oct 2019

The author discusses the role of nurses in changing attitudes to dementia to ensure that care needs are recognised and managed, with topics mentioned such as the National Dementia Strategy, the Alzheimer's Disease International, and ageing.

[Vascular dementia: diagnosis, treatment and medical management](#)

- Linda Nazarko

British Journal of Neuroscience Nursing Volume 15, Issue 5 02 Oct 2019

Abstract

In the UK, an estimated 954 000 people have dementia. Vascular dementia (VaD) is the second most common type of dementia and affects around 257 607 people ([Prince et al, 2014:16—Table 4](#)). This article explains about the pathophysiology and clinical features of VaD, how it can be prevented, how it is diagnosed and the medication used to treat VaD.

[Admiral Nursing: supporting families affected by dementia within a holistic intermediate care team](#)

Zena Aldridge, Victoria Davies, Karen Harrison Denning

British Journal of Neuroscience Nursing Volume 15, Issue 502 Oct 2019

Abstract

There are increasing pressures on the health and social care system, particularly within acute hospital care. This has led to significant changes being implemented throughout the **NHS England Long Term Plan (2019)**, such as moving services closer to home and improving 'out of hospital' care. Intermediate care services are being developed to improve timely discharge from hospital and prevent unnecessary hospital admissions and premature transfer to residential care. An innovative intermediate care model, inclusive of Admiral Nursing, has been developed within Olympus Care Services to support families living with dementia, implementing an intensive 8-week intervention model. It is essential that intermediate services are accessible for people with dementia, inclusive of the needs of the family, and that they work within the context of integrated and collaborative models of care across traditional organisational boundaries. The aim is not only to improve resilience and quality of life, but also to offer opportunities to promote the narrative of living well with dementia. This service model illustrates how this can be achieved with inclusion of Admiral Nursing working within reablement services.

[The effectiveness of home-based exercise programmes on mobility and functional independence in community-dwelling adults with Alzheimer's disease: a critical review](#)

Samantha Rachael Brown

Samantha Yoward

International Journal of Therapy and Rehabilitation Volume 26, Issue 1002 Oct 2019

Abstract

Background/Aims

In the UK, two-thirds of people with dementia are community-dwelling. Guidelines recommend exercise to promote independence among this population, however evidence to support this is scarce. This study aimed to evaluate the effectiveness of home-based exercise programmes on mobility and functional independence in people with Alzheimer's disease living in the community.

Anticholinergic and benzodiazepine medication use and risk of incident dementia: a UK cohort study.

Author(s): Grossi, Carlota M.; Richardson, Kathryn; Fox, Chris; Maidment, Ian; Steel, Nicholas; Loke, Yoon K.; Arthur, Antony; Myint, Phyo Kyaw; Campbell, Noll; Boustani, Malaz; Robinson, Louise; Brayne, Carol; Matthews, Fiona E.; Savva, George M.

Source: BMC Geriatrics; Oct 2019; vol. 19 (no. 1)

Publication Date: Oct 2019

Publication Type(s): Academic Journal

PubMedID: 31638906

Available at [BMC Geriatrics](#) - from EBSCO (MEDLINE Complete)

Available at [BMC Geriatrics](#) - from BioMed Central

Available at [BMC Geriatrics](#) - from Europe PubMed Central - Open Access

Available at [BMC Geriatrics](#) - from ProQuest (Health Research Premium) - NHS Version

Available at [BMC Geriatrics](#) - from Unpaywall

Abstract: Background: Studies suggest that anticholinergic medication or benzodiazepine use could increase dementia risk. We tested this hypothesis using data from a UK cohort study. Methods: We used data from the baseline (Y0), 2-year (Y2) and 10-year (Y10) waves of the Medical Research Council Cognitive Function and Ageing Study. Participants without dementia at Y2 were included (n = 8216). Use of benzodiazepines (including nonbenzodiazepine Z-drugs), anticholinergics with score 3 (ACB3) and anticholinergics with score 1 or 2 (ACB12) according to the Anticholinergic Cognitive Burden scale were coded as ever use (use at Y0 or Y2), recurrent use (Y0 and Y2), new use (Y2, but not Y0) or discontinued use (Y0, but not Y2). The outcome was incident dementia by Y10. Incidence rate ratios (IRR) were estimated using Poisson regression adjusted for potential confounders. Pre-planned subgroup analyses were conducted by age, sex and Y2 Mini-Mental State Examination (MMSE) score. Results: Dementia incidence

was 9.3% (N = 220 cases) between Y2 and Y10. The adjusted IRRs (95%CI) of developing dementia were 1.06 (0.72, 1.60), 1.28 (0.82, 2.00) and 0.89 (0.68, 1.17) for benzodiazepines, ACB3 and ACB12 ever-users compared with non-users. For recurrent users the respective IRRs were 1.30 (0.79, 2.14), 1.68 (1.00, 2.82) and 0.95 (0.71, 1.28). ACB3 ever-use was associated with dementia among those with Y2 MMSE > 25 (IRR = 2.28 [1.32-3.92]), but not if Y2 MMSE ≤ 25 (IRR = 0.94 [0.51-1.73]). Conclusions: Neither benzodiazepines nor ACB12 medications were associated with dementia. Recurrent use of ACB3 anticholinergics was associated with dementia, particularly in those with good baseline cognitive function. The long-term prescribing of anticholinergics should be avoided in older people.

Database: CINAHL

An audit of dementia education and training in UK health and social care: a comparison with national benchmark standards.

Author(s): Smith, S. J.; Parveen, S.; Sass, C.; Drury, M.; Oyebode, J. R.; Surr, C. A.

Source: BMC Health Services Research; Oct 2019; vol. 19 (no. 1)

Publication Date: Oct 2019

Publication Type(s): Academic Journal

PubMedID: 31638974

Available at [BMC Health Services Research](#) - from EBSCO (MEDLINE Complete)

Available at [BMC Health Services Research](#) - from BioMed Central

Available at [BMC Health Services Research](#) - from Europe PubMed Central - Open Access

Available at [BMC Health Services Research](#) - from ProQuest (Health Research Premium) - NHS Version

Available at [BMC Health Services Research](#) - from Unpaywall

Abstract: Background: Despite people living with dementia representing a significant proportion of health and social care users, until recently in the United Kingdom (UK) there were no prescribed standards for dementia education and training. This audit sought to review the extent and nature of dementia education and training offered to health and social care staff in the UK against the standards described in the 2015 Dementia Training Standards Framework, which describes the knowledge and skills required of the UK dementia workforce. Methods: This audit presents national data concerning the design, delivery, target audience, length, level, content, format of training, number of staff trained and frequency of delivery within existing dementia training programmes offered to health and social care staff. The Dementia Training Standards Framework was used as a reference for respondents to describe the subjects and learning outcomes associated with their training. Results: The findings are presented from 614 respondents offering 386 training packages, which indicated variations in the extent and quality of training. Many training packages addressed the subjects of 'person-centred care', 'communication', 'interaction and behaviour in dementia care', and 'dementia awareness'. Few training packages addressed subjects concerning 'pharmacological interventions in dementia care', 'leadership' and 'end of life care'. Fewer than 40% of The Dementia Training Standards Framework learning outcomes targeted to staff with regular contact with people with dementia or in leadership roles were covered by the reported packages. However, for training targeted at increasing dementia awareness more than 70% of the learning outcomes identified in The Dementia Training Standards Framework were addressed. Many training packages are not of sufficient duration to derive impact; although the majority employed delivery methods likely to be effective. Conclusions: The development of new and existing training and education should take account of subjects that are currently underrepresented and ensure that training reflects the Training Standard Framework and evidence regarding best practice for delivery. Lessons regarding the limitations of training in the UK serve as a useful illustration of the challenge of implementing national dementia training standards; particularly for countries who are developing or have recently implemented national dementia strategies.

Database: CINAHL

Enhancing the care environment for people living with dementia.

Author(s): Glasper, Alan

Source: British Journal of Nursing; Oct 2019; vol. 28 (no. 18); p. 1216-1217

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [British Journal of Nursing](#) - from MAG Online Library

Available at [British Journal of Nursing](#) - from EBSCO (CINAHL Plus with Full Text)

Abstract: Emeritus Professor Alan Glasper, from the University of Southampton, discusses aspects of a recently published briefing paper report on dementia from the House of Commons Library

Database: CINAHL

Stress and Blood Pressure in Dementia Caregivers: The Moderator Role of Mindfulness.

Author(s): Vara-García, Carlos; Romero-Moreno, Rosa; Márquez-González, María; Mausbach, Brent T.; von Känel, Roland; Gallego-Alberto, Laura; Olmos, Ricardo; Losada, Andrés

Source: *Clinical Gerontologist*; Oct 2019; vol. 42 (no. 5); p. 512-520

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Clinical Gerontologist](#) - from Unpaywall

Abstract: Objective: Dementia caregiving has been described as a chronically stressful situation with adverse cardiovascular effects. Psychological resources such as mindfulness may reduce the impact of stress on caregivers' cardiovascular health. The objective of this study was to analyze the moderating effect of trait mindfulness on the relationship between frequency of disruptive behaviors of the care recipient and blood pressure (BP) in dementia caregivers. Method: Participants were 110 dementia family caregivers. Two hierarchical regressions (for systolic and diastolic BP) were conducted to analyze whether mindfulness moderates the relationship between disruptive behaviors and BP after controlling for known predictors of cardiovascular outcomes. Results: A significant moderator effect of mindfulness was found between the frequency of disruptive behaviors and diastolic BP ($\beta = -.195, p < .05$). Among those caregivers reporting low levels of mindfulness, the relationship between frequency of disruptive behaviors and diastolic BP was relatively stronger than among those reporting high mindfulness levels. Conclusions: The results suggest that a high level of trait mindfulness may have protective effect on BP when caregivers face high levels of stress. Clinical Implications: Mindfulness seems to be an important variable with potential for buffering the effects of caregiving stressors on caregivers' blood pressure.

Database: CINAHL

Developing a tool to support diagnostic delivery of dementia.

Author(s): Moghaddam, Nima G; Bennett, Claire E; De Boos, Danielle

Source: *Dementia* (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2505-2525

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia \(14713012\)](#) - from Unpaywall

Abstract: It is increasingly recognised that there are challenges affecting the current delivery of dementia diagnoses. Steps are required to address this. Current good practice guidelines provide insufficient direction and interventions from other healthcare settings do not appear to fully translate to dementia care settings. This project has taken a sequential two-phase design to developing a tool specific to dementia diagnostic delivery. Interviews with 14 participants explored good diagnostic delivery. Thematic analysis produced key themes (overcoming barriers, navigation of multiple journeys and completing overt and covert tasks) that were used to inform the design of a tool for use by clinicians, patients and companions. The tool was evaluated for acceptability in focused group discussions with 13 participants, which indicated a desire to use the tool and that it could encourage good practice. Adaptations were highlighted and incorporated to improve acceptability. Future research is now required to further evaluate the tool.

Database: CINAHL

Caregivers' interactions with health care services – Mediator of stress or added strain? Experiences and perceptions of informal caregivers of people with dementia – A qualitative study.

Author(s): Karran, Terence; Siriwardena, A Niroshan; Laparidou, Despina; Middlemass, Jo

Source: *Dementia* (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2526-2542

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract: Background: There are an estimated 46.8 million people worldwide living with dementia in 2015, being cared for usually by family members or friends (informal caregivers). The challenges faced by informal caregivers often lead to increased levels of stress, burden and risk of care-recipient institutionalisation. Aim: The overarching aim of this study was to explore the experiences and perceptions of informal caregivers of people with dementia when interacting with the health care system, and whether the support received acted as a mediator of caregiver stress. The secondary aim was to investigate healthcare professionals' views and current practice regarding people with dementia and their interactions with informal caregivers. Method: We employed a qualitative research design, using focus groups and one face-to-face interview with a purposive sample of informal caregivers and healthcare professionals in Lincolnshire, UK. Data were collected between March and July 2015. We used the stress-process model of stress in caregivers as a theoretical framework. Results: We interviewed 18 caregivers and 17 healthcare professionals. Five themes, mapped to the stress-process in caregivers' model, captured the main challenges faced by caregivers and the type of support they wanted from health care services. Primary stressors included the challenge of diagnosing dementia; caregivers' needs and expectations of an in-depth knowledge and understanding of dementia from healthcare professionals; and need for carer education. Secondary role strain included lack of support and mismatch of communication and expectations. Caregiver involvement in monitoring care and disease was a potential mediator tool. Conclusions: Fragmentation of dementia care services, lack of training for healthcare professionals and the dearth of information for caregivers means health care services are only partially fulfilling a support role. In turn, lack of support may be intensifying caregiver stress leading to worsening in their health and well-being; thus, potentially increasing the risk of institutionalisation of their care-recipient.

Database: CINAHL

Managing behavioural and psychological symptoms in community dwelling older people with dementia: 1. A systematic review of the effectiveness of interventions.

Author(s): Gage, Heather; Hamilton, Laura; Goodman, Claire; Ashaye, Kunle; Iliffe, Steve; Manthorpe, Jill; Trivedi, Daksha P; Braun, Andreas; Dickinson, Angela

Source: *Dementia* (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2925-2949

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract: Background: Two-thirds of people living with dementia live at home in the UK and many experience distressing behavioural and psychological symptoms. This systematic review evaluates the effectiveness of non-pharmacological interventions for behavioural and psychological symptoms among community-dwelling people living with dementia. Methods: This two-stage review undertook an initial mapping of the literature followed by a systematic review of relevant randomised controlled trials. We searched electronic databases for pertinent studies reporting outcomes from interventions from January 2000 to March 2015 and updated searches in October 2016. We included studies that considered behavioural and psychological symptom management for older people living with dementia who live at home and excluded studies conducted in long-term care settings. This paper presents findings from a narrative synthesis of 48 randomised controlled trials evaluating interventions for people living with dementia alone, family carers alone and patient-carer dyads. Results: We retrieved 17,871 de-duplicated records and screened them for potential inclusion. Evidence from 48 randomised controlled trials suggests that family carer training and educational programmes that target problem behaviours and potential triggers can improve outcomes. Nurses and occupational therapists appear to help people with dementia with behavioural and psychological symptoms, but professional comparisons are lacking and there is no shared language about or understanding of behavioural and psychological symptoms amongst professionals, or between professionals and family carers. Conclusions: Future research should focus on the effectiveness of components of multi-faceted programmes and their cost effectiveness and include qualitative data to better target interventions for behavioural and psychological symptoms. It is important

to consider family carer readiness to use non-pharmacological strategies and to develop a shared language about the inherent needs and communications of behavioural and psychological symptoms.

Database: CINAHL

Managing behavioural and psychological symptoms in community dwelling older people with dementia:

2. A systematic review of qualitative studies.

Author(s): Gage, Heather; Ashaye, Kunle; Iliffe, Steve; Manthorpe, Jill; Braun, Andreas; Trivedi, Daksha P; Dickinson, Angela; Hamilton, Laura; Goodman, Claire

Source: Dementia (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2950-2970

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract: Background: People living with dementia often develop distressing behavioural and psychological symptoms (BPSD) that can affect their quality of life and the capacity of family carers and staff providing support at home. This systematic review of qualitative studies considers the views and experiences of people living with dementia and care providers about these symptoms and what helps to reduce their impact. Methods: The two-stage review involved (a) An initial mapping of the literature to understand the range of BPSD, and how it is operationalised by different groups, to develop a search strategy; (b) A search of electronic databases from January 2000 to March 2015, updated in October 2016. Included studies focused on people living in their own homes. Data extraction and thematic analysis were structured to provide a narrative synthesis of the evidence. Results: We retrieved 17, 871 records and included relevant qualitative papers (n = 58) targeting community-dwelling people with dementia and family carers around the management of BPSD. Five key themes were identified: (1) Helpful interventions/support for BPSD management, (2) Barriers to support services for BPSD management, (3) Challenges around recognition/diagnosis of BPSD, (4) Difficulties in responding to aggression and other BPSD, and (5) Impact of BPSD on family carers and people living with dementia. Conclusions: Family carers sometimes feel that their experiences of BPSD may not be evident to professionals until a crisis point is reached. Some helpful services exist but access to support, lack of knowledge and skills, and limited information are consistently identified as barriers to their uptake. The lack of common terminology to identify and monitor the range of BPSD that people with dementia living at home may experience means that closer attention should be paid to family carer accounts. Future research should include qualitative studies to evaluate the relevance of interventions.

Database: CINAHL

How are people with dementia involved in care-planning and decision-making? An Irish social work perspective.

Author(s): Begley, Emer; O'Brien, Marita; Donnelly, Sarah

Source: Dementia (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2985-3003

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract: In recent years, there have been national and international policy advances around capacity and decision-making and an apparent burgeoning rights-based approach to the issue, all of which have the potential to impact on the experience for people with dementia in Ireland. There is little evidence however on whether these policies and principles are being translated into practice and whether traditional paternalistic approaches to decision-making are being challenged. To gain insight into current practice, research was undertaken with social workers working with older people in Ireland; reporting on the involvement of people living with dementia in care-planning processes. Data collection included a mixed method approach; an on-line survey of social workers from across the country who reported on their open caseload during the month of June 2015 (N = 38 social workers reporting on the experiences of 788 older people, of which 39% of older people had a formal diagnosis of dementia). In addition, semi-structured telephone interviews were conducted with social workers working in the nine Community Health Organisation areas (N = 21). Findings show that people with dementia were high users of social work

services, accounting for 44.5% of the client group. Social workers reported that there were no standardised approaches to how Health and Social Care Professionals involved people with dementia in care planning and decision-making. Overall, people with dementia were more likely to be excluded from decision-making processes due to (i) assumptions that they lacked capacity, (ii) family members preferences that the person was not involved, (iii) communication difficulties, (iv) time constraints, (v) little or no opportunity given or (vi) the person delegated decision-making to others. Good practices were identified through multidisciplinary team approaches and formal care planning meetings. This research highlights variability in how people with dementia participate in decision-making around their care. It sheds light on existing barriers which challenge the full implementation of the Irish Assisted Decision-Making legislation; highlighting the need for appropriate guidance and education for Health and Social Care Professionals. The findings also show that family dynamics and existing relationships can play a role in how people with dementia participate and are involved. To ensure consistent opportunities for participation, effective practices and approaches to supporting the participation of people living with dementia in care planning needs to be developed and rolled out in all care settings through increased training and adoption of standardised approaches.

Database: CINAHL

'How do they want to know?' Doctors' perspectives on making and communicating a diagnosis of dementia.

Author(s): Dooley, Jemima; McCabe, Rose; Bailey, Cate

Source: *Dementia* (14713012); Oct 2019; vol. 18 (no. 7/8); p. 3004-3022

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract: Recent drives to facilitate earlier identification of dementia have led to increased memory clinic referrals and diagnoses. This study explored the perspectives of memory clinic doctors on making and delivering diagnoses. Four focus groups were conducted with 13 psychiatrists and two geriatricians in the UK. Transcripts were coded line by line using NVIVO. Thematic analysis identified 39 categories, 18 sub-themes and eight overarching themes. Inter-rater reliability on 31% of the data was 0.89. Increased public awareness of dementia was viewed positively in facilitating access to diagnosis and treatment. Doctors viewed diagnosis as a process and expressed concerns about limited pre-diagnostic counselling and post-diagnostic support. In diagnostic delivery doctors sought to develop a narrative drawing on the patient's report of symptoms and adjust explanations to patient preferences and awareness. However, tailoring the delivery to the individual patient was challenging when meeting for the first time. These consultations often involved three participants (doctor, patient and relative), who were felt to have differing needs and expectations. Doctors emphasized that delicacy was required in deciding in what could be discussed in front of both parties, however also stressed the importance of explicitly naming 'dementia'. Efforts were made to balance honesty and hope when discussing prognosis and medication. The work was sometimes emotionally distressing, with limited supervision. Existing communication training was felt to be inadequate for consultations involving triads or people with cognitive impairment. Delivering a dementia diagnosis is a nuanced and challenging task. Negotiating honest descriptions of a life-limiting condition whilst instilling hope is further complicated when cognitive impairment affects comprehension. Misunderstandings at the time of feedback may limit patient opportunities for informed future planning afforded by early diagnosis. Doctors in memory clinics would benefit from evidence based training and supervision to prepare them for these emotionally challenging and complex consultations.

Database: CINAHL

The development and use of the assessment of dementia awareness and person-centred care training tool in long-term care.

Author(s): Creese, Byron; Garrod, Lucy; Chenoweth, Lynn; Griffiths, Alys Wyn; Surr, Claire A

Source: *Dementia* (14713012); Oct 2019; vol. 18 (no. 7/8); p. 3059-3070

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia \(14713012\)](#) - from Unpaywall

Abstract:Policy and practice guidelines recommend person-centred care to support people to live well with dementia in long-term care. Therefore, staff working in long-term care settings need to be trained in dementia awareness and person-centred care. However, the access to, content of and reach of training across long-term care settings can be varied. Data on current and ongoing access to person-centred care training can form an important component of data gathered on usual care in research studies, in particular clinical trials within long-term care. However, no suitable assessment tools are available to measure dementia awareness and person-centred care training availability, content and reach. This paper describes the development of a training audit tool to meet this need for a usual care measure of dementia awareness and person-centred care training. The 'Assessment of Dementia Awareness and Person-centred care Training' tool was based on a review of published person-centred care literature and consultation with dementia and aged care experts. The Assessment of Dementia Awareness and Person-centred care Training tool was piloted in 13 long-term care facilities the UK and Australia, before being used to assess the content of dementia and person-centred care awareness training in 50 UK settings in a randomized controlled trial as part of usual care recording. Following pilot testing, modifications to the Assessment of Dementia Awareness and Person-centred care Training tool's wording were made to enhance item clarity. When implemented in the randomized controlled trial, pre-baseline training assessment data showed that the Assessment of Dementia Awareness and Person-centred care Training tool was able to differentiate between the training in different long-term care settings and identify settings where further dementia awareness training was required. The Assessment of Dementia Awareness and Person-centred care Training tool was then used as a method of recording data on dementia awareness and person-centred care training as part of ongoing usual care data collection. The Assessment of Dementia Awareness and Person-centred care Training tool is suitable for use by researchers to establish the availability, content and reach of dementia and person-centred care awareness training to staff within research studies.

Database: CINAHL

Visioning change: Co-producing a model of involvement and engagement in research (Innovative Practice).

Author(s): Doors, Open; EDUCATE; Davis, Katie; Keady, John; Swarbrick, Caroline M

Source: [Dementia \(14713012\)](#); Oct 2019; vol. 18 (no. 7/8); p. 3165-3172

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract:The involvement of people living with dementia in research has traditionally been located in the realms of 'subject' or 'participant'. However, there has been an increase in demand for greater transparency by academic bidding teams (particularly within the UK) in demonstrating how people with a lived experience have been and will be involved in the research process. Located within the Economic and Social Research Council/National Institute for Health Research (ESRC/NIHR)-funded Neighbourhoods and Dementia Study (2014–2019), led by The University of Manchester (UK), this paper outlines the development of the CO-researcher INVOLVEMENT and ENGAGEMENT in Dementia (COINED) Model, which was co-produced alongside three independent groups of people living with dementia: Open Doors, the Scottish Dementia Working Group and EDUCATE.

Database: CINAHL

Effective public involvement in the HoST-D Programme for dementia home care support: From proposal and design to methods of data collection (innovative practice).

Author(s): Roe, Brenda; Hodgson, Anthony; Britt, David; Clarkson, Paul; Giebel, Clarissa

Source: [Dementia \(14713012\)](#); Oct 2019; vol. 18 (no. 7/8); p. 3173-3186

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Dementia: The International Journal of Social Research and Practice](#) - from Unpaywall

Abstract:Public involvement is an important element in health and social care research. However, it is little evaluated in research. This paper discusses the utility and impact of public involvement of carers and

people with dementia in a five-year programme on effective home support in dementia, from proposal and design to methods of data collection, and provides a useful guide for future research on how to effectively involve the public. The Home Support in Dementia (HoST-D) Programme comprises two elements of public involvement, a small reference group and a virtual lay advisory group. Involving carers and people with dementia is based on the six key values of involvement – respect, support, transparency, responsiveness, fairness of opportunity, and accountability. Carers and people with dementia gave opinions on study information, methods of data collection, an economic model, case vignettes, and a memory aid booklet, which were all taken into account. Public involvement has provided benefits to the programme whilst being considerate of the time constraints and geographical locations of members.

Database: CINAHL

Understanding and Measuring the Wellbeing of Carers of People With Dementia.

Author(s): Cunningham, Nicola A; Cunningham, Tom R; Roberston, Jane M

Source: Gerontologist; Oct 2019; vol. 59 (no. 5)

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Gerontologist](#) - from Unpaywall

Abstract:Background and Objectives To determine how the wellbeing of carers of people with dementia is understood and measured in contemporary health research. Research Design and Methods A systematic review of reviews was designed, registered with PROSPERO, and then conducted. This focused on systematic reviews of research literature published from 2010 onwards; with the wellbeing of carers of people with dementia being a primary focus. N = 19 studies met the inclusion criteria. Quality appraisal was conducted using the AMSTAR tool (2015). A narrative synthesis was conducted to explore how wellbeing is currently being understood and measured. Results Contemporary health research most frequently conceptualizes wellbeing in the context of a loss–deficit model. Current healthcare research has not kept pace with wider discussions surrounding wellbeing which have become both more complex and more sophisticated. Relying on the loss–deficit model limits current research in understanding and measuring the lived experience of carers of people with dementia. There remains need for a clear and consistent measurement of wellbeing. Discussion and Implications Without clear consensus, health professionals must be careful when using the term "wellbeing". To help inform healthcare policy and practice, we offer a starting point for a richer concept of wellbeing in the context of dementia that is multi-faceted to include positive dimensions of caregiving in addition to recognized aspects of burden. Standardized and robust measurements are needed to enhance research and there may be benefit from developing a more mixed, blended approach to measurement.

Database: CINAHL

Online information and support for carers of people with young-onset dementia: A multi-site randomised controlled pilot study.

Author(s): Metcalfe, Anna; Jones, Bridget; Mayer, Johannes; Gage, Heather; Oyebode, Jan; Boucault, Sarah; Aloui, Sabrina; Schwertel, Uta; Böhm, Markus; Tezenas du Montcel, Sophie; Lebbah, Said; De Mendonça, Alexandre; De Vugt, Marjolein; Graff, Caroline; Jansen, Sabine; Hergueta, Thierry; Dubois, Bruno; Kurz, Alexander

Source: International Journal of Geriatric Psychiatry; Oct 2019; vol. 34 (no. 10); p. 1455-1464

Publication Date: Oct 2019

Publication Type(s): Academic Journal

PubMedID: 31111516

Available at [International Journal of Geriatric Psychiatry](#) - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract:Objectives: The European RHAPSODY project sought to develop and test an online information and support programme for caregivers of individuals diagnosed with young onset dementia. The objectives were to assess user acceptability and satisfaction with the programme and to test outcome measures for a larger effectiveness study.Design: A pilot randomised controlled trial in England, France, and Germany was conducted with 61 caregivers for adults with young onset Alzheimer's disease or frontotemporal

degeneration. Evaluations at baseline, week 6, and week 12 assessed user acceptability and satisfaction. Use of the programme was measured from online back-end data. Qualitative feedback on user experiences was collected via semi-structured interviews. Measures of caregiver well-being (self-efficacy, stress, burden, frequency of patient symptoms, and caregiver reactions) were explored for use in a subsequent trial. Results: Participants logged in online on average once a week over a 6-week period, consulting approximately 31% of programme content. Seventy percent of participants described the programme as useful and easy to use. Eighty-five percent expressed intent to use the resource in the future. Reductions in reported levels of stress and caregivers' negative reactions to memory symptoms were observed following use of the programme. Conclusions: Results indicated that the RHAPSODY programme was acceptable and useful to caregivers. The programme may be complementary to existing services in responding to the specific needs of families affected by young onset dementia. Distribution of the programme is underway in England, France, Germany, and Portugal.

Database: CINAHL

The effectiveness of home-based exercise programmes on mobility and functional independence in community-dwelling adults with Alzheimer's disease: a critical review.

Author(s): Brown, Samantha Rachael; Yoward, Louise

Source: International Journal of Therapy & Rehabilitation; Oct 2019; vol. 26 (no. 10); p. 1-14

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [International Journal of Therapy & Rehabilitation](#) - from MAG Online Library

Abstract: Background/Aims: In the UK, two-thirds of people with dementia are community-dwelling. Guidelines recommend exercise to promote independence among this population, however evidence to support this is scarce. This study aimed to evaluate the effectiveness of home-based exercise programmes on mobility and functional independence in people with Alzheimer's disease living in the community. Methods: The following electronic databases were searched: AMED, CINAHL, EMBASE, Medline, SPORTsDiscus, The Cochrane Library, PEDro, OpenGrey and Online Thesis. All included trials were assessed for methodological quality using PEDro bias scores and McMaster's Critical Appraisal Tool and Guideline. English language restrictions were applied. Results: A total of seven trials were included within the review. Trial quality was mixed. All trials reported measures for mobility, while five trials included measures of functional independence. Results for the effectiveness of home-based exercise on mobility were mixed, with only two studies reporting significant improvements. Functional independence significantly improved in all trials. Conclusions: The effectiveness of home-based exercise programmes on mobility in community-dwelling people with Alzheimer's disease remains inconclusive, while a growing body of evidence indicates its effectiveness in improving functional independence. However, high quality trials are scarce. Larger, randomised, controlled trials specific to this population are thus warranted.

Database: CINAHL

Dementia in the Bangladeshi diaspora in England: A qualitative study of the myths and stigmas about dementia.

Author(s): Hossain, Muhammad Zakir; Khan, Hafiz T.A.

Source: Journal of Evaluation in Clinical Practice; Oct 2019; vol. 25 (no. 5); p. 769-778

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Available at [Journal of Evaluation in Clinical Practice](#) - from Wiley Online Library Medicine and Nursing Collection 2019 - NHS

Abstract: Rationale, aims and objectives: Although Bangladeshis are three times more likely to be carers than White British, Bangladeshi family carers are the most deprived, neglected, and effectively a hidden group in the United Kingdom.¹ There is a paucity of research within the Bangladeshi community that is capable of explaining and predicting the experiences and concerns of Bangladeshi family carers providing care for their relatives with dementia. The purpose of this study is to explore the perspectives of Bangladeshi family carers' knowledge and day-to-day experiences living in England. Methods: This is a qualitative study involving semistructured face-to-face interviews with six Bangladeshi family carers living

in London and Portsmouth. Interviews were recorded with the consent and transcribed verbatim. Data were managed by using NVivo software, and thematic analysis was performed. Results: This paper explores that most carers have a lack of knowledge and awareness of the symptoms of dementia. The results of this study are in contrast to previous studies, where South Asian carers perceived dementia as being possessed by evil spirits or God's punishment for previous life's sins; this study reveals that Bangladeshi family carers believed dementia was a medical condition. Unlike earlier South Asian studies, however, all family carers in this study also believed that there was no stigma attached to dementia. Conclusions: Further research is warranted to investigate the religious beliefs, familism, and interpersonal motives as theoretical perspectives to explain how Bangladeshi family carers negotiate and construct their caregiving roles for their relatives with dementia.

Database: CINAHL

Does personal experience of dementia change attitudes? The Bristol and South Gloucestershire survey of dementia attitudes.

Author(s): Hancock, Jude; White, Paul; Cheston, Richard

Source: Dementia (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2596-2608

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Abstract: Background: It is unclear how attitudes towards people with dementia are formed and whether, for instance, increased contact with people with dementia, either through work or personal experience alters attitudes. This study used a validated questionnaire (the Approaches to Dementia Questionnaire) to examine whether having experience of dementia (either as a result of work, or by being affected by dementia) is associated with differences in attitudes towards dementia. Methods: A modified version of the Approaches to Dementia Questionnaire was completed by 2201 participants, either online or in written form. Participants also recorded their age, gender and ethnicity as well as whether they worked with people with dementia or had been personally affected by dementia. Results: Increased contact with people with dementia was associated with increases in both total Approaches to Dementia Questionnaire scores and across both sub-scales reflecting more positive person-centred attitudes toward dementia. The highest levels of increase were found amongst non-white participants. Conclusions: This study is, we believe, the first attempt to look systematically at whether greater contact with people with dementia is associated with changes in attitudes. The results strongly support the contention that increased contact with people with dementia leads to more person-centred attitudes, and by inference, less stigmatising views.

Database: CINAHL [Request this article from the library](#)

The impact of life story work on person-centred care for people with dementia living in long-stay care settings in Ireland.

Author(s): O'Shea, Eamon; Cooney, Adeline

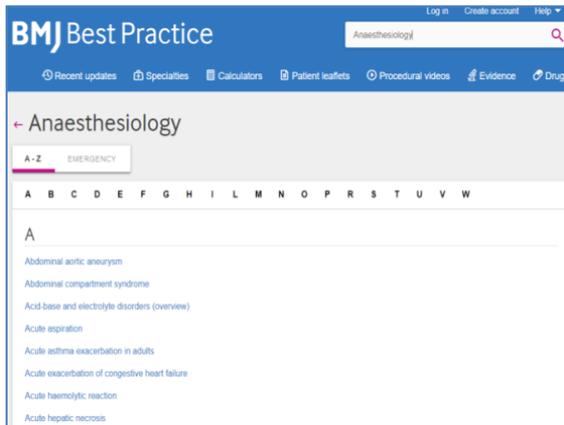
Source: Dementia (14713012); Oct 2019; vol. 18 (no. 7/8); p. 2731-2746

Publication Date: Oct 2019

Publication Type(s): Academic Journal

Abstract: The potential of life story work to add quality to dementia care is widely acknowledged. Whether this potential is always realised in practice and under what circumstances is less clear. This paper explores whether knowing the person's life story enhances healthcare professionals' understanding of the person with dementia and whether this understanding impacts on the person's care. In-depth interviews were conducted with 11 registered nurses and 12 healthcare assistants who had used life story work with people with dementia living in long-stay care settings. Data were analysed using the constant comparative technique. Engaging in life story work enabled staff to see the person behind the dementia. Understanding (as opposed to knowing) the person with dementia's life story changed staff's thinking on what is important when delivering care to people with dementia, with staff giving concrete examples of changes in how they delivered care to the person with dementia and what they considered important when delivering that care. It was concluded that life story work can facilitate a shift to person centred dementia care but how it is implemented matters if this outcome is to be achieved.

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Patrick Glaister	Clinical Librarian
Judith Aquino	E-Resources Librarian
Sarah Glover	Library Services Officer
Charlotte Holden	Library Services Officer
Lauren Kay	Library Services Officer

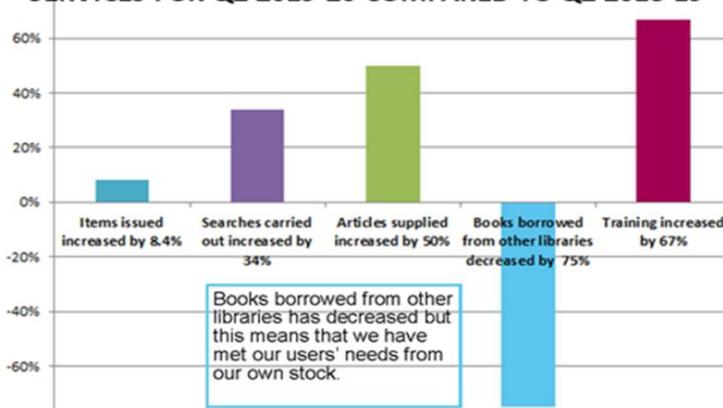
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Performance Indicators – In Q2, we have increased delivery on many of our training

PERFORMANCE FOR ELHT LIBRARY AND KNOWLEDGE SERVICES FOR Q2 2019-20 COMPARED TO Q2 2018-19



programmes. This includes literature searches and our social media training. To ensure that these programmes are of benefit to the learner, we have implemented a range of tools to measure the quality and the impact of what we do. For example, our learners tell us that *our library induction is the best induction that they have ever had at any Trust (FY2s)*. In addition to this, our social media training questionnaire has received

very favourable comments, including *“the training received has been brilliant and I can’t wait to use this to promote all the things that we do”*.

Education @ELHT is produced every two months and it highlights all the wonderful work that the department does. Our **Library Guide** highlights all the services that we offer. Click on the Bulletin or Guide and find out more about how we can support you, whether you are staff, student, or volunteers.



Education @ ELHT News

September 2019

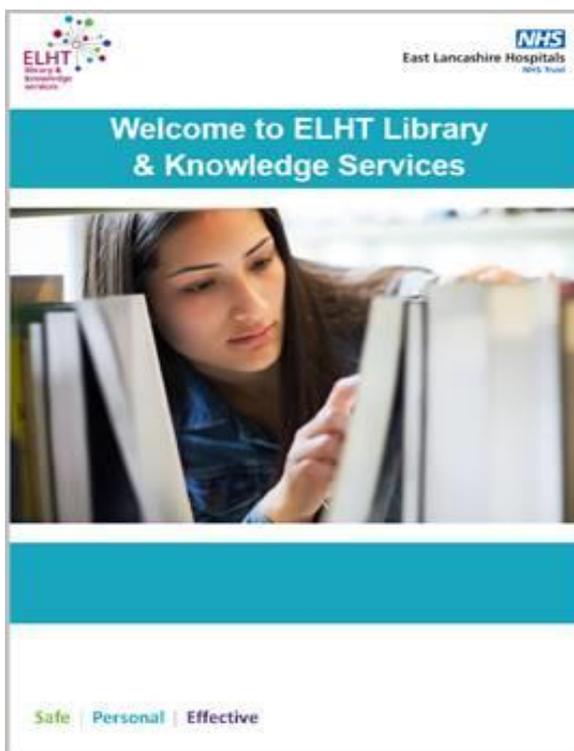
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