NHS
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Dementia
Current Awareness Bulletin

February 2018

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From NHS Academy of Fab Stuff:

Myography is a life story book for older adults, it was designed to not only record a person's life story but prompt and promote engagement not only from the author but also their family, friends and carers.

Myography contains hundreds of unique autobiographical stickers, maps, and adult colouring helping you to create a personalised book, It's your story your way. It has been designed not just for the individual but with the family in mind.

You simply remove one of the many autobiographical stickers place it at the top of a page and answer it, this could be from the individuals perspective or the family members.

Ultimately we would like to see Myography at someone's funeral, being used as book condolences, bursting open at the seems with children colouring, old photos and dog-eared pages so the family don't just take home a book of signatures but their loved one's story to pass onto grandchildren so they can have a real connection with those that came before.

Our initial version was originally designed for older adults living with a diagnosis of dementia, however, due to already popular demand, we are currently creating a version for adults so anyone from 18 upwards can start recording their story.

Whilst we aren't quite ready to release Myography, you can check us out at www.indiegogo.com/projects/myography or at our website www.myography.co.uk

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If your surrounding does not feel & look like home it's logical that you start looking for the exit to set off home.

What would you do when somebody is trying to stop you on your way home? Saying "you may not go, this is your home". Do you tell him "This is not my home, let me through".

Or would you start shouting and become violence as it feel as your right to be allowed to go to your own house. And of course you are standing in your right, you can't help it that the dementia fog has relocates your home to the past and is making your present surrounding incomprehensible.

This is a big problem in dementia care, causes much stress, fear and unrest by a person with dementia and is a physical and time burden for the nurses and carers.

How to help:
How can we prevent the despair, the anger and the violence?

How can we give a person with dementia a home feeling?

By creating a recognizable environment.

The benefits:
Less anger, violence and frustrations

Reduced wandering and runaway urges

Happy residence & happy nurses

What you need to know:
A favorable environment produces favorable behavior

How to do:
By putting furniture, photos and objects into the surrounding, which are recognized by the person with dementia.

What to use:
Small furniture: chair – lamp – radio……

Objects like: working/hobby/household tools

Photo’s of: parental home, working environment, beloved spots ect…..

How to find the right (fabulous) stuff:

Go with the person with dementia to a thrift shop or a flea market.
Observe which objects the person recognized, happy or enthusiastic made.

Make photos of the object or even better buy them.

The recognized objects give you an indication of the period and era of objects which you can use to create a home feeling.

When it not possible to go outside, use your phone or tablet as a flea market.

For example search in Google for “daily life in the 60’s in the UK” select images, there you go, the digital flea market.

How to find the right photos:

Walk with the person with dementia through his photo albums.

Don’t say, look there is aunt Betty, or that’s a lovely picture of your husband.

The person with dementia will follow you, saying yes yes.

But you don’t know if the person with dementia really recognizes the photo.

Let the person be your photo guide.

Don’t choose for the person.

Not puttin’ on the Ritz:
Every photo, which makes the person with dementia feel good or happy, is a good photo! So not what the family, caregiver or management likes or not likes, but what person with dementia likes, that’s what counts.

Remember you not styling a room in the Ritz, but you try to give a person with dementia a home feeling.

Working 9 to 5:
Think about the job of the person.
Are the pictures of the job, the shop, or colleagues?
If not, search on the Internet for a similar working environment.

On canvas:
When you are sure you have the right photos.
Print them, for example on canvas.
And hang them on the wall.

No postcard sizing:
I am not talking about postcard format photos.
Think big; calculate the costs of tranquillizers and the time you spent finding a person or arguing over not to be allowed to leave?

Add these costs of a whole year up. I think you can order a wall size photo, you get my drift.

Family present:
The photo could also given by the family as a birthday present.
Is giving home feelings to a person with dementia not the most wonderful birthday present you can give?

Job tools:
Look if you can you put working tools in the room.
What job had the person? Which tools has he/she used?
Besides being a beacon, the tools might become a day-filling activity.

Household Tools:
Cleaning & Household objects could also become beacons, daily activities and at the same time giving the feeling of being useful.

Think about:
Needle & Thread plus a pile of clothing to repair
Polishes & silver or copper to brush
Dusters & Dusting

Hobby tools:
What were the person's hobbies? Are they still present in the brain?
For example stamp collecting, painting, sculpture etc…

What did they make in those years during the crafts lessons at school?

Even when a person is not able to work with the tools anymore, they can give comfort just by being there. They will be lighthouses in the dementia fog.

***Music instruments*:**
Musical skills are not affected by dementia.

So when a person has played a music instrument he or she can often play that instrument in spite of the dementia.

Find out if the person has played an instrument.

If so, put that instrument in the room.
Play the kind of music the person did play on that instrument.
Don't push just look what happens, read the transverse flute story below.

The Fab Nutshell of Tool Three:

1- A favorable environment produces favorable behavior
2- Create a surrounding where the person with dementia feels at home
3- Find, together with the person with dementia recognizable objects
4- Decorate the room with furniture, photo's & objects which being recognized
5- Look if some objects can become an activity
7- Involve the family in the search for the right objects
6- Everything you do for a person with dementia is coming back to you

An innovative new service is helping patients in Cumbria at risk of becoming confused during their stay in hospital.

Delirium is mental confusion, which can sometimes occur when people are unwell. It can be caused by a number of things, including infections, dehydration and pain, but with the right support it can be managed or even avoided.

The Memory and Later Life services at Cumbria Partnership NHS Foundation Trust are launching 'Reach-Out' (Reduce, Educate, Assess & Care with Hope) to do just that.

This service is the first of its kind in the UK and has been co-produced by mental health specialists and clinicians from across the North Cumbria Health and Care System with input from patients and their carers.

David Storm, Senior Clinical Service Manager, explains "The service will work seven days per week and will proactively check on hospital patient information systems for anyone admitted to hospital who is at risk of developing delirium. The service will check if they are known to local memory services and if not arrange a referral. These patients will then be screened every day of their hospital admission until they are discharged to try to prevent them developing delirium but also ensuring quick treatment if they do. In addition the service will provide twice daily social and mental stimulation to those at high risk of delirium, support hospital staff in their management and work closely with families and carers. For example, someone with Dementia or a high risk of Delirium, which can be caused by infections, dehydration, pain, constipation, sleep deprivation etc being admitted to hospital, would be picked up soon after admission. This would have numerous benefits; checking existing memory service is aware of admission, making sure medications are not changed without discussions, connecting with carers to understand how the person was before hospital admission. This will help the person return to their usual place of residence, avoid going in to long term care and ensure any additional concerns are considered".

Anna Munch-Andersen, Elderly Care Consultant at North Cumbria University Hospitals NHS Trust, said: "It's important that we take a holistic approach to patient care and increase awareness of delirium, especially for those with dementia who are often more at risk. Sometimes it isn't possible to identify the specific cause of the delirium, but it is a treatable condition and we'll be working very closely with the service to ensure our patients receive the best possible care."

This service was identified as a priority for hospital, community and social care services as part of our integrated North Cumbria Health and Care system.

This is the way in which health and care providers and commissioners are working together across Copeland, Allerdale, Carlisle and Eden.

Reach-Out is a dedicated service for Delirium and has several key elements; prevention, effective screening, support, treatment, liaising with other services to support discharge and education.

Health professionals will work with patients at the Cumberland Infirmary and the West Cumberland Hospital who are at risk of developing Delirium. Reach-Out will also provide education and practical support to other hospital staff which aims to improve awareness and recognition of Delirium.

From King's Fund

Promising approaches to living well with dementia

This report outlines a number of scaleable and cost-effective interventions that can support people with dementia. It includes case studies of services and projects that support wellbeing and living well for people with dementia.

Journal Articles

Title: The challenges of implementing and evaluating a pilot music and movement intervention for people with dementia: Innovative practice.

Citation: Dementia (14713012); Nov 2017; vol. 16 (no. 8); p. 1064-1068
Authors: Mc Parland, Patricia; Cutler, Clare; Innes, Anthea

Abstract: This paper reports on the challenges associated with implementing and evaluating an innovative pilot music and movement project. The evaluation documents that participants enjoyed the sessions and that they created the opportunity for social engagement although there is little to suggest this is unique to this particular type of intervention. Difficulties included matching the programme to the needs of participants, communicating effectively, and over burdensome paperwork. The paper also comments on the challenges associated with last minute, limited funding opportunities for both the organisation commissioning a project and the team evaluating it. In this case, the evaluation team found that many of the more difficult issues associated with the pilot could have been resolved with more time for planning and preparation.

Title: Familiar communication partners' facilitation of topic management in conversations with individuals with dementia.

Citation: International journal of language & communication disorders; Jan 2018

Author(s): Hall, Karinna; Lind, Christopher; Young, Jessica A; Okell, Elise; van Steenbrugge, Willem

Background: Language and memory impairments affect everyday interactions between individuals with dementia and their communication partners. Impaired topic management, which compromises individuals' construction of relevant, meaningful discourse, is commonly reported amongst individuals with dementia. Currently, limited empirical evidence describes the sequential patterns of behaviour comprising topic-management practices in everyday conversation between individuals with dementia and their communication partners.

Aims: To describe the sequential patterns of behaviour relating to the manifestation of topic-management impairments and facilitative behaviours in everyday interactions between individuals with dementia and their familiar communication partners (FCPs).

Methods & Procedures: Three 20-min conversations between individuals with moderate to severe dementia and their FCPs were recorded. Conversation Analysis was used to examine sequences in which topic-management appeared to be impaired.

Outcomes & Results: Conversational behaviours that reflected a difficulty in contributing on-topic talk were pervasive in the talk of the three individuals with dementia. FCPs responded to these conversational difficulties by using two categories of facilitative behaviours. The first involved responding to an individual with dementia's explicit repair-initiation by performing repair. In the second category, explicit repair-initiation was absent; instead, the distance of the conversational difficulty from the prior topic-shifting turn mediated the form and outcome of the FCPs' facilitative behaviours. Each category successfully facilitated the individual with dementia to contribute on-topic talk.

Conclusions & Implications: The findings contribute to a growing understanding of topic-management abilities in everyday interactions involving individuals with dementia. Individuals with dementia took a proactive role in eliciting topic-management support. The FCPs responded with turns that facilitated the individuals with dementia to talk on-topic. Clinically, the results support and extend the current topic-management recommendations available in communication partner training programmes, and promote conversations which attend to the personhood of the individual with dementia.

Title: From Research to Application: Supportive and Therapeutic Environments for People Living With Dementia.

Citation: The Gerontologist; Jan 2018; vol. 58 ; p. S114

Author(s): Calkins, Margaret P

Abstract: The evidence about the role the designed and built environment plays in supporting individuals living with dementia has been steadily mounting for almost 40 years. Beginning with the work of M. Powell Lawton at the Weiss Pavilion at the Philadelphia Geriatric Center, there are now dozens of researchers who are exploring how the environment can be either supportive and therapeutic, indeed even serving as a prosthetic for various changes in cognition, or be a barrier to independent functioning and high quality of life. Two recent literature reviews published on the impact of environmental factors and characteristics on individuals living with dementia clearly delineate evidence that the environment can have a therapeutic or a debilitating impact on individuals living with dementia. Rather than duplicate these excellent reviews, this article puts the knowledge gleaned from this research into the shifting context that is long-term care. This article begins with an exploration of the evolution of approaches to the design of spaces for individuals living with dementia from traditional or medical models, to special care units (SCUs), to person-centered care (PCC), which is the organizing theme of this supplemental issue. A novel, person-centered way of conceptualizing the domains of environmental systems is then presented and used as the framework for structuring recommendations and creating supportive and therapeutic environments for individuals living with dementia. Although there are distinct pathophysiological and behavioral manifestations of different forms of dementia, there is almost no evidence that suggests alternative environmental characteristics are better for one type of dementia over another. Thus, this article will refer to "individuals living with dementia" as opposed to Alzheimer's disease or other specific forms of dementia. Further, this article only addresses residential environments: homes in the community, independent and assisted living residences and nursing homes. It does not address other settings, such as hospitals or hospice, or work and public community spaces, such as stores. It is recognized that individuals living with dementia do spend time in all these spaces, and fortunately, there is growing interest in creating more dementia-friendly communities, but they will not be addressed in this article. Most of the research that has been done has focused on shared residential settings, so that will be the primary focus on this article.

Title: Emergency Department Use by Community-Dwelling Individuals with Dementia in the United States: An Integrative Review.

Citation: Journal of gerontological nursing; Jan 2018; p. 1-17

Author(s): Hunt, Lauren J; Coombs, Lorinda A; Stephens, Caroline E

Abstract: As part of the National Plan to Address Alzheimer's Disease, reducing potentially avoidable emergency department (ED) use by individuals with dementia has been identified as a component of enhancing the quality and efficiency of care for this population. To help inform the development of interventions to achieve this goal, an integrative review was conducted to: (a) compare rates and reasons for ED visits by community-dwelling individuals with and without dementia, considering also the effect of dementia subtype and severity; and (b) identify other risk factors for increased ED use among community-dwelling individuals with dementia. Nineteen articles met inclusion criteria. Individuals with dementia had higher rates of ED visits compared to those without dementia, although differences were attenuated in the last year of life. Increased symptoms and disability were associated with increased rates of ED visits, whereas resources that enabled effective management of increased need decreased rates. Gerontological nurses across settings are on the frontlines of preventing potentially avoidable ED visits by community-dwelling individuals with dementia through patient and family education and leadership in the development of new models of care. [Journal of Gerontological Nursing, xx(x), xx-xx.].

Title: Evidence-Based Interventions for Transitions in Care for Individuals Living With Dementia.

Citation: The Gerontologist; Jan 2018; vol. 58 ; p. S129

Author(s): Hirschman, Karen B; Hodgson, Nancy A

Background and Objectives: Despite numerous, often predictable, transitions in care, little is known about the core elements of successful transitions in care specifically for persons with dementia. The paper examines available evidence-based interventions to improve the care transitions for persons with dementia and their caregivers.

Research Design and Methods: A state-of-the-art review was conducted for research published on interventions targeting transitions in care for persons living with dementia and their caregivers through January 2017.

Results: Our review revealed seven evidence-based interventions to postpone/prevent or reduce care transitions specific to persons living with dementia. Effective approaches appear to be those that involve the individual and caregiver in establishing goals of care, educate the individual and caregiver about likely transitions in care; provide timely communication of information about the individual, create strong inter professional teams with competencies in dementia care, and implement evidence-based models of practice.

Discussion and Implications: Five essential features for consistent and supported care transitions for persons with dementia and their caregivers are recommended. Findings reinforce the need for additional research and adaptation of evidence-based transitions in care interventions.

Title: Quality of family relationships and outcomes of dementia: a systematic review.

Citation: BMJ open; Jan 2018; vol. 8 (no. 1); p. e015538

Author(s): Edwards, Hannah B; Ijaz, Sharea; Whiting, Penny F; Leach, Verity; Richards, Alison; Cullum, Sarah J; Cheston, Richard Il; Savović, Jelena

Objectives: To evaluate the association between the quality of relationship between a person with dementia and their family carer and outcomes for the person with dementia.

Design: Systematic review.

Eligibility Criteria: Cohort studies of people with clinically diagnosed dementia and their main carers. Exposures of interest were any elements of relationship quality, for example, attachment style, expressed emotion and coping style. Our primary outcome was institutionalisation, and secondary outcomes were hospitalisation, death, quality of life and behavioural and psychiatric symptoms of dementia ('challenging behaviour').

Data Sources: MEDLINE, Embase, Web of Science, PsycInfo, the Cochrane Library and Opengrey were searched from inception to May 2017.

Study Appraisal And Synthesis Methods: The Newcastle-Ottawa Scale was used to assess risk of bias. A narrative synthesis of results was performed due to differences between studies.

Results: Twenty studies were included. None of the studies controlled for all prespecified confounding factors (age, gender, socioeconomic status and severity of dementia). Reporting of results was inadequate with many studies simply reporting whether associations were 'statistically significant' without providing effect size estimates or CIs. There was a suggestion of an association between relationship factors and global challenging behaviour. All studies evaluating global challenging behaviour provided statistical evidence of an association (most P values below 0.02). There was no consistent evidence for an association for any other outcome assessed.

Conclusions: There is currently no strong or consistent evidence on the effects of relationship factors on institutionalisation, hospitalisation, death or quality of life for people with dementia. There was a suggestion of an association between relationship factors and challenging behaviour, although the evidence for this was weak. To improve our ability to support those with dementia and their families, further robust studies are needed.

Prospero Registration Number: CRD42015020518.

Title: The nutritional care of people living with dementia at home: A scoping review.

Citation: Health & social care in the community; Jan 2018

Author(s): Mole, Louise; Kent, Bridie; Abbott, Rebecca; Wood, Chloë; Hickson, Mary

Abstract: There are an increasing number of people with dementia living in their own home for longer, often supported by a family member. The symptoms of dementia can affect an individual's nutritional status, which can lead to a reduced quality of life for the person with dementia and their family members. A scoping review was conducted from July 2016 until September 2016, using a recognised framework, to explore what is currently known, and identify any gaps in the research regarding the nutritional care of people living with dementia at home. This included any interventions that may have been trialled or implemented, and the views of those living with dementia, carers and clinicians. Six electronic databases were searched from inception to July 2016. A review team was involved in screening and data extraction for selected articles. Published qualitative and quantitative studies were included that explored the nutritional care of people living with dementia at home. Methods included data extraction and conventional content analysis. Stakeholders were involved in the development of final categories. Following screening, 61 studies reported in 63 articles were included. Most studies were cross-sectional (n = 24), cohort (n = 15) or qualitative (n = 9). Only three were randomised controlled trials. Three overarching categories represented the results: Timely identification of nutritional risk and subsequent regular monitoring of nutritional status, multi-component tailored interventions and the influence of the care-giving dyad on nutritional status. Many studies identify people living at home with dementia as a vulnerable group prone to malnutrition; however, a lack of interventions exists to address the increased risk. There is a lack of research exploring the role of home care providers and healthcare professionals in the provision of nutritional care. Further research is required to explore how the emotional aspect of the care-giving dyad influences nutritional care

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Title: The barriers and facilitators for recognising distress in people with severe dementia on general hospital wards.

Citation: Age and ageing; Jan 2018

Author(s): Crowther, G J E; Brennan, C A; Bennett, M I

Introduction: psychological symptoms and delirium are common, but underreported in people with dementia on hospital wards. Unrecognised and untreated symptoms can manifest as distress. Identifying distress accurately therefore could act as a trigger for better investigation and treatment of the underlying causes. The challenges faced by healthcare professionals to recognise and report distress are poorly understood.

Methods: semi-structured interviews with a purposive sample of 25 healthcare professionals working with older people in general hospitals were conducted. Interviews were analysed generating themes that describe the facilitators and barriers of recognising and caring for distress in dementia.

Results: regardless of training or experience all participants had a similar understanding of distress, and identified it as a term that is easily understood and communicated. All participants believed they recognised distress innately. However, the majority also believed it was facilitated by experience, being familiar with their patients and listening to the concerns of the person's usual carers. Barriers to distress recognition included busy ward environments, and that some people may lack the skill to identify distress in hypoactive patients.

Conclusion: distress may be a simple and easily identified marker of unmet need in people with dementia in hospital. However, modifiable and unmodifiable barriers are suggested that reduce the chance of distress being identified or acted on. Improving our understanding of how distress is identified in this environment, and in turn developing systems that overcome these barriers, may improve the accuracy with which distress is identified on hospital wards.

Title: Evidence-Based Nonpharmacological Practices to Address Behavioral and Psychological Symptoms of Dementia.

Citation: The Gerontologist; Jan 2018; vol. 58 ; p. S88

Author(s): Scales, Kezia; Zimmerman, Sheryl; Miller, Stephanie J

Background and Objectives: To draw from systematic and other literature reviews to identify, describe, and critique nonpharmacological practices to address behavioral and psychological symptoms of dementia (BPSDs) and provide evidence-based recommendations for dementia care especially useful for potential adopters.

Research Design and Methods: A search of systematic and other literature reviews published from January 2010 through January 2017. Nonpharmacological practices were summarized to describe the overall conceptual basis related to effectiveness, the practice itself, and the size and main conclusions of the evidence base. Each practice was also critically reviewed to determine acceptability, harmful effects, elements of effectiveness, and level of investment required, based on time needed for training/implementation, specialized care provider requirements, and equipment/capital requirements.

Results: Nonpharmacological practices to address BPSDs include sensory practices (aromatherapy, massage, multi-sensory stimulation, bright light therapy), psychosocial practices (validation therapy, reminiscence therapy, music therapy, pet therapy, meaningful activities), and structured care protocols (bathing, mouth care). Most practices are acceptable, have no harmful effects, and require minimal to moderate investment.

Discussion and Implications: Nonpharmacological practices are person-centered, and their selection can be informed by considering the cause and meaning of the individual's behavioral and psychological symptoms. Family caregivers and paid care providers can implement evidence-based practices in home or residential care settings, although some practices require the development of more specific protocols if they are to become widely used in an efficacious manner.

Title: Falls and Hospitalizations Among Persons With Dementia and Associated Caregiver Emotional Difficulties.

Citation: The Gerontologist; Jan 2018

Author(s): Leggett, Amanda N; Polenick, Courtney A; Maust, Donovan T; Kales, Helen C

Background and Objectives: Falls and hospitalizations are adverse health events commonly experienced by persons with dementia (PWDs). These events often require urgent care from a family caregiver and may increase caregiver stress. We examine falls and hospitalizations among PWDs as predictors of caregivers' reported care-related emotional difficulty, in addition to care-related stressors.

Research Design and Methods: Cross-sectional telephone survey of 652 informal caregivers for PWDs. A multinomial logistic regression examined falls (last month) and hospitalizations (prior year) experienced by PWDs as predictors of caregivers' care-related emotional difficulty, accounting for demographic characteristics and primary and secondary caregiving stressors.

Results: Over 20% of caregivers reported high levels of care-related emotional difficulty. Controlling for demographic characteristics and primary and secondary caregiving stressors, the PWD's prior month fall was significantly associated with greater care-related emotional difficulty; the PWD's hospitalizations were not associated with care-related emotional difficulty.

Discussion and Implications: Approximately 30% of PWDs had experienced a past year hospitalization and prior month fall, and one in five caregivers reported high emotional difficulty related to care. Although secondary strains and resources of caregiving were strong predictors of care-related emotional difficulty, PWDs' falls represent a significant stressor that increases odds of caregiver emotional difficulty over and above other strains. Consequently, a fall experienced by a PWD may represent a key time for clinicians to assess caregiver well-being.

Title: Proactive approaches to identifying dementia and dementia risk; a qualitative study of public attitudes and preferences.

Citation: BMJ open; Feb 2018; vol. 8 (no. 2); p. e018677

Author(s): Robinson, Louise; Dickinson, Claire; Magklara, Eleni; Newton, Lisa; Prato, Laura; Bamford, Claire

Objectives: The aim of this study was to critically explore the views of the public about the acceptability and feasibility of proactive approaches to earlier dementia diagnosis and also identification of people at high risk of dementia.

Design: Qualitative study using task group methodology and thematic data analysis.

Setting: Task groups were held either at the university (n=5) or at a carers' centre (n=1).PARTICIPANTSA convenience sample of 31 of 54 participants identified by local non-statutory agencies took part in a task group. All were aged between 40 years and 80 years, 21 were women and 10men participated.

Results: Despite the use of task group methodology, participants expressed limited understandings of dementia and confusion between proactive approaches. Nevertheless, they highlighted a range of potential benefits and limitations of proactive approaches and the ethical issues raised. There was a preference to embed risk assessment within routine health checks, which focused on achieving a healthier lifestyle, rather than specifically on dementia. Participants emphasised the need to ensure informed consent prior to use of proactive approaches and to provide appropriate support. They also suggested alternative approaches that could potentially facilitate the early detection of dementia or reduce risk at a population level.

Conclusions: As international policy on dementia shifts towards a prevention agenda there is growing interest in identifying those at risk of developing dementia. This study provides useful insights into the acceptability of the use of such proactive approaches among the public. The introduction of proactive approaches to dementia identification raises complex practical and ethical issues, particularly in the context of low public understanding of dementia. The importance of better quality information about dementia (and the likelihood of developing dementia) and provision of psychological support for those undergoing risk assessment were highlighted.

Title: People with dementia and carer preferences for home support services in early-stage dementia.

Citation: Aging & mental health; Feb 2018; vol. 22 (no. 2); p. 270-279

Author(s): Chester, Helen; Clarkson, Paul; Davies, Linda; Sutcliffe, Caroline; Davies, Sue; Feast, Alexandra; Hughes, Jane; Challis, David; Members of the HOST-D (Home Support in Dementia) Programme Management Group.

Objectives: To examine people with dementia and carer preferences for home support attributes in early-stage dementia, building on the paucity of evidence in this area.

Method: Preferences from 44 people with dementia and 103 carers, recruited through memory clinics and an online questionnaire, were assessed with a Discrete Choice Experiment survey, with attributes informed by an evidence synthesis and lay consultation. A conditional logit model was used to estimate preference weights for the attributes within a home support 'package'.

Results: The most preferred attributes were support with personal feelings and concerns, provided by a trained counsellor at home (coefficient 0.67, p = <0.001) and information on coping with dementia, provided by an experienced worker at home (coefficient 0.59, p = <0.001). However, for people with dementia, opportunities for social and recreational activities were considered the most important (coefficient 0.48, p = <0.001).

Conclusions: These preferences concur with emerging evidence on psychosocial interventions in dementia. Support with personal feelings, information and social engagement are important components. Additionally, knowledge of preferences of people with dementia and their carers can identify other attributes that may be important to effectiveness in 'living well' but for which there remains limited evidence.

Title: Understanding important issues in young-onset dementia care: the perspective of healthcare professionals.

Citation: Neurodegenerative disease management; Feb 2018; vol. 8 (no. 1); p. 37-47

Author(s): Spreadbury, John H; Kipps, Christopher M

Aim: Psychosocial research on the lived experiences of young-onset dementia patients and caregivers has identified salient issues about their care, however, views on care from the perspective of young-onset dementia healthcare professionals is less well known. The aim of this study was to investigate and identify important issues in young-onset dementia care provision from a healthcare provider perspective.

Methods: The design was an exploratory qualitative interview study. In-depth semistructured interviews were conducted with healthcare professionals with clinical expertise in young-onset dementia drawn from medicine, nursing and allied health. Thematic analysis was applied to interview transcripts to identify themes representing important underlying issues in care across the dementia clinical pathway (i.e., prediagnosis, diagnosis and postdiagnosis).

Results: In prediagnosis, it is important for healthcare professionals to recognize symptoms as organic and degenerative and more than psychological, and to refer patients to an appropriate clinical facility for assessment. During diagnosis, it may be challenging to determine dementia, and methods are employed to manage diagnostic uncertainty. Following diagnosis, optimizing routine clinical care is important and can include the provision of practical informational guidance, empathic concern and psychoeducational support. Meeting service-user requirements in the community is an important aspect of care, and may be facilitated by the involvement of clinical nurse specialists.

Conclusion: The findings are presented as a paradigm for holistic young-onset dementia care. The paradigm offers a framework for contemplating and evaluating the criteria and quality of young-onset dementia care.

Title: The experience of lived space in persons with dementia: a systematic meta-synthesis.

Citation: BMC geriatrics; Feb 2018; vol. 18 (no. 1); p. 33

Author(s): Førsund, Linn Hege; Grov, Ellen Karine; Helvik, Anne-Sofie; Juvet, Lene Kristine; Skovdahl, Kirsti; Eriksen, Siren

Background: Identifying how persons with dementia experience lived space is important for enabling supportive living environments and creating communities that compensate for the fading capabilities of these persons. Several single studies have explored this topic; however, few studies have attempted to explicitly review and synthesize this research literature. The aim of this systematic meta-synthesis was therefore to interpret and synthesize knowledge regarding persons with dementia's experience of space.

Methods: A systematic, computerized search of AgeLine, CINAHL Complete, Embase, Medline and PsycINFO was conducted using a search strategy that combined MeSH terms and text words for different types of dementia with different descriptions of experience. Studies with 1) a sample of persons with dementia, 2) qualitative interviews as a research method and 3) a description of experiences of lived space were included. The search resulted in 1386 articles, of which 136 were identified as eligible and were read and assessed using the CASP criteria. The analysis was inspired by qualitative content analyses.

Results: This interpretative qualitative meta-synthesis included 45 articles encompassing interviews with 672 persons with dementia. The analysis showed that living in one's own home and living in long-term care established different settings and posed diverse challenges for the experience of lived space in persons with dementia. The material revealed four main categories that described the experience of lived space: (1) belonging; (2) meaningfulness; (3) safety and security; and (4) autonomy. It showed how persons with dementia experienced a reduction in their lived space due to the progression of dementia. A comprehensive understanding of the categories led to the latent theme: "Living with dementia is like living in a space where the walls keep closing in".

Conclusion: This meta-synthesis reveals a process whereby lived space gradually becomes smaller for persons with dementia. This underscores the importance of being aware of the experiences of persons with dementia and the spatial dimensions of their life-world. To sustain person-centred care and support the preservation of continuity and identity, one must acknowledge not only the physical and social environment but also space as an existential experience for persons with dementia.

Title: The role of music in the lives of older adults with dementia ageing in place: A scoping review.

Citation: Dementia (London, England); Feb 2018; vol. 17 (no. 2); p. 199-213

Author(s): Elliott, Melanie; Gardner, Paula

Abstract: The number of people around the world living with dementia is predicted to rise from 44 million to 135 million by 2050. Traditional treatments for dementia have been largely unsuccessful and prompted the emergence of alternative strategies. Music is emerging as an effective therapeutic strategy for older adults with dementia however, most of the work to date has focused on institutions. The purpose of this scoping review was to summarize what is known about the role and impact that music plays in the lives of community-dwelling older adults with dementia. Using a five-stage framework for conducting a scoping review,

analysis revealed three ways in which music influences the lives of community-dwelling older adults with dementia: (a) reduced agitation, (b) improved cognition, and (c) enhanced social well-being. The concept of personhood provided a lens with which to conceptualize the findings and highlights the need for continued research.

Title: Pilot test of a six-week group delivery caregiver training program to reduce sleep disturbances among older adults with dementia (Innovative practice).

Citation: Dementia (London, England); Feb 2018; vol. 17 (no. 2); p. 234-243

Author(s): Tewary, Sweta; Cook, Nicole; Pandya, Naushira; McCurry, Susan M

Abstract: The purpose of the pilot program was to examine the adaptability and feasibility of a modified group-delivery sleep education program (NITE-AD) designed to reduce nocturnal disturbances in community-dwelling older adults with dementia. We recruited seven caregivers of persons with dementia from two adult day care centers in South Florida into a six-week group program at adult day care centers. A trained sleep educator taught caregivers about the impact of aging and dementia on sleep and how non-pharmacological interventions such as increasing light, regular exercise, and sleep hygiene strategies can improve sleep in persons with dementia. The curriculum incorporated ongoing problem solving and goal setting. Results suggest improvement in caregiver depression and persons with dementia sleep problems. Caregivers reported that the program provided them support and valuable strategies that they will continue to apply. Educating caregivers in a group setting about non-pharmacologic strategies for managing sleep may reduce caregiver burden and improve sleep among persons with dementia.

Title: The Unforgettables: a chorus for people with dementia with their family members and friends.

Citation: International psychogeriatrics; Jan 2018 ; p. 1-11

Author(s): Mittelman, Mary Sherman; Papayannopoulou, Panayiota Maria

Summary/Abstract: Our experience evaluating a museum program for people with dementia together with their family members demonstrated benefits for all participants. We hypothesized that participation in a chorus would also have positive effects, giving them an opportunity to share a stimulating and social activity that could improve their quality of life. We inaugurated a chorus for people with dementia and their family caregivers in 2011, which rehearses and performs regularly. Each person with dementia must be accompanied by a friend or family member and must commit to attending all rehearsals and the concert that ensues. A pilot study included a structured assessment, take home questionnaires and focus groups. Analyses of pre-post scores were conducted; effect size was quantified using Cohen's d. Results showed that quality of life and communication with the other member of the dyad improved (Effect size: Cohen's d between 0.32 and 0.72) for people with dementia; quality of life, social support, communication and self-esteem improved (d between 0.29 and 0.68) for caregivers. Most participants stated that benefits included belonging to a group, having a normal activity together and learning new skills. Participants attended rehearsals in spite of harsh weather conditions. The chorus has been rehearsing and performing together for more than 6 years and contributing to its costs. Results of this pilot study suggest that people in the early to middle stage of dementia and their family members and friends can enjoy and learn from rehearsing and performing in concerts that also engage the wider community. It is essential to conduct additional larger studies of the benefits of participating in a chorus, which may include improved quality of life and social support for all, and reduced cognitive decline among people with dementia.

Title: Evaluating a dementia learning community: exploratory study and research implications.

Citation: BMC health services research; Feb 2018; vol. 18 (no. 1); p. 83

Author(s): Sheaff, Rod; Sherriff, Ian; Hennessy, Catherine Hagan

Background: Access times for, the costs and overload of hospital services are an increasingly salient issue for healthcare managers in many countries. Rising demand for hospital care has been attributed partly to unplanned admissions for older people, and among these partly to the increasing prevalence of dementia. The paper makes a preliminary evaluation of the logic model of a Dementia Learning Community (DLC) intended to reduce unplanned hospital admissions from care homes of people with dementia. A dementia champion in each DLC care home trained other staff in dementia awareness and change management with the aims of changing work routines, improving quality of life, and reducing demands on external services.

Methods: Controlled mixed methods realistic evaluation comparing 13 intervention homes with 10 controls in England during 2013-15. Each link in the assumed logic model was tested to find whether that link appeared to exist in the DLC sites, and if so whether its effects appeared greater there than in control sites, in terms of selected indicators of quality of life (DCM Well/Ill-Being, QUALID, end-of-life planning); and impacts on ambulance call-outs and hospital admissions.

Results: The training was implemented as planned, and triggered cycles of Plan-Do-Study-Act activity in all the intervention care homes. Residents' well-being scores, measured by dementia care mapping, improved markedly in half of the intervention homes but not in the other half, where indeed some scores deteriorated markedly. Most other care quality indicators studied did not significantly improve during the study period. Neither did ambulance call-out or emergency hospital admission rates.

Conclusions: PDSA cycles appeared to be the more 'active ingredient' in this intervention. The reasons why they impacted on well-being in half of the intervention sites, and not the others, require further research. A larger, longer study would be necessary to measure definitively any impacts on unplanned hospital admissions. Our evidence suggested revising the DLC logic model to include care planning and staff familiarisation with residents' personal histories and needs as steps towards improving residents' quality of life.

Title: Targeting Behavioral Symptoms and Functional Decline in Dementia: A Randomized Clinical Trial.

Citation: Journal of the American Geriatrics Society; Feb 2018; vol. 66 (no. 2); p. 339-345

Author(s): Gitlin, Laura N; Arthur, Paul; Piersol, Catherine; Hessels, Virginia; Wu, Samuel S; Dai, Yunfeng; Mann, William C

Background/Objectives: Dementia-related behavioral symptoms and functional dependence result in poor quality of life for persons with dementia and their caregivers. The goal was to determine whether a home-based activity program (Tailored Activity Program; TAP-VA) would reduce behavioral symptoms and functional dependence of veterans with dementia and caregiver burden.

Design: Single-blind (interviewer), parallel, randomized, controlled trial (Clinicaltrials.gov: NCT01357564).

Setting: Veteran's homes.

Participants: Veterans with dementia and their family caregivers (N = 160 dyads).

Intervention: Dyads in TAP-VA underwent 8 sessions with occupational therapists to customize activities to the interests and abilities of the veterans and educate their caregivers about dementia and use of customized activity. Caregivers assigned to attention control received up to 8 telephone-based dementia education sessions with a research team member.

Measurements: Primary outcomes included number of behaviors and frequency of their occurrence multiplied by severity of occurrence; secondary outcomes were functional dependence, pain, emotional well-being, caregiver burden (time spent caregiving, upset with behaviors) and affect at 4 (primary endpoint) and 8 months.

Results: Of 160 dyads (n = 76 TAP-VA; n = 84 control), 111 completed 4-month interviews (n = 51 TAP-VA; n = 60 control), and 103 completed 8-month interviews (n = 50 TAP-VA; n = 53 control). At 4 months, compared to controls, the TAP-VA group showed reductions in number (difference in mean change from baseline = -0.68, 95% CI = -1.23 to -0.13) and frequency by severity (-24.3, 95% CI = -45.6 to -3.1) of behavioral symptoms, number of activities needing assistance with (-0.80, 95% CI = -1.41 to -0.20), functional dependence level (4.09, 95% CI = 1.06, 7.13), and pain (-1.18, 95% CI = -2.10 to -0.26). Caregivers of veterans in TAP-VA reported less behavior-related distress. Benefits did not extend to 8 months.

Conclusion: TAP-VA had positive immediate effects and no adverse events. Because TAP-VA reduces behavioral symptoms, slows functional dependence, and alleviates pain and caregiver distress, it is a viable treatment option for families.

Title: A systematic review of non-pharmacological treatments for apathy in dementia.

Citation: International journal of geriatric psychiatry; Feb 2018; vol. 33 (no. 2); p. e177

Author(s): Theleritis, Christos; Siarkos, Kostas; Politis, Anastasios A; Katirtzoglou, Everina; Politis, Antonios

Objective: Apathy is one of the most frequent neuropsychiatric symptoms encountered in dementia. Early diagnosis and timely treatment of apathy in dementia are crucial because apathy has been associated with poor disease outcome, reduced daily functioning, and caregiver distress.

Design: Extensive electronic search from the databases included in the National Library of Medicine as well as PsychInfo and Google Scholar for studies which have investigated the effect of non-pharmacological treatments of apathy in dementia. Quality of the studies was appraised.

Results: A total of 1303 records were identified and 120 full-texts assessed. Forty-three unique studies were reviewed. A variety of interventions were found to be effective in reducing apathy in demented patients, particularly when provided in a multidisciplinary manner. However, quantification of the effect was limited by the marked methodological heterogeneity of the studies and the small number of studies where apathy was the primary outcome measure.

Conclusions: Treatment of apathy in dementia is a complex and underexplored field. Certain studies suggest promise for a variety of non-pharmacological interventions. Standardized and systematic efforts primarily focusing on apathy may establish a benefit from individualized treatments for specific disease groups.

Title: "It was then that I thought 'whaat? This is not my Dad": The implications of the 'still the same person' narrative for children and young people who have a parent with dementia.

Citation: Dementia (London, England); Feb 2018; vol. 17 (no. 2); p. 180-198

Author(s): Sikes, Pat; Hall, Mel

Abstract: This research used auto/biographical interviews to explore the experiences of 19, 8 to 31 year olds who had a parent with dementia. Thematic analysis revealed challenges occasioned by the master narrative that people with dementia are 'still' the same person they were prior to the onset of their condition. While this notion is - rightly - at the heart of person-centered care in dementia services, the 'still' discourse conflicts with the experiences of young people. Their accounts suggest that the construction of their parent as the same person is not helpful and that, furthermore, expectations that they will behave and feel towards that parent as they did before are a source of distress in what is already a challenging situation. This paper highlights the need to equip young people with support that acknowledges that their parent may well be drastically different to the Mum or Dad they previously 'knew'.

Title: Living with a partner with dementia: a systematic review and thematic synthesis of spouses' lived experiences of changes in their everyday lives.

Citation: Aging & mental health; Feb 2018 ; p. 1-10

Author(s): Egilstrod, Barbara; Ravn, Maiken Bay; Petersen, Kirsten Schultz

Objectives: Dementia causes dramatic changes in everyday-living for spouses. Occured changes in marital relationship, force spouses to perform more both mentally and physically. Leading to a spousal perceived burden. To improve understanding of spouses' needs, spouses lived experiences is needed. The aim was to identify and synthesise qualitative studies on spouses' lived experiences of living with a partner with dementia.

Methods: A systematic search was undertaken in January 2017. Six databases (CINAHL, Cochrane Library, Embase, PubMed, PsycINFO and Sociological Abstracts) were searched, using search terms in accordance with PICo. A descriptive synthesis and a thematic synthesis were undertaken.

Findings: Fifteen studies met the inclusion criteria. Three themes derived from the analysis 1) Noticing changes in everyday life 2) Transformation to a new marital relation in everyday life, with corresponding sub-themes; changes in marital relationship, management of the transitioned marital relation in everyday life 3) Planning the future.

Conclusion: Findings provide an overview of how spouses notice changes and transform their marital relationships in everyday-life. Findings offer a deeper understanding of changes that occurs over time while the partner is living at home. Findings contribute with knowledge on spouses' experiences of changes in early-stages of dementia. Interventions supporting spouses are needed.

Title: Systematic review of behaviour change techniques to promote participation in physical activity among people with dementia.

Citation: British journal of health psychology; Feb 2018; vol. 23 (no. 1); p. 148-170

Author(s): Nyman, Samuel R; Adamczewska, Natalia; Howlett, Neil

Purpose: The objective of this study was to systematically review the evidence for the potential promise of behaviour change techniques (BCTs) to increase physical activity among people with dementia (PWD).

Methods: PsychINFO, MEDLINE, CINAHL, and the Cochrane Central Register of Controlled Trials databases were searched 01/01/2000-01/12/2016. Randomized controlled/quasi-randomized trials were included if they recruited people diagnosed/suspected to have dementia, used at least one BCT in the intervention arm, and had at least one follow-up measure of physical activity/adherence. Studies were appraised using the Cochrane Collaboration Risk of Bias Tool, and BCTs were coded using Michie et al., 2013, Annals of Behavioral Medicine, 46, 81. taxonomy. Intervention findings were narratively synthesized as either 'very promising', 'quite promising', or 'non-promising', and BCTs were judged as having potential promise if they featured in at least twice as many very/quite promising than non-promising interventions (as per Gardner et al., 2016, Health Psychology Review, 10, 89).

Results: Nineteen articles from nine trials reported physical activity findings on behavioural outcomes (two very promising, one quite promising, and two non-promising) or intervention adherence (one quite promising and four non-promising). Thirteen BCTs were used across the interventions. While no BCT had potential promise to increase intervention adherence, three BCTs had potential promise for improving physical activity behaviour outcomes: goal setting (behaviour), social support (unspecified), and using a credible source.

Conclusions: Three BCTs have potential promise for use in future interventions to increase physical activity among PWD. Statement of contribution What is already known on this subject? While physical activity is a key lifestyle factor to enhance and maintain health and wellbeing amongst the general population, adults rarely participate in sufficient levels to obtain these benefits. Systematic reviews suggest that specific behaviour change techniques can increase physical activity, although one review suggested that self-regulatory techniques may be counterproductive when promoting physical activity among older people. Until now, no systematic review has been conducted to assess which behaviour change techniques may be associated with greater participation in physical activity among people with dementia. What does this study add? Interventions showed mixed promise for increasing physical activity and little effect on participant adherence. Goal setting (behaviour), social support (unspecified), and using a credible source are promising approaches. No technique showed promise for increasing adherence to physical activity interventions among people with dementia.

Title: Identifying patterns of communication in patients attending memory clinics: a systematic review of observations and signs with potential diagnostic utility.

Citation: The British journal of general practice : the journal of the Royal College of General Practitioners; Feb 2018; vol. 68 (no. 667); p. e123

Author(s): Bailey, Cate; Poole, Norman; Blackburn, Daniel J

Background: Subjective cognitive complaints are commonly encountered in primary care and often result in memory clinic referral. However, meta-analyses have shown that such concerns do not consistently correspond to objective memory impairment or predict future dementia. Memory clinic referrals are increasing, with greater proportions of patients attending who do not have dementia. Studies of interaction during memory clinic assessments have identified conversational profiles that can differentiate between dementia and functional disorders of memory. To date, studies exploring communication patterns for the purpose of diagnosis have not been reviewed. Such profiles could reduce unnecessary investigations in patients without dementia.

Aim: To identify and collate signs and observable features of communication, which could clinically differentiate between dementia and functional disorders of memory.

Design and Setting: This was a systematic review and synthesis of evidence from studies with heterogeneous methodologies.

Method: A qualitative, narrative description and typical memory clinic assessment were employed as a framework.

Results: Sixteen studies met the criteria for selection. Two overarching themes emerged: 1) observable clues to incapacity and cognitive impairment during routine assessment and interaction, and 2) strategies and accounts for loss of abilities in people with dementia.

Conclusion: Whether the patient attends with a companion, how they participate, give autobiographical history, demonstrate working memory, and make qualitative observations during routine cognitive testing are all useful in building a diagnostic picture. Future studies should explore these phenomena in larger populations, over longer periods, include dementia subtypes, and develop robust definitions of functional memory disorders to facilitate comparison.

Title: Towards the end of life: An in-depth exploration of the role of Admiral Nursing in dementia care (Innovative practice).

Citation: Dementia (London, England); Feb 2018; vol. 17 (no. 2); p. 244-251

Author(s): Evans, Simon C; Harrison-Dening, Karen; Read, Kate

Abstract: There are approximately 150 Admiral Nurses in the UK who work alongside other health and social care professionals to support people with dementia and their family carers. However, the stigma of the disease and the lack of recognition that dementia is a life limiting illness have led to neglect in addressing the end of life challenges. The small in-depth study reported here aimed to add to an extremely limited formal evidence base for the effectiveness of this approach and to develop a greater understanding of the range of knowledge and skills required of them in ensuring they are better able to support families in the later stages of the illness. Findings focus on the experiences of family carers, the impact of performing the Admiral Nurse role and the use of qualitative measures in this setting.

Sources Used:

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

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