

Dementia

Current Awareness Bulletin

June 2024

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The Economic Impact of Dementia

Alzheimer's Society commissioned CF (Carnall Farrar Ltd) to estimate current and future economic and health care costs of dementia in the UK. Using the records of 26,000 people, dating back seven years, it revealed that people living with dementia and their families are shouldering 63% of all dementia costs. It also showed that as the disease progresses, total costs increase significantly, rising from £29,000 per year for mild dementia to £81,000 for severe dementia.

Gardening Sessions for Dementia Patients in Bristol

Bristol's Dementia Health Integration Team has been working with local partners to create a positive experience for those living with dementia who find themselves in hospital. Using outdoor and indoor spaces, activities include wreath making, planting and potting which have been described as the highlight of the week by both patients and staff.

Improving dementia diagnosis: widening the focus

Dementia strategies need to look at the whole pathway and take a system approach, says Leila Morris.

Improving End of Life Experience for People with Dementia

New £1 million partnership research call from Marie Curie and Alzheimer's Society

Recent estimates suggest that there are currently 982,000 people living with dementia in the UK and that this will rise by 40% to 1.4 million in 2040. Despite dementia and Alzheimer's Disease being the leading cause of death in the UK, there are significant gaps in both evidence and service provision for people dying of, or with, dementia. This means that many are not receiving the right care and support to have the best possible experience at the end of their lives.

That is why Marie Curie and Alzheimer's Society have come together to make available £1,000,000 for new research that can improve the end of life experience for people with any form of dementia, and for those who care for and support them.

We invite you to sign up to our discovery webinar from 2-3pm on Tuesday 11 June to learn more about the call, ask questions and network with others interested in research in this space.

1. Adapting the Serious Illness Conversation Guide for Dementia Care

Authors: Berry, Charlotte E.; Montgomery, Sophie H.; Santulli, Robert and Cullinan, Amelia

Publication Date: /08// ,2024

Journal: American Journal of Hospice & Palliative Medicine 41(8), pp. 942-951

Abstract: Introduction: Advance care planning (ACP), a critical component of quality dementia care, is underutilized due to lack of clinician comfort and the challenging nature of ACP in this context. The Serious Illness Conversation Guide (SICG) is a well-validated clinician-facing tool, developed with patient and clinician input, to facilitate ACP. The aim of this project was to adapt the SICG for dementia for the first time to promote high-quality ACP. Methods: This study uses a mixed-methods approach to adapt the SICG tool for use in dementia care. Experts with relevant clinical, ethical, and topical knowledge were interviewed to develop alterations to the SICG for dementia care. Patients and caregivers were shown a mock interview of the adapted SICG for dementia (SICG-D) to elicit feedback. Results: 8 relevant experts were interviewed. Adaptations included topical alterations to make the conversation more applicable to dementia as well as alterations to the structure of the conversation to accommodate the patient-caregiver dyad. Twenty interviews were conducted with 14 patients and 18 caregivers (either together or separately). A thematic content analysis of interview transcripts demonstrated positive impressions of the tool. In anonymous survey results, 94% reported a positive impression of the conversation and 89% endorsed incorporation of the adapted guide into dementia healthcare. Conclusion: This paper presents the SICG-D, an adapted version of the SICG for use in dementia care. This guide leverages the strengths of the SICG to promote values-based ACP

conversations and has been adapted to better facilitate patient-caregiver-clinician triadic communication.

2. Meaningful co-production to bring meaningful change: Developing the Allied Health Professionals Dementia Framework for Wales together

Authors: Braithwaite Stuart, Laura; Elliott, Natalie; Hanmer, Rebecca and Woodhead, Andrew

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 724-740

Abstract: In line with increasing participatory approaches to service and research design, there is a growing appreciation of the need to understand the lived experience of people accessing care and support, including people living with dementia, their carers and supporters. This article describes the process and value of co-production, used alongside principles of appreciative inquiry and evidence-informed practice, as an approach to developing a strategic workforce framework, aimed at increasing access to Allied Health Professionals (AHPs) for people living with dementia and their carers. Engaging in the co-production approach throughout the project lifecycle resulted in positive outcomes as reported by people with lived experience and professionals who were involved, as well as a published national framework that is rooted in the first-hand experiences of people living with dementia, their carers and supporters.

3. "I know now that it's something that you can do something about": Deductive thematic analysis of experiences at an arts-based dementia risk reduction exhibit

Authors: Chandler, Connor R. A.; Catanzaro, Michelle and Siette, Joyce

Publication Date: /08// ,2024

Journal: Archives of Gerontology and Geriatrics 123, pp. 105440

Abstract: Dementia is one of the leading global health crises. Despite the devastating impacts of the illness, general population knowledge pertaining to risk reduction is still limited. Previous research on the impact of dementia risk reduction campaigns has largely focused on awareness rather than behaviour change. Our research introduced an arts-based exhibit to address dementia modifiability, aiming to enhance effectiveness by providing an immersive experience for altering adults' perceptions of risk reduction and lifestyle behaviours. Interviews were conducted with adults (n = 38 13 male, 25 female]) who attended an interactive dementia awareness and risk reduction exhibit. Data was analysed using deductive thematic analysis within the Health Belief Model framework to determine key mechanisms of behaviour change. Four key themes encompassing exhibit significance and factors underlying behaviour change were identified. Participants recounted positive experiences, particularly being engaged by the artistic aspects of the exhibit, and recorded heightened engagement in behaviours supporting dementia risk reduction post-exhibit. Areas for improvement included the need for a take-home summary and variation in formats. Participants described prior encounters with dementia and their age as factors which influenced their engagement with dementia risk reduction behaviour, with younger participants reporting lesser engagement with risk reduction information. Our research found that arts-based educational initiatives have the potential to advance public understanding and promote behavioural changes for dementia risk reduction. Our study recommends enhancing the impact of future interventions by employing innovative formats and tailoring them to varied audiences, with a specific emphasis on engaging younger individuals.: Competing Interests: Declaration of competing interest None. (Copyright © 2024 The Author(s). Published by Elsevier B.V. All rights reserved.)

4. Unpaid carers of people with dementia and information communication technology: Use, impact and ideas for the future

Authors: Damant, Jacqueline; Freddolino, Paul; Dangoor, Margaret; Hu, Bo; King, Derek and Wittenberg,

Raphael

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 779-799

Abstract: Objectives: Several 100,000s of people living with dementia in the UK are cared for at home by a spouse or relative. Few studies have considered the ICT needs and experiences of unpaid carers. This study explores the types of ICT unpaid carers use, the ways they use ICT, the impact of ICT-use, and their ideas for how ICT could be more supportive of their role as a carer. Methods: Six focus groups with 32 unpaid carers of people living with dementia discussed their experiences of – and barriers to – using ICT. Transcripts were analysed thematically according to three types of ICT (mainstream, accessible and formal) and five functions (supporting domestic tasks, care management, monitoring, communication and information and education). Results: Participants predominantly used mainstream ICT devices such as laptops and smartphones and internet-enabled applications including videoconferencing and social media platforms to support their daily activities and assist them in their caring role. A few participants discussed using accessible devices such as memory clocks and formal telecare and care-phone services for care management and monitoring functions. Participants' ideas for improvements centred on personalised communication applications that facilitate remote interactions and promote persons living with dementia's independence. Others expressed concerns about the growing need to use ICT to access formal care services and the inadequacy of the ICT infrastructure in some care homes. Conclusions: Unpaid carers mostly turn to readily available mainstream ICT to support their personal and care activities. Further research is required to understand the social impact of the increasing reliance of ICT across health, social and residential care service sectors. Improved cooperation between unpaid carers, technology developers and care services providers could align ICT development to the needs and experiences of families living with dementia and assist unpaid carers with identifying ICTs that optimally support their personal circumstances.

5. Combined healthy lifestyle behaviours and incident dementia: A systematic review and doseresponse meta-analysis of cohort studies

Authors: Gao, Yinyan; Zhang, Zixuan; Song, Jinlu; Gan, Ting; Lin, Yali; Hu, Mingyue and Wu, Irene Xinyin

Publication Date: /08// ,2024

Journal: International Journal of Nursing Studies 156, pp. N.PAG

Abstract: The associations of combined healthy lifestyle behaviours and incident dementia have not been systematically reviewed and the dose-response relationship was uncertain. To evaluate the associations of combined healthy lifestyle behaviours with incident dementia and other cognitive outcomes, assess the dose-response relationship between the number of lifestyle behaviours and incident dementia, and summarise the adherence to healthy lifestyle behaviours. Systematic review and meta-analysis. PubMed, EMBASE, Web of Science and PsycINFO were searched from inception to 20 Jan 2024. Cohort studies reporting associations of combined healthy lifestyle behaviours with incident dementia or other cognitive outcomes were included. We used the random-effects metaanalysis to pool the risk estimates and the robust error meta-regression method to examine the doseresponse relationship. The methodological quality was assessed using the Newcastle-Ottawa Scale. A total of 22 articles including 25 cohort studies mostly from high-income economics were included, with all assessed as high methodological quality. Adherence to a healthy lifestyle was associated with a decreased risk of incident dementia, either per healthy lifestyle behaviour increase (pooled hazard ratio 0.89, 95 % confidence interval 0.85-0.94) or the highest level versus the lowest level (pooled hazard ratio 0.61, 95 % confidence interval 0.49-0.76). An inverse, linear dose-response relationship (P nonlinear = 0.845) between the number of healthy lifestyle behaviours and incident dementia was observed, with an 11 % risk reduction for each healthy behaviour increase. A relatively limited number of included studies indicated that adherence to a healthy lifestyle combination could yield benefits for

cognitive decline, global cognition, memory and executive function. In addition, the adherence rates typically decreased as the number of healthy lifestyle behaviours increased. Adherence to a healthy lifestyle was associated with a lower risk of incident dementia and other cognitive outcomes. It is important to find a subtle balance between the benefits and adherence. Further large cohort studies for combined lifestyle behaviours with specific cognitive outcomes and dose–response relationships are required, especially based on middle- and low-income populations. The study was registered in PROSPERO (CRD42023418509). Engaging in a greater number of healthy lifestyle behaviours yields increased benefits in preventing dementia, albeit with lower adherence rates as a trade-off. Finding a delicate balance between the benefits and adherence is crucial.

6. Reflections on co-production: Developing a dementia research funding application with a diverse lived experience group

Authors: Griffiths, Sarah; Robertson, Martin; Kaviraj, Chandrika; Davies, Firoza; McDevitt,

Marie; Richards, Al and Russell, Marcelline

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 709-723

Abstract: Introduction and Background to Study: Published work on dementia research co-production focuses on developing health and social care interventions. Less is written about practicalities and experiences of co-producing dementia research funding applications. UK public contributors are typically from white middle class populations. Widening involvement is essential for co-produced research that meaningfully addresses health inequalities. We provide an example of a diverse lived experience group co-producing a dementia research funding application. An NIHR Dementia Career Development award funded PPIE work to develop a broad research idea. A culturally diverse lived experience group consisted of one person living with dementia, four carers and one former carer. Virtual group sessions drew on each person's unique experiences and expertise. Two co-leads collaborated closely with the researcher. Methods: We reflected on our experiences of diversity and inclusion within the group, based on a coproduced set of questions to guide reflection. Written records of reflections were captured and refined by the group. Results: We structured reflections into three overarching categories: Diversity and inclusion, Benefits to group members and Challenges. The group felt empowered, heard, and like equals in the process. Members valued diversity and mutual learning within the group. Involvement of co-leads was seen as democratic and inclusive. Some members felt Equality, Diversity and Inclusion (EDI) discussions were challenging. Discussion and Conclusions: We share valuable lessons learned in the process, including suggestions for facilitating EDI discussions, building in funding for time and travel to support relationship building, and ensuring PPIE remuneration processes are accessible and streamlined.

7. Living with a person with young onset dementia - spousal experience

Authors: Håkansson, Tania; Svensson, Hilda and Karlsson, Staffan

Publication Date: /12// ,2024

Journal: International Journal of Qualitative Studies on Health and Well-Being 19(1), pp. 2330233

Abstract: Purpose: Being of working age while at the same time needing to help a partner with young onset dementia has specific consequences for spouses. Research to date has been sparse concerning this particular group of spouses. The aim of the study was to explore spouses' everyday experiences when living with a person with young onset dementia.; Method: The study had a descriptive qualitative design with semi-structured interviews with nine spouses. The interviews were analysed using content analysis.; Result: The interviewed spouses experienced emotions that varied from feelings of loneliness, frustration, and worry to peace of mind. They said that they used coping strategies, which included adopting a positive mindset, adapting to inabilities, adopting an avoidant approach, and finding ways to recharge. Spouses also felt that they could use more support, both formal and

informal.; Conclusion: The spouse of a person with young onset dementia has a range of emotional experiences and has resourceful ways of handling everyday life. Various types of support are offered to spouses, however, they seemed to desire more from health care services.

8. Enablers and Barriers to Hearing aid Use in People Living With Dementia

Authors: Hooper, Emma;Brown, Laura J. E.;Cross, Hannah;Dawes, Piers;Leroi, Iracema and Armitage, Christopher J.

Publication Date: /07// ,2024

Journal: Journal of Applied Gerontology: The Official Journal of the Southern Gerontological Society 43(7), pp. 978-989

Abstract: Hearing loss is highly prevalent in dementia; however, people with dementia are less likely to use hearing aids consistently than people with intact cognition are. This qualitative study is the first of its kind to explore factors that influence hearing aid use from the perspective of community-living people with mild to moderate dementia and their care partners. Eleven UK-based dyads from the European SENSE-Cog Randomized Controlled Trial of a sensory intervention for people with dementia completed semi-structured interviews based on the Theoretical Domains Framework (TDF). Our findings suggest that the TDF domains environmental context and resources, behavioral regulation, reinforcement, and social influences are of greatest relevance to hearing aid use in dementia. Within these domains, we identified a range of factors that may influence the target behavior of hearing aid use. The findings suggest that adoption of multifaceted, flexible intervention approaches may support hearing aid use in dementia.; Competing Interests: Declaration of Conflicting InterestsThe author(s) declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

9. The experiences of caring for someone with dementia and a learning disability: A qualitative systematic review

Authors: Hughes, Michelle; Hanna, Kerry; Wiles, Akpevwoghene; Taylor, Ellie and Giebel, Clarissa

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 817-849

Abstract: Background: The life expectancy of people with a learning disability is increasing and with this comes a greater risk of developing dementia. Dementia poses new challenges for both family and formal learning disability carers as they try to support dementia's progressive nature and quality of life for their care recipient. This qualitative systematic review explores the evidence base of family and formal carers' experiences and needs of caring for someone with both a learning disability and dementia. Methods: Six electronic databases (PubMed, PsycINFO, Cochrane Library, Prospero, Scopus, CINAHL), were searched in May 2022, utilising a predefined search strategy. Thirteen papers fulfilled inclusion criteria and were included in in the review. Results: Thematic synthesis was used to explore and synthesise the qualitative findings of the studies. Four conceptual themes were identified following analysis: Knowledge and skills, Accessing support, Repercussions of dementia for carers, Influences of continuity of caring role. Conclusion: There are significant training and educational needs for all carers who support the dual diagnosis of dementia and learning disability. Differences between family and formal carers relate to the organisational support and process available to formal carers. Parity across services combined with sufficiently trained carers may support dementia diagnosis and improve quality of care provided. Further research is needed to address environmental, and economic barriers carers face to facilitate ageing in place for their care recipients.

10. Researching Pain in People Living with Dementia: Barriers and Potential Solutions Authors: Hussein, Areej; Moullin, Joanna; Hughes, Jeffery and Stafford, Andrew

Publication Date: /06// ,2024

Journal: Ageing International 49(2), pp. 293-302

Abstract: There are a number of challenges in recruiting people living with dementia for research purposes, and consequently, studies may be underpowered or fail. This commentary describes barriers experienced by a research study in recruiting people with early-stage dementia living in the community, for a focus group about their perceptions of using a technology-enabled pain assessment tool to detect and quantify pain. Four potentially important groups of barriers encountered during the recruitment phase are discussed, namely dementia, pain, mobile health application (mHealth) technology and COVID-19. The strategies used in an attempt to overcome these barriers are also discussed. Despite a comprehensive approach to recruitment, the required participant number was not achieved. It is recommended careful consideration be given to recruitment including flexibility in recruitment strategies tailored to the unique contexts of a study.

11. Exploring the experiences of a person with dementia and their spouse who attended a telehealth music therapy programme: Two case examples from Ireland

Authors: Kelly, Lisa; Kenny, Niamh; McGlynn, Cathy; Richardson, Ita and Moss, Hilary

Publication Date: /07// ,2024

Journal: Nordic Journal of Music Therapy 33(4), pp. 281-298

Abstract: There is an increased need for accessible psychosocial interventions that support both people with dementia and their spouses. Recent research demonstrates the benefits of music therapy and caregiver-delivered music therapy for this population. This paper contributes to the emerging evidence base on telehealth music therapy for people with dementia outside of a COVID-19 era when in-person services were available. This exploratory phenomenological study explores the experiences of two couples who attended a six-week telehealth music therapy programme via two detailed case examples. Online semi-structured interviews with each couple were conducted pre and post intervention and analysed using Interpretative Phenomenological Analysis. Three shared themes emerged from the data analysis including (1) social isolation and lack of confidence linked to dementia diagnosis is worsened in rural locations, (2) song singing and song writing enables us to revisit happy memories, and (3) telehealth delivery increases access due to geographical location. The findings are presented in a narrative case study format to provide rich detailed descriptions of the music therapy programme and to illuminate the experiences of the participants. In both examples, telehealth delivery expanded access to music therapy (which was otherwise unavailable) and stimulated reminiscence which in turn encouraged meaningful engagement between the couple. The delivery of music therapy via telehealth, alongside in-person delivery, has the potential to expand access to music therapy to those who may not have access to or are no longer able to attend community support services due to geographical location, increased cognitive decline or reduced mobility. The successful delivery of telehealth music therapy is dependent on several factors including digital literacy, access to appropriate technological devices, caregiver support and level of cognitive decline.

12. Interprofessional collaboration in palliative dementia care

Authors: Khemai, C.;Leão, D. L. L.;Janssen, D. J. A.;Schols, J. M. G. A. and Meijers, J. M. M.

Publication Date: /07// Jul-Aug ,2024

Journal: Journal of Interprofessional Care 38(4), pp. 675-694

Abstract: Interprofessional collaboration (IPC) is essential for high-quality palliative care (PC) for persons with dementia. The aim of this scoping review was to identify IPC approaches in palliative dementia care and explore the elements constituting these approaches. We performed a search in PubMed, CINAHL, and PsychINFO using the Joanna Briggs Institute Reviewers' manual and PRISMA

guidelines, and conducted content analysis of the included articles. In total, 28 articles were included, which described 16 IPC approaches in palliative dementia care. The content analysis revealed three overall elements of these approaches: 1) collaborative themes, 2) collaborative processes, and 3) resources facilitating collaboration. Frequently reported collaborative themes embraced pain management and providing care in the dying phase. These themes were addressed through intertwined collaborative processes including communication, coordination, assessing and monitoring, and reflecting and evaluating. To ensure optimal IPC in palliative dementia care, various resources were required, such as PC knowledge, skills to manage symptoms, skills to communicate with collaborators, and a facilitating environment. In conclusion, the identified IPC approaches in palliative dementia care involve diverse collaborating professionals who mainly manage symptoms, prepare for the dying phase and require material and immaterial resources to enable optimal IPC in palliative dementia care.

13. Protective Effects of β -Blockers on Bone in Older Adults with Dementia

Authors: Khuc, Khiem;des Bordes, Jude;Ogunwale, Abayomi;Madel, Maria-Bernadette;Ambrose, Catherine;Schulz, Paul;Elefteriou, Florent;Schwartz, Ann and Rianon, Nahid J.

Publication Date: /07// ,2024

Journal: Calcified Tissue International 115(1), pp. 14-22

Abstract: Increased β-adrenergic receptor activity has been hypothesized to cause bone loss in those with dementia. We investigated the effect of long-term β-blocker use on rate of bone loss in older adults with dementia. We used a linear mixed-effects model to estimate the relationship between long-term β-blocker use and rate of bone loss in participants from the Health Aging and Body Composition study. Records of 1198 participants were analyzed, 44.7% were men. Among the men, 25.2% had dementia and 20.2% were on β-blockers, while in the women, 22.5% had dementia and 16.6% received β-blockers. In the 135 men with dementia, 23 were taking β-blockers, while 15 of 149 women with dementia were using β-blockers. In men with dementia, β-blocker users had 0.00491 g/cm 2 less bone mineral density (BMD) loss per year at the femoral neck (i.e., 0.63% less loss per year) than non-users (p < 0.05). No differences were detected in women with or without dementia and men without dementia. (© 2024. The Author(s), under exclusive licence to Springer Science+Business Media, LLC, part of Springer Nature.)

14. What exercise strategies are best for people with cognitive impairment and dementia? A systematic review and meta-analysis

Authors: Li, Zecheng; Guo, Hongpeng and Liu, Xuebin

Publication Date: /09// ,2024

Journal: Archives of Gerontology and Geriatrics 124, pp. 105450

Abstract: Objective: Explore the types of exercise that are appropriate for people with dementia, as well as the intensity and frequency of exercise training that is appropriate for older patients to carry out.; Methods: Cochrane Library, PubMed, Embase, Web of Science, Scopus databases were searched by computer to collect RCT studies that met the inclusion criteria of this article. The search time limit was until January 2024. Two reviewers independently screened literature, extracted data, and assessed the quality and risk of bias of the included studies. Then, meta-analysis was performed using RevMan 5.4 and Stata 15.1 software.; Results: The results of our study showed that physical exercise improved patients' cognitive ability and walking ability, with aerobic and multicomponent training showing the best improvement, and that the number of training sessions should not be too high, with the experimental group showing the best results when the total number of interventions was less than 30.; Conclusion: We recommend long-term exercise training for middle-aged and elderly patients with dementia or those who are predisposed to dementia. The type of training we recommend is multicomponent training and aerobic training, and we recommend 2-3 sessions of exercise per week for

about 60 min each.; Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. (Copyright © 2024 Elsevier B.V. All rights reserved.)

15. General anesthesia is not associated with dementia in older adults with osteoarthritis for hip/knee replacements, a national population-based nested case-control study

Authors: Lin, Yuting; Chen, Chun-Chia; Dong, Chen; Luan, Yu-Ze; Huang, Jing-Yang; Wei, James Cheng-Chung and Chiou, Jeng-Yuan

Publication Date: /08// ,2024

Journal: Journal of Clinical Anesthesia 95, pp. 111449

Abstract: Background: Dementia is a prevalent neurological condition, yet the relationship between dementia and general anesthesia remains uncertain. The study aimed to explore the association between general anesthesia and dementia using a nationwide population-based database.; Methods: The study extracted data from Taiwan's national health insurance, which encompassed the records of one million insured residents. A total of 59,817 patients aged 65 years and above, diagnosed with osteoarthritis between 2002 and 2010, were included. Among these patients, 3277 individuals with an initial diagnosis of dementia between 2004 and 2013 were matched with non-dementia patients based on age, gender, and the date of osteoarthritis diagnosis. Following a 1:2 random matching, the case group included 2171 patients with dementia, while the control group consisted of 4342 patients without dementia. The data was analyzed using conditional and unconditional logistic regressions.; Results: No significant differences in the odds of dementia were found between individuals exposed to general and regional anesthesia during hip/knee replacement surgeries (OR = 1.11; 95%CI: 0.73-1.70), after adjusting for age, sex, and co-morbidities. Similarly, there were no significant differences in the odds of dementia based on different durations of anesthesia exposure (General: 4 h: OR = 0.39, 95%CI = 0.15-1.01; compared to no exposure. Regional: 4 h: OR = 0.55, 95%CI = 0.15-1.96; compared to no exposure). Likewise, no significant differences were observed in the odds of dementia based on the number of replacement surgeries (twice: OR = 0.74, 95%CI = 0.44-1.23, compared to once).; Conclusion: Neither general anesthesia nor regional anesthesia in hip/knee surgery was associated with dementia. Different numbers and durations of anesthesia exposure showed no significant differences in the odds for dementia.; Competing Interests: Declaration of competing interest The authors declare that they have no conflicts of interest. (Copyright © 2024. Published by Elsevier Inc.)

16. The role and impact of therapeutic counselling on the emotional experience of adults living with dementia: A systematic review

Authors: Mathews, Gill; Li, Xiaoyang and Wilkinson, Heather

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 882-902

Abstract: Introduction There is limited psychological support available to help people living with dementia to deal with the emotional consequences of their condition. Anxiety and depression are commonly experienced in this population, yet the use of counselling and psychotherapeutic interventions is not well documented. Aim This systematic review sought to understand the current knowledge on the role and impact of therapeutic counselling on the emotional experience of adults living with dementia. Methods Qualitative and quantitative research designs were accepted for review. A comprehensive search of the main biomedical, nursing and other specialist databases was performed to access articles published between 2015 and 2022. Trial registers and academic journals were also searched. 43 original studies were included: qualitative (n = 15); RCTs (n = 9); other designs (n = 19); plus eight systematic reviews. Results The majority of studies were conducted in Europe, the United Kingdom in particular, although a range of countries from across the globe were represented. The combined evidence from the different study designs suggest a range of ways that people living

with different stages of dementia can participate in, and gain emotional benefit from, therapeutic counselling. Key themes identified: (1) The emotional and well-being benefits of therapeutic counselling; (2) No one size fits all - relational and tailored approaches driven by person-centred values; (3) Training, supervision and building community for counsellors; (4) Involvement of people with dementia in therapeutic interventions. Conclusions Our findings from this systematic review show that different therapeutic approaches have been tested with people at different stages of a dementia diagnosis. The results suggest the value of therapeutic counselling as a supportive medium to help with the processing and coping of difficult emotions and feelings across the trajectory of a dementia illness.

17. A randomised controlled trial of the Learning Skills Together (LST) intervention to improve dementia family caregivers' self-efficacy with complex care

Authors: Meyer, Kylie;Lee, Kyungmi;Thorngthip, Sutthinee;Burant, Patricia;Lippe, Megan;Neidre, Daria;White, Carole;Norman, Rocio;Choi, Byeong Yeob;Glover, Crystal M.;Bell, Janice and Hepburn, Kenneth

Publication Date: /06/08/ ,2024

Journal: Trials 25(1), pp. 1-15

18. Life story templates in dementia care: Ambiguous direction and purpose

Authors: Möllergren, Glenn and Harnett, Tove

Publication Date: /07// ,2024

Journal: Dementia (14713012) 23(5), pp. 741-756

Abstract: Background: The use of life stories in dementia care has been described as a way of seeing every person as an individual, looking beyond their dementia. Life stories have become synonymous with high-quality care, while in Sweden their mere existence in dementia care settings is taken to indicate quality in national comparisons. Such life stories are often standardised, generated by a family member answering predetermined questions in a template. Aim and methods: Using a constructionist approach, this study will (1) chart what versions of a person's life story the templates produce, and (2) establish the intended purpose of such life stories, as communicated by the templates. This study departs from the assumption that life story templates communicate something about the conceptions of people living with dementia. The thematic analysis used data comprising 30 blank templates, totalling about 1,700 questions. Findings: The life story templates were found to generate two very different versions of the individual: (1) a person before symptoms of dementia or (2) a patient with dementia. We also found contradictions about what information should be included, whose life story it was, and the intended use. Discussion: Despite strong pressure on dementia care providers to collect life stories from residents, the life story templates they use are without clear direction, ideology, or purpose. The lack of direction is key given that life stories can be considered actants that shape assumptions about people with dementia and construct realities in dementia care settings. We highlight the need to develop ethical guidelines for life story template design, matched with guidelines for their intended use.

19. Usability of web-based tools designed for communication and decision-making in dementia: Systematic review and design brief

Authors: Monnet, Fanny; Craven, Michael P.; Dupont, Charlèss; Van den Block, Lieve and Pivodic, Lara

Publication Date: /08// ,2024

Journal: International Journal of Medical Informatics 188, pp. N.PAG

20. Does resistance training in older adults lead to structural brain changes associated with a lower risk of Alzheimer's dementia? A narrative review

Authors: Nicola, Louisa;Loo, Stephanie Jyet Quan;Lyon, Gabrielle;Turknett, Josh and Wood, Thomas

R.

Publication Date: /07// ,2024

Journal: Ageing Research Reviews 98, pp. 102356

Abstract: Dementia, particularly Alzheimer's Disease (AD), has links to several modifiable risk factors, especially physical inactivity. When considering the relationship between physical activity and dementia risk, cognitive benefits are generally attributed to aerobic exercise, with resistance exercise (RE) receiving less attention. This review aims to address this gap by evaluating the impact of RE on brain structures and cognitive deficits associated with AD. Drawing insights from randomized controlled trials (RCTs) utilizing structural neuroimaging, the specific influence of RE on AD-affected brain structures and their correlation with cognitive function are discussed. Preliminary findings suggest that RE induces structural brain changes in older adults that could reduce the risk of AD or mitigate AD progression. Importantly, the impacts of RE appear to follow a dose-response effect, reversing pathological structural changes and improving associated cognitive functions if performed at least twice per week for at least six months, with greatest effects in those already experiencing some element of cognitive decline. While more research is eagerly awaited, this review contributes insights into the potential benefits of RE for cognitive health in the context of AD-related changes in brain structure and function.; Competing Interests: Declaration of Competing Interest L.N. is the founder and owner of NeuroAthletics. J.T. is the founder of Brainjo, a company that creates educational programs for adult learners, and President of Physicians for Ancestral Health. G.L. is the founder and owner of Muscle Centric Medicine™. T.R.W. is a paid scientific advisor for Hintsa Performance, Sidekick Health, Thriva LLC, and Rewire Fitness, and is a founding trustee and Treasurer of the British Society of Lifestyle Medicine. (Copyright © 2024 Elsevier B.V. All rights reserved.)

21. Acceptability of virtual reality to screen for dementia in older adults

Authors: Siette, Joyce; Adam, Patrick J. and Harris, Celia B.

Publication Date: /06/05/ ,2024

Journal: BMC Geriatrics 24(1), pp. 1-9

22. 'We had conversations we wouldn't have had otherwise'-Exploring home-dwelling people with dementia and family members' experiences of deliberating on ethical issues in a literature-based intervention

Authors: Skov, Sofie Smedegaard; Berg, Marie Eva; Andersen, Josefine Ranfelt; Schou-Juul, Frederik; Jensen, Anja M. B.; Folker, Anna Paldam and Lauridsen, Sigurd

Publication Date: /07// ,2024

Journal: Journal of Clinical Nursing 33(7), pp. 2719-2731

Abstract: Aim: To explore home-dwelling people with dementia and family members' perceptions of the feasibility and acceptability of an intervention using dementia-related literature excerpts to facilitate conversations on ethical issues related to living with dementia.; Background: Ethical issues in dementia care emerge throughout the illness. In the early stages, they may involve decisions about disclosing the illness to the family, shifting roles and responsibilities, and considerations of transitioning to a nursing home. Addressing ethical issues and providing adequate support to home-dwelling people with dementia and their families are often lacking.; Design: An exploratory-descriptive qualitative study.; Methods: We conducted eight interviews with 14 home-dwelling persons with dementia and their family caregivers. Six were dyadic interviews, and two were individual interviews with family caregivers. We analysed the interview data using template analysis. We adhered to the COREQ checklist in reporting

this study.; Results: Using excerpts from dementia-related literature was a feasible and acceptable way of initiating discussions on ethical issues among home-dwelling persons with dementia and family caregivers. However, engaging the families of newly diagnosed individuals was challenging due to emotional distress. The intervention provided peer support, including identifying with others and sharing experiences. Moreover, participating couples found intimacy and relational attunement through shared reflections.; Conclusion: Based on the findings, it appears that the participants in this study felt that using excerpts from dementia-related literature to deliberate on ethical issues was feasible and acceptable. Deliberating on ethical issues with peers and family caregivers offers valuable social support and opportunities for strengthening relationships.; Implications for Patient Care: This study makes an important contribution by providing valuable insights into how ethical issues related to living with dementia can be addressed using related literature and suggests how the intervention can be integrated into existing care initiatives for home-dwelling people with dementia and their families.; Reporting Method: We have adhered to relevant EQUATOR guidelines with the COREQ reporting method.; Patient or Public Contribution: A healthcare professional working as a so-called dementia coordinator (a title used in the Danish context) was involved in the conduct of this study by being responsible for the recruitment of home-dwelling people with dementia and their family members. Moreover, she had joint responsibility for facilitating the intervention along with the first author. (© 2024 The Authors. Journal of Clinical Nursing published by John Wiley & Sons Ltd.)

23. Long-term, home-based transcranial direct current stimulation coupled with computerized cognitive training in frontotemporal dementia: A case report

Authors: Tippett, Donna C.;Neophytou, Kyriaki;Tao, Yuan;Gallegos, Jessica;Morrow, Christopher;Onyike, Chiadi U. and Tsapkini, Kyrana

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Journal: Journal of Central Nervous System Disease, pp. 1-9

Abstract: We present the case of a 62-year-old woman with probable behavioral variant of frontotemporal dementia (bvFTD) with cognitive/language deficits who demonstrated improved performance on cognitive/language testing and in functional tasks following long-term, home-based transcranial direct current stimulation (tDCS) coupled with computerized cognitive training (CCT). The patient underwent home-based tDCS (anode on the left prefrontal cortex and cathode on the right homologue) for 46 sessions over 10 weeks along with CCT. On post-treatment testing, the patient improved by 3 points on the Mini-Mental State Exam (MMSE) (23 to 26). She also showed improvement on several cognitive/language tasks, such as immediate recall of single words and word pairs, total accurate words in sentence repetition, delayed recall, semantic processing, and sentence level comprehension. There was no decline in several other cognitive and language tasks. Family members reported subjective improvements in expressiveness, communication, and interaction with others as well as increased attention to grooming and style which contrasted with her pre-treatment condition. This report suggests that home-based tDCS combined with CCT for an extended period may slow decline, and improve cognitive/language performance and everyday function in FTD. Plain Language Summary: Long-term, Home-based Transcranial Direct Current Stimulation Coupled with Computerized Cognitive Training in Frontotemporal Dementia: A Case Report: A 62-year-old woman with probable behavioral variant of frontotemporal dementia (bvFTD) improved on cognitive/language testing and in functional tasks following long-term, home-based transcranial direct current stimulation (tDCS) coupled with computerized cognitive training (CCT). The patient underwent home-based tDCS for 46 sessions over 10 weeks along with CCT. On post-treatment testing, the patient improved by three points on the Mini-Mental State Exam (MMSE) (23 to 26). She also improved immediate recall of single words and word pairs, total accurate words in sentence repetition, delayed recall, semantic processing, and sentence level comprehension. There was no decline in several other cognitive and language tasks. Family members described improvements in expressiveness, communication, and interaction with others and increased attention to grooming and style which was different from her pretreatment condition. This case report suggests that home-based tDCS combined with CCT for an extended period may slow decline and improve cognitive/language performance and everyday function in FTD.

24. Association between gabapentin use and risk of dementia in adults with chronic pain: A nested case-control study

Authors: Tsai, Sheng-En; Yang, Shun-Fa; Wang, Yu-Hsun and Yeh, Chao-Bin

Publication Date: /08// ,2024

Journal: Journal of Affective Disorders 358, pp. 205-210

25. Association and prediction of Life's Essential 8 score, genetic susceptibility with MCI, dementia, and MRI indices: A prospective cohort study

Authors: Wang, Qi;Yu, Ruihong;Dong, Caiyun;Zhou, Chunmiao;Xie, Ziwei;Sun, Huizi;Fu, Chunying

and Zhu, Dongshan

Publication Date: /09/01/ ,2024

Journal: Journal of Affective Disorders 360, pp. 394-402

Abstract: Background: To examine the associations of Life's Essential 8 (LE8) and its predictive performance with mild cognitive impairment (MCI), dementia and brain MRI indices.; Methods: We used cohort data from UK Biobank. LE8 was categorized into low (<50 score), moderate (50-79 score), and high (≥80 score) levels. Cox regression models considering death as a competing risk were used to estimate the hazard ratios (HRs) and 95%CI on the association between LE8 and MCI and dementia. Multivariable linear regression models were used to analyze LE8 every 10-score increase and brain MRI indices. Area under the curve (AUC) was used to measure the predictive performances of LE8.; Results: We included 126,785 participants with a mean (SD) age of 56.0 (8.0) years and 53.5 % were female. The median follow-up was 13.0 years. Compared to individuals with a low LE8 score, those with a high LE8 score were associated with decreased risk of MCI (0.49, 95%CI: 0.40-0.62), allcause dementia (0.60, 0.44-0.80), vascular dementia (VD, 0.44, 0.21-0.94), and non-Alzheimer nonvascular dementia (NAVD, 0.55, 0.35-0.84). High LE8 score was associated with increased total brain volume, hippocampus volume, grey matter volume, and grey matter in hippocampus volume (p all ≤0.001). LE8 combined age and sex had good performance for predicting all-cause dementia (AUC: 84.1 %), AD (85.4 %), VD (87.6 %), NAVD (81.4 %), and MCI (75.3 %).; Limitations: Our findings only reflect the characteristics of UKB participants.; Conclusions: High LE8 score was associated with reduced risk of MCI and dementia. It was also linked to brain MRI indices. LE8 score had good predicting performance for future risk of MCI and dementia.; Competing Interests: Declaration of competing interest None. (Copyright © 2024 Elsevier B.V. All rights reserved.)

26. Improving Dementia Caregiver Activation With a Brief Communication Module

Authors: Wittenberg, Elaine; Sullivan, Suzanne S. and Rios, Melissa

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Journal: American Journal of Hospice & Palliative Medicine 41(7), pp. 805-813

Abstract: Objective: Palliative care often plays a pivotal role in supporting informal caregivers of persons living with dementia who experience a lack of continuity in care. Dementia caregiver activation, the caregiver's willingness and ability to navigate care needs, requires communication skills for developing relationships with healthcare providers. Communication activation is important because caregivers facilitate physician and patient information exchange. This study aimed to explore changes in communication outcomes (attitude, knowledge, and skills) and impact on caregiver communication activation (confidence, self-report) following completion of a brief communication module. Methods: A 15-minute asynchronous online module was developed to provide caregivers with communication skills for working with doctors and nurses. Caregivers completed pre/post module measures of

communication outcomes, a vignette for applying communication strategies and were interviewed within a week of module completion to assess self-reported communication activation. Module acceptability was also evaluated. Results: Communication knowledge (P <.01) significantly increased and nearly all participants (99%) demonstrated use of module-specific communication skills after completing the module. While not statistically significant, caregiver attitudes were in the expected direction. Caregiver self-reported communication confidence (P <.001) significantly increased and 84% of caregivers described communication activation at post-module. Caregivers (83%) were likely to recommend the module. Conclusions: The brief communication module for dementia caregivers in this project offers an online resource with low time-burden that results in caregiver communication activation. Future testing in the clinical setting will increase understanding of its efficacy and integration and could be a viable resource for palliative care providers.

27. Adult-onset hearing loss and incident cognitive impairment and dementia - A systematic review and meta-analysis of cohort studies

Authors: Yu, Ruan-Ching; Proctor, Danielle; Soni, Janvi; Pikett, Liam; Livingston, Gill; Lewis, Glyn; Schilder, Anne; Bamiou, Doris; Mandavia, Rishi; Omar, Rumana; Pavlou, Menelaos; Lin, Frank; Goman, Adele M. and Gonzalez, Sergi Costafreda

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Journal: Ageing Research Reviews 98, pp. 102346

Abstract: Background: We comprehensively summarized the cohort evidence to date on adult-onset hearing loss as risk factor for incident cognitive impairment and dementia, and examined the evidence for dose-response, risk for various dementia subtypes, and other moderators. Previous meta-analyses were less comprehensive.; Methods: We included cohort studies with participants without dementia and with hearing assessments at baseline, minimum 2 years follow-up and incident cognitive outcomes. We used random-effect models and subgroup and meta-regression on moderator analyses.; Results: We identified fifty studies (N=1,548,754). Hearing loss (yes/no) was associated with incident dementia risk (HR=1.35 95% CI = 1.26 - 1.45), mild cognitive impairment (MCI HR=1.29 95% CI = 1.11 - 1.50]), cognitive decline not specified as MCI or dementia (HR=1.29 95% CI = 1.17 - 1.42]), and Alzheimer's disease dementia (ADD, HR=1.56 95% CI = 1.30 - 1.87]), but not with vascular dementia (HR, 1.30 95% CI = 0.83 - 2.05]). Each 10-decibel worsening of hearing was associated with a 16% increase in dementia risk (95% CI = 1.07 - 1.27). The effect of hearing loss did not vary across potential moderators.; Conclusions: Cohort studies consistently support that adult-onset hearing loss increases the risk of incident cognitive decline, dementia, MCI, and ADD.; Competing Interests: Declaration of Competing Interest None of the authors have any financial or other conflicts of interest to disclose. (Copyright © 2024 The Authors. Published by Elsevier B.V. All rights reserved.

28. Exploring Experiences of Pain Management Among Family Caregivers of Community-Dwelling Older Adults With Dementia

Authors: Zhao, Hui;Kulbok, Pamela A.;Williams, Ishan C.;Manning, Carol;Logan, Jeongok G. and Romo, Rafael D.

Publication Date: /08// ,2024

Journal: American Journal of Hospice & Palliative Medicine 41(8), pp. 927-933

Abstract: Background: Pain is often underreported and under-treated in older adults with dementia. The role of family caregivers (FCGs) in managing pain for their loved ones with dementia living in community has been significantly burdensome. Surprisingly, research has not delved into the experiences of FCGs' concerning pain management in this context. Methods: A qualitative descriptive study was conducted to gain a deep understanding of FCGs' experiences in managing pain for their loved ones. Family caregivers participated in semi-structured face-to-face or telephone interviews. Inclusion criterion included being an adult providing care to community-dwelling older adults with

dementia. Recruitment stopped upon reaching thematic saturation. Basic demographic characteristics was also collected. Constant comparison analytic method was employed. Results: The study included 25 FCGs in central Virginia, spanning ages from 29 to 95. Participants were predominantly white, female, married, and had a minimum high school education. Most of them were adult children (52%) or the spouses (28%) of the care recipients. Four thematic categories emerged around exploring FCGs' pain management experiences: (1) Values; (2) Barriers; (3) Support; and (4) Adaptation. Each theme included sub-themes. Conclusion: Family caregivers follow their values to make decisions in pain management. Barriers existed for effective pain management. Adaptation and support from professional or formal caregivers greatly improved FCGs' perception of their competence in pain management. The finding underscores the need for further research and the development of interventions aimed at enhancing FCGs' perception of self-efficacy in this crucial aspect of caregiving.

29. High plasma homocysteine levels predict the progression from mild cognitive impairment to dementia

Authors: Zuliani, Giovanni;Brombo, Gloria;Polastri, Michele;Romagnoli, Tommaso;Mola, Gianmarco;Riccetti, Raffaella;Seripa, Davide;Trentini, Alessandro and Cervellati, Carlo

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Journal: Neurochemistry International 177, pp. 105763

Abstract: High levels of blood homocysteine (HCy), a well-known cardiovascular risk factor and promoter of oxidative stress, have been associated with the incidence of cognitive impairment and dementia. Nonetheless, contrasting data are still present on its involvement in the progression from Mild Cognitive Impairment (MCI) to overt dementia. In this study we aimed to observe whether blood HCy level are associated with the evolution from MCI, divided into amnestic MCI (aMCI) and nonamnestic MCI (naMCI), to dementia. Blood HCy was measured in 311 MCI subjects (aMCI: 64%, naMCI: 36%) followed-up for a median of 33 months (range 10-155 months). At follow-up, 137 individuals converted to dementia (naMCl, n = 34; aMCl, n = 103). Based on HCy distribution, subjects in the highest tertile had a greater risk to convert to dementia compared to tertile I (Hazard Ratio (95% confidence interval): 2.25 (1.05-4.86); p = 0.04). aMCI subjects did not show increased risk to convert to dementia with increasing HCy concentration, but was significant in naMCI (p = 0.04). We observed a non-significant increase in the risk of progression to dementia from naMCI/low HCy (reference group, HCy cutoff value = 16 µmol/L) to naMCl/high HCy, but it was significant from aMCl/low HCy (HR: 2.73; 95%CI: 1.06-7.0; p:0.03), to aMCI/high HCy (HR: 3.24; 95%CI: 1.17-8.47; p:0.02). Our results suggest that HCy levels are associated with the progression from MCI to dementia. This association seems significant only for the naMCI group, indirectly supporting the notion that hyperhomocysteinemia damages the nervous system through its role as a vascular risk factor.; Competing Interests: Declaration of competing interest The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper. (Copyright © 2024 The Authors. Published by Elsevier Ltd.. All rights reserved.)

30. The usability and reliability of a smartphone application for monitoring future dementia risk in ageing UK adults.

Authors: Reid G.

Publication Date: 2024

Journal: British Journal of Psychiatry 2024;224(6):245-251.

Abstract: [The rising number of dementia diagnoses and imminent adoption of disease-modifying treatments necessitate innovative approaches to identify individuals at risk, monitor disease course and intervene earlier in the disease course. Digital assessments of dementia risk and cognitive function have the potential to outperform in-person assessments in terms of their affordability, accuracy and longitudinal tracking abilities. However, their accessibility and reliability in older adults is unclear.

31. Predicting patients with dementia most at risk of needing psychiatric in-patient or enhanced community care using routinely collected clinical data: retrospective multi-site cohort study.

Authors: London SR.

Publication Date: 2024

Journal: British Journal of Psychiatry 2024;224(6):221-229.

Abstract: [Dementia is a common and progressive condition whose prevalence is growing worldwide. It is challenging for healthcare systems to provide continuity in clinical services for all patients from diagnosis to death. The authors sought to test whether individuals who are most likely to need enhanced care later in the disease course can be identified at the point of diagnosis, thus allowing the targeted intervention.]

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

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