Aged Care Research & Industry Innovation Australia

A review summary:

Interventions for people living with dementia in receipt of aged care

February 2022

Prepared by Raechel Damarell and Bethany Wilton-Harding. Knowledge and Implementation Hub, Aged Care Research and Industry Innovation Australia, Flinders University

Key Points

- A scoping review of systematic reviews identified 200 reviews on dementia in the aged care context published since 2011.
- The most synthesised topics in dementia care during this time were training and support for family carers, exercise therapy, and psychosocial interventions for people living with dementia. Responsive behaviours (also known as 'behavioural and psychological symptoms of dementia') were the most frequently researched outcome of interest to researchers.
- Most reviews highlight difficulties in drawing conclusions on the effectiveness of interventions due to the heterogeneity, small sample sizes, and the high or unknown risk of bias of their included studies. These methodological shortcomings may reflect the challenges of conducting research with people living with dementia.
- This review also looked at primary studies on dementia in aged care published in the last 5 years. This identified clusters of studies on topics not yet synthesised as part of a systematic review.

Background

The remit of the newly established Knowledge and Implementation Hub of the Aged Care Research and Industry Innovation Australia is to identify and synthesise the existing evidence of best practices in aged care provision. The Centre has prioritised the care of people living with dementia (PLwD), just as the Australian Royal Commission into Aged Care Quality and Safety did when handing down its final recommendations in 2021. [1] This report summarises preliminary findings of a scoping review of the existing synthesised literature on dementia care. The review was undertaken to identify the types of practices and interventions that have been researched to date, as well as the range of dementia care outcomes of interest to researchers.

Dementia in Australia

Dementia is a progressive, degenerative syndrome that impacts a person's memory, executive function, and ability to communicate. [2] It can also affect the ability to perform activities of daily living, leading to disability and dependency on others. [3] As the disease progresses, behavioural and psychological symptoms will typically emerge. These include agitation, aggression, wandering, hallucinations, depression, apathy, and sleep problems. [4] These cognitive and neuropsychiatric changes can make care of the person living with dementia challenging for aged care workers and family carers. [5]

Dementia is currently thought to affect more than 55 million people globally. Its prevalence is expected to increase to 78 million over the next 10 years. [6] Dementia is also a terminal condition, although often not recognised as such. With a median survival time of 1.3 years, [7] it is currently one of the leading causes of mortality worldwide and the excess risk of death of those with dementia is growing. [8] In 2019, dementia became the second leading cause of death in Australia—an increase in mortality of 66.8% since 2010. [9] While aged care services in this country provide a range of community-based home care support to assist the person living with dementia and their carer, many people with dementia will transition to a residential aged care home where they will stay until their death. [10]

Dementia and aged care services

It is estimated that between 50-70% of people currently living in residential aged care in Australia have a diagnosis of dementia, which should make dementia care a core business of the sector. [1] In 2021, the Royal Commission into Aged Care Quality and Safety singled out dementia care provision as a major area of concern, citing a workforce ill-equipped with the requisite knowledge and skills to meet the complex needs of this population. [1] Families and staff had provided the Commission with numerous accounts of the deficient quality of care received within the sector and the impact this had on people's quality of life and well-being.

In its recommendations, the Commission called on the Australian Government to act immediately on two major fronts. First, it asked that the Government establish a comprehensive, national dementia support pathway that runs across the care continuum from diagnosis to palliative care. It also recommended that all aged care workers in direct contact with PLwD undertake regular training on dementia care. [1] As dementia care will be a prime concern in the home care setting, as well as in residential aged care over the coming years, the education and training needs of home care nurses and primary care providers may also require attention.

Objectives of this review

Improving the skills and knowledge of people providing direct care to PLwD requires an understanding of the existing evidence of what works to raise the level of health and psychosocial well-being of PLwD and their families and/or family carers. We therefore undertook a scoping review of the published systematic review literature to gauge the size, breadth, and nature of the research evidence on dementia care within the aged care context. This was informative in identifying the range and types of interventions already tested, outcomes of interest to researchers, and the general quality of the evidence. This document summarises the initial findings of the scoping review.

Methods

The review sought evidence of the benefits or harms associated with non-pharmacological interventions intended for PLwD, their families and care workers within aged care. As there are currently thousands of primary studies on dementia care, the review restricted its focus to systematic reviews of primary studies. Targeting existing syntheses would identify the subject areas and outcomes already well researched and indicate dementia concerns that have received less attention in primary studies (i.e., the evidence 'gaps').

Search strategy

Six major databases were searched using an extensive range of search terms describing (1) dementia, (2) aged care (home-based and residential), and (3) systematic reviews. The databases searched were: Cochrane Database of Systematic Reviews, Joanna Briggs Evidence Based Practice Database (OVID), Medline (Ovid), Emcare (Ovid), Ageline (EBSCOhost), and CINAHL (EBSCOhost). Key curated systematic review collections (EPPI-Centre, OTSeeker, PEDro, Practice-Based Evidence in Nutrition (PEN) and CareSearch) were also scanned for dementia-related syntheses.

Inclusion criteria

Eligible reviews were those that:

- Included people living with dementia (all types and levels of severity) in receipt of aged care services. This might be home care or residential aged care.
- Involved an intervention that might be feasibly administered by or within a residential or home care service.
- Measured outcomes quantitatively or using mixed methods
- Were in the English language
- Were published between 2011 and December 15, 2021
- Documented their processes for reducing bias, including a comprehensive and replicable search strategy and a formal critical appraisal of their included studies.

Results

The 1066 retrieved citations were reviewed independently by the two authors of this review summary and included or excluded from the results set based on their eligibility according to the include criteria. This process created a final set of 200 systematic reviews for analysis. The relevant data from each review was extracted in duplicate by the two authors and used to inform this report.

Study participants

Participants in most reviews (n=136) were PLwD in either the community or residential care setting. A further 31 reviews were interested in the PLwD-family carer dyad while 16 were solely concerned with the family carer. Ten reviews looked at the impact of interventions on the PLwD and care workers and 4 focused on care worker outcomes alone. Three of the reviews studied outcomes on PLwD, care workers, and family carers.

The types of questions asked

Reviews asked their questions of the research literature in three ways. Questions either:

- queried the effectiveness of a named intervention on a specific pre-specified outcome or set of outcomes (n=91), e.g., What impact does exercise therapy have on cognitive function in PLwD?
- focused on outcomes of interest rather than a particular intervention (n=61), e.g., What are the effective interventions for managing apathy in PLwD?
- or sought to understand the effectiveness of a specific intervention on unspecified outcomes (n=48), e.g., What impact does horticultural therapy have on outcomes for PLwD?

Interventions named a *priori* across dementia care reviews

The 200 reviews investigated the effectiveness of a wide range of named interventions. Table 1 lists them by intervention category and frequency. Categorisation approach is based on Mohr 2021. [11]

Table 1. Reviews by intervention category (based on Mohr 2021 [11])

Intervention type and description	Description	Number of reviews
Training and support for informal carers	Interventions delivered by professionals to support informal carers, usually in the community setting. Their purpose is to educate, train or support the physical, mental, or social wellbeing of the carer so that they can continue their role. Interventions range from information provision through psychotherapy (e.g., cognitive behavioural therapy), psychoeducation, practical skills training, and respite care.	21
Physical activity or exercise	The provision of structured exercise opportunities such as walking, resistance training, and tai chi. May be used to maintain cognitive or physical function or counterbalance responsive behaviours.	17
Psychosocial interventions including the PLwD	Individual or group psychotherapy and other psychosocial interventions (e.g., dance, mindfulness, individual or group counselling) targeting the PLwD (n=5) or the carer-PLwD dyad (n=10).	15
Structured care approaches	Case conferences, case management, care protocols, specific care delivery models, transitional care coordination, and planned care transitions. Also includes interventions aimed at creating a person-centred care culture in the workplace (e.g., dementia care mapping) where the choices and individuality of the PLwD are respected.	14
Sensory interventions	Encompasses treatments that focus on the sensory processing of the client. Includes aromatherapy, massage and touch, music and sounds, and the specific multisensory program 'Namaste Care'. May be intended to counterbalance the negative impact of sensory deprivation.	11
Meaningful occupation or participation	Interventions designed to promote engagement and participation in an activity or stimulate social engagement to counterbalance limited contact with others or responsive behaviours. May involve activities of personal interest to the PLwD (e.g., gardening or horse-riding) or social contact (e.g., intergenerational groups or Montessori-based activities).	9
Dementia-friendly environments	Includes small scale housing, design considerations, environmental light, built environment, use of the physical environment etc.	8
Support for activities of daily living	Includes studies into the effectiveness of interventions, or services such as home care support, that help the PLwD and carers to complete everyday activities such as dressing, feeding, and bathing.	8
Assistive technologies	Includes technologies for safety (e.g., electronic medication dispensers, robotic devices trackers, motion detectors).	7
Training and support for aged care staff	Educational initiatives for care staff to develop their knowledge, change attitudes, or teach skills to improve care delivery and, consequently, the experiences of PLwD. Includes training in managing responsive behaviours.	6

Intervention type and description	Description	Number of reviews
Cognitive therapies	Includes standard tasks designed to stimulate cognitive functions such as memory, attention, or problem solving. Examples include memory recall, computer-based training, and cognitive stimulation therapy.	6
Life history-oriented support	Individualised therapies that promote personhood and may impact responsive behaviours. Includes reminiscence therapy, life story work production and simulated presence therapy (i.e., video-recorded message from a family member).	6
Respite care	Effectiveness of respite services on carers and/or PLwD outcomes (i.e. adult day services)	5
Medicines optimisation strategies	Interventions designed to change the prescribing behaviour of clinicians or to prompt a review of current medications	5
Occupational or physical therapy	Clinician-based care interventions aimed to increase or maintain function and provide support for activities of daily living (AoDL)	5
Palliative and end-of-life care provision	Includes strategies to increase goals of care and advance care planning uptake in aged care settings	5
Nutrition and hydration	Includes studies on enteral nutrition, oral supplementation, and the impact of coffee/tea consumption on BPSD	3
Behavioural interventions for responsive behaviours	Functional assessment-based interventions, de-escalation strategies, and rapid response teams	3
Training and support for formal and informal carers	Includes online dementia training programs and communication skills training for both care workers and family carers	2
Animal-assisted therapies	The impact of live animals, robots, or stuffed toy 'companions' on social functioning, affect, and the behaviour of the PLwD	2

Outcomes of concern across dementia care reviews

The most frequently investigated outcome was the management of the responsive behaviours of people living with dementia. These behaviours are generally considered to include mood disorders, depression, agitation, psychosis, sleep disturbances, anxiety, apathy, wandering, and verbal or physical aggression, amongst others. [12] Table 2 lists by frequency the outcomes investigated or identified by the reviews in this study. Where reviews examined individual behavioural symptoms as outcomes rather than global responsive behaviours (commonly depression and agitation), these are listed on their own.

Table 2. Outcomes described across n=200 reviews by participant type

Outcomes	Number of reviews
PLwD	
Responsive behaviours of dementia (also called 'behavioural and psychological symptoms of dementia', 'challenging behaviours' or the 'neuropsychiatric symptoms of dementia')	66
Quality of life	43
Mood, depression, affect	41
Cognitive function	39
Agitation	30
Social function (Loneliness, communication, relationship quality, social interaction and engagement)	24
Activities of daily living (functional independence in ADL, n=5)	19
Falls	13
Physical function and mobility	13
Food and fluid intake and nutritional outcomes	12
Residential care admission	12
Sleep quality	9
End-of-life outcomes	9
Psychotropic/antipsychotic use	9
Anxiety	8
Admission to hospital or emergency department	7
Mortality	7
Family carers	
Burden of care	25
Carer psychological health/mental well-being	15
Depression	12
Quality of life	11
Skills, competence, confidence, preparedness for/willingness to undertake role	7
Care workers	
Stress and burnout	3
Job satisfaction	3
Competence	3
Social interaction with the PLwD	1
Patient-centred attitudes and behaviour towards care recipients	1
Perceived confidence	1
Knowledge	1
Resilience	1
Staff retention	1
Use of restraints	1

Other outcomes explored within reviews include pain management, quality of care, apathy, oral health, family inclusion in decision making, refusals in personal care, wandering, incontinence, sense of self, self-esteem, and enjoyment and pleasure.

While the mapping of review findings for this project is ongoing, some preliminary findings are reported here for the most frequently synthesised topics.

Statement on overall evidence quality

Many of the reviews based on randomised controlled trials reported high or unknown risk of bias and small sample sizes associated with their included primary studies. These methodological shortcomings possibly reflect the challenges in conducting research with PLwD populations. Most reviews also highlight difficulties in drawing conclusions on the effectiveness of interventions due to the considerable heterogeneity of their included studies. Many combine studies with participants at different stages of the disease; interventions with different delivery modalities, intensities, or components; and include eclectic mixes of outcomes of interest and tools for measuring them. Where multicomponent interventions have demonstrated effectiveness, there often remains a need to identify the individual component(s) responsible.

Interventions with high quality supporting evidence

Support for family carers

Controlled trial evidence from across reviews suggests that multicomponent psycho-educative programs providing combinations of psychotherapy, information provision, and skills training are more effective in reducing family carer depressive symptoms and anxiety than single component interventions alone. However, the impact of these programs on carer burden and the likelihood of residential aged care placement for the PLwD was mixed across reports. There is promising evidence for the online delivery of these interventions, especially if support is provided in real-time, although beneficial effects appear to decrease over time. Supervised physical activity programs of low-medium intensity have a positive effect on carer burden, as do the efforts of occupational therapists to increase carer self-efficacy and self confidence in their caring role.

Physical activity and exercise for the PLwD

Of the 12 reviews synthesising evidence of the impact of exercise on cognitive function, only 3 found either no effect on cognitive outcomes, inclusive evidence for effect, or benefit only in younger populations of PLwD. In addition to cognition benefits, exercise appears to improve activities of daily living and functional independence while reducing the risk of falls by 34%. The impact of exercise or physical activity on BPSD were mixed, although there was some evidence for a reduction in depression.

Psychosocial interventions including the PLwD

Out of 15 reviews, three found psychosocial or psycho-educative interventions achieved successful results in reducing responsive behaviours or agitation. A further two demonstrated that psychosocial interventions involving the PLwD could lead to a substantial reduction of antipsychotic drug prescription in nursing homes.

Interventions targeting responsive behaviours

Across reviews there is consistent evidence of significant benefits associated with the following interventions for managing responsive behaviours or aspects of it such as apathy, depression, and anxiety:

- Music-based interventions, although there is still no consensus on the effective format (group or individual sessions), intensity, or active versus receptive approaches
- Multisensory stimulation
- Pet therapy
- Cognitive stimulation
- Functional analysis-based interventions
- Cognitive behavioural therapy
- Care planning
- Interventions with a high-level of personalisation.

Interventions requiring further research

- Respite care (day or residential)
- Interventions fostering family-staff partnerships in residential aged care
- Interventions building carer resilience
- Simulated presence therapy
- Life story work
- Dance movement therapy
- Special care units: the impact of design on social interaction.

What is missing?

A search of PubMed Clinical Queries (narrow clinical therapy studies option) using terms for dementia and aged care and restricted to the past 5 years reveals batches of primary studies on topics not yet, or only partially reflected in the systematic reviews mapped as part of this project. Some of the topics explored that may be ready for synthesis include:

- Doll therapy
- Tailored activity programs (tablets, digital photos, pernalised music)
- Remote activity monitoring technology for the home
- Bright light treatment
- Telehealth/telegerontology for rural dementia care dyads
- Assistive technology and telecare for maintaining independent living
- E-learning programs and tools for home and residential care workers
- Online support for family carers

- Dementia care mapping
- Interventions for people with early onset dementia
- Dementia sensitive communication training for nursing home staff
- Ethnic and cultural considerations in care of the PLwD.

References

1. Royal Commission into Aged Care Quality and Safety. Final report: Care, dignity and respect - volume 1 summary and recommendations [Internet]. Canberra, ACT: Commonwealth of Australia; 2021 [cited 2022 Jun 9]. Available from: https://agedcare.royalcommission.gov.au/publications/final-report-volume-1.
2. Banovic S, Zunic LJ, Sinanovic O. Communication Difficulties as a Result of Dementia. Mater Sociomed. 2018;30(3):221-4.
3. World Health Organization. Global action plan on the public health response to dementia 2017-2025 [Internet]. Geneva, Switzerland: Department of Mental Health and Substance Abuse, World Health Organization; 2017 [cited 2021 Dec 9]. Available from: https://apps.who.int/iris/rest/bitstreams/1092215/retrieve.
4. Lyketsos CG, Carrillo MC, Ryan JM, Khachaturian AS, Trzepacz P, Amatniek J, et al. Neuropsychiatric symptoms in Alzheimer's disease. Alzheimers Dement. 2011;7(5):532-9.
5. Feast A, Orrell M, Charlesworth G, Melunsky N, Poland F, Moniz-Cook E. Behavioural and psychological symptoms in dementia and the challenges for family carers: systematic review. Br J Psychiatry. 2016;208(5):429-34.
6. World Health Organization. Dementia [Internet]. Geneva, Switzerland: WHO; 2021 [cited 2021 Dec 9]. Available from: https://www.who.int/news-room/fact-sheets/detail/dementia.
7. Mitchell SL, Teno JM, Kiely DK, Shaffer ML, Jones RN, Prigerson HG, et al. The clinical course of advanced dementia. N Engl J Med. 2009;361(16):1529-38.
8. Global mortality from dementia: Application of a new method and results from the Global Burden of Disease Study 2019. Alzheimers Dement (N Y). 2021;7(1):e12200.
9. Australian Bureau of Statistics. Causes of death, Australia, 2019 [Internet]: ABS; 2019 [cited 2021 Dec 9]. Available from: https://www.abs.gov.au/statistics/health/causes-death/causesdeath-australia/2019.
10. Zafeiridi E, McMichael AJ, Passmore AP, McGuinness B. Factors influencing transition to care homes for people with dementia in Northern Ireland. Alzheimers Dement (N Y). 2021;7(1):e12120.
11. Mohr W, Rädke A, Afi A, Edvardsson D, Mühlichen F, Platen M, et al. Key Intervention Categories to Provide Person-Centered Dementia Care: A Systematic Review of Person-Centered Interventions. J Alzheimers Dis. 2021;84(1):343-66.
12. Kales HC, Gitlin LN, Lyketsos CG. Assessment and management of behavioral and psychological symptoms of dementia. BMJ : British Medical Journal. 2015;350:h369.

Cite as: ARIIA Knowledge & Implementation Hub. A review summary: Interventions for people living with dementia in receipt of aged care. Adelaide, SA: ARIIA; 2022.

www.ariia.org.au

For more information email ariia@ariia.org.au or call 08 7421 9134

ARIIA - Level 2, Tonsley Hub, South Rd, Tonsley SA 5042

ARIIA was established as an independent, not-for-profit organisation, set up to lead the advancement of the aged care workforce capability by promoting and facilitating innovation and research to improve the quality of aged care for all Australians.

ariia Aged Care Research & Industry Innovation Australia

Flinders University

Australian Government Department of Health and Aged Care