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Title: Psychosocial interventions for community dwelling people following diagnosis of mild to moderate dementia. Findings of a systematic scoping review.

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Abstract

National policies and evidence reviews recommend psychosocial interventions (PIs) as an essential support, particularly in the period following dementia diagnosis. However, the availability and uptake of these interventions is comparatively low. One of the reasons for this is that clinicians lack information about what might be provided and the potential benefits of different interventions. This paper identifies and describes psychosocial interventions for community dwelling people following diagnosis of mild to moderate dementia and presents the available evidence to inform practice decisions. A systematic scoping review was employed to map the evidence relating to PIs for this group. This identified 63 relevant studies, testing 69 interventions, which could be grouped into six categories; 20 cognition-oriented interventions; 11 behaviour-oriented; 11 stimulation-oriented; 13 emotion-oriented, 5 social-oriented and 9 multi-modal. There were three targets for outcome measurement of these PIs; the person with dementia, the family carer and the person-carer dyad. Over 154 outcome measures were identified in the studies with outcomes measured across 11 main domains. The lack of a classification framework for PIs means it is difficult to create a meaningful synthesis of the breadth of relevant evidence to guide clinical practice. Possible dimensions of a classification framework are proposed to begin to address this gap.

Introduction

With any effective medication for dementia deemed to be 'a long way off' (1), psychosocial interventions are one of the few treatments that clinicians can offer following diagnosis. Psychosocial interventions (PIs) can be defined as physical, cognitive or social activities that may maintain or improve 'functioning, interpersonal relationships and well-being in people with dementia' (2). PIs do not involve the use of medication although they can be used in conjunction with medication (3). The policy-led drive for earlier treatment of dementia following diagnosis, exemplified in the Global Action Plan on Dementia (4) and US National Plan to Address Alzheimer's Disease (5) underlines the importance of post-diagnostic interventions.

A systematic review of research into the experiences of people with dementia in the post-diagnostic period identified that psychosocial care pathways and interventions can help people to live successfully (6) and the value of early interventions for the well-being of people with dementia and their relatives has been demonstrated (7).

However, the use of PIs remains low. While 99% of memory services in England provide pharmacological treatments (acetylcholinesterase inhibitors or memantine) to eligible patients following diagnosis, provision of psychosocial interventions is limited (8). The only mention of psychosocial provision in the Alzheimer's Association Dementia Care Practice Recommendations (9) is in relation to the management of behavioural and psychiatric symptoms of dementia. The poor availability of PIs in Ireland is recognised in the priority actions being implemented as part of the National Dementia Strategy (10). This low use of PIs may be due to the lack of intervention development (11), particularly for people in the early stages of dementia, combined with a low evidence base for existing interventions. Until relatively recently studies tended to focus on people at the later stages of dementia in residential settings,

resulting in relatively sparse information on the needs of people with dementia at earlier stages of the disease, a noted gap in the evidence (12).

However, a more fundamental gap is the lack of clarity regarding what constitutes a PI? The term ‘psychosocial interventions’ is used to describe a variety of programmes, events and activities, for people with dementia, carers and various combinations of both, seeking to produce a wide range of different outcomes using a variety of modes of delivery. There is a lack of a conceptual clarity across the field and a distinct lack of a theoretical framework for the study of psychosocial prescribing (2).

To begin to address these gaps, this review sought to address the question; what is the nature of the evidence for the use of psychosocial interventions that might be feasibly delivered through health services, for community dwelling people with mild to moderate dementia? The evidence is mapped across several features of PIs which are relevant to clinical decision making, such as mode of delivery, intervention target, and potential outcomes. The findings are used to inform a classification framework for PIs which will enable the research and practice communities to progress the development of effective theory-based interventions and facilitate the production of broad, evidence-informed guidance to encourage wider use.

Methods

A systematic scoping review was employed in this study (13) to identify and select studies of psychosocial interventions that have been subjected to research, extract data and organise results. A scoping review is particularly useful when the body of literature is complex or heterogeneous and 'not amenable to a more precise systematic review of the evidence' (14). A scoping review differs from a systematic review in a number of key respects. The scoping review aims to map a body of literature in a specific area in order to identify gaps in the knowledge base or clarify key concepts. This mapping of the evidence does not usually take the quality of evidence into account and is instead focused on providing an overview.

Although systematic reviews of specific psychosocial interventions have been conducted, to our knowledge there have been no scoping reviews mapping the evidence for psychosocial interventions focusing on a particular stage of dementia.

Search strategy & study selection

The search was limited to studies published in the English language from 1990 onwards as studies published earlier than this were considered to lack relevance to current service provision, due to previous poor rates of early diagnosis.
Searches were conducted on NHS Evidence (Medline, PsycINFO, CINAHL), Web of Science, Scopus and Cochrane databases using the terms: (dement* OR Alzheimer*) AND (mild* OR early OR newly OR initial OR "home-based" OR "home based" OR "home-dwelling" OR "home dwelling") AND (therap* OR counse?ling OR training OR intervention* OR education* OR rehabilitation OR reminiscence OR psycho*) NOT (severe OR "long term" OR "long-term" OR institution* OR "nursing home*" OR "nursing-home*" OR "care home*" OR "care-home*" OR hospital*) NOT (drug* OR medic* OR pharmacologic*).

Database searches were complemented by following up results from existing reviews and the reference lists of key papers and relevant book chapters.
Additional search terms such as ‘therapies’ (e.g. art therapy) and names of specific interventions were not used within this review.

Inclusion criteria

- Primary research and evidence reviews
- Interventions designed for people with a confirmed diagnosis of mild/ moderate dementia,
- Interventions designed for the person alone or with a nominated informal carer
- Only involved people living in the community in their own homes
- Published in English and from 2000 onwards

Exclusion criteria

- Did not involve people with a diagnosis of mild/moderate dementia
- Interventions designed primarily for people with other health conditions who also have cognitive loss
- Involved people living in residential care, or other institutional settings
- Interventions for family carers only
- Interventions for staff
- Case study reports, study protocols, conference abstracts and non-research publications

There were difficulties with applying these criteria as there was a lack of clarity in some cases regarding the stage of dementia of participants or the setting through which the intervention was delivered. Where there were such difficulties decisions

were agreed by reviewers using other evidence contained within the papers. For example, whether people were living in the community had to be inferred for some studies where location was not stated, using factors such as outpatient attendance and lifestyle activities.

Significant variation was found in the definitions of ‘mild’ and ‘moderate’ stages of dementia. While most papers reported results from application of the Mini Mental State Examination (MMSE) or other validated assessment tool, the evidence search demonstrated that there is no consensus regarding which assessment instruments should be used to assess dementia stage and for some studies there were no details provided of the cognitive state of participants, in which case the studies were excluded.

Data extraction

All search results were transferred into bibliographic packages, and duplicates deleted. Titles and abstracts were independently screened for inclusion by two researchers. Additional papers resulting from subsequent searches were screened by one researcher with a second researcher then checking 10% of these. Disagreements between data extractors were resolved through discussion and reference back to the search criteria until consensus was reached.

Results

The search strategy identified 2,275 abstracts, which were screened by two reviewers for relevance. This resulted in 420 papers. Of these, 264 duplicates were identified and excluded. Full texts of 156 papers were accessed and read with reference to the review inclusion/ exclusion criteria. This resulted in 43 relevant studies. A further 20 relevant studies were identified from other sources such as study reference lists giving a total of 63 relevant studies. Figure 1 summarises the data extraction process.

Figure 1 about here: **Figure 1: Flow chart describing data extraction**

Three of these (15-17) were randomised controlled trials (RCTs) of more than one intervention, delivered separately to different groups of patients. We judged these to be a test of each of these interventions and so they are reported individually under the relevant headings (giving a total of 69 intervention studies reported in the tables). Analysis of the search yield identified evidence for a variety of interventions that might be delivered to community dwelling people with mild to moderate dementia. Table 1 describes these interventions and categorises them according to the four broad groups of psychosocial treatments for dementia described in the American Psychiatric Association (APA) practice guidelines (18), with the addition of two groups. The allocation of specific interventions to these categories was a challenge as several could potentially be included under more than one heading.

Table 1 about here: **Table 1: Description of interventions identified in this review categorised by approach (adapted from APA 1997)**

Cognition-oriented approaches were the most frequently reported with a total of 20 studies or 30% of the total, followed by emotion-oriented approaches at 20%.

Table 2 presents the identified studies, classified by mode of delivery and target group. The mode was typically an individual or group session delivered or facilitated by a trained therapist or instructor. The intervention target was solely the person with dementia in 38 studies, solely the dyad in 21 studies with the remainder involving carers in joint, separate or parts of sessions. Carers were involved as supervisor or facilitator of the intervention in eight studies.

Table 2 about here: **Table 2: Identified interventions, mode of delivery and target groups.**

Table 3 presents the outcome domains that were measured in all 63 studies and those which reported significant effects. A total of 154 outcome measures were used, reflecting the diversity in thinking regarding what might be the benefits of PIs. Cognitive functioning was most frequently measured as an outcome, followed by psychiatric symptoms such as depression and anxiety. For family carers, the most frequently assessed outcome was caregiver burden or distress. Only a small number of studies reported any significant effects on these outcomes, for example, 46% of studies which measured ADLs or physical functioning reported a significant effect and 40% of studies which measured cognitive functioning reported an effect.

Table 3 about here: **Table 3: Main outcome domains measured and studies reporting significant effects**

A number of designs were employed in the 63 studies; 36 were RCTs, 14 before-after design with no control group, 7 controlled before-after and 6 qualitative.

Discussion

This review has identified a growing body of evidence for psychosocial interventions for community dwelling people with mild to moderate dementia with 63 studies identified, reporting on the effectiveness of 69 interventions which can be classified into six categories. The heterogeneity of the interventions studied and approaches taken towards evidence generation is broad. At least three possible target groups of beneficiaries can be identified; the person, the carer and the dyad in a variety of combinations; there several modes of intervention delivery (individual, group or a combination of these); four broad types of study design (56% were RCTs) and 154 outcome measures were applied, covering a large number of domains. Most studies relate to interventions aimed at improving cognitive functioning (n=20), followed by emotion oriented approaches (n=13) such as psychotherapy. Given that the quality of the evidence has not been assessed as part of this study it is difficult to provide a wide ranging comment on the state of the literature. Through working with this literature it is evident that the gaps are concerned with the lack of a classification framework for such interventions (which is demonstrated by the confusing range of terms used to describe the same or similar interventions) and the need for methodologies beyond RCTs if we are determine effectiveness in real world settings.

Information about interventions, the potential choice of mode of delivery and target group can be used by the clinician to identify what might be most appropriate for a given patient. However, the lack of a classification framework for PIs makes it difficult to synthesise evidence in the area and to produce practical and evidence-informed guidance for clinicians who prescribe PIs, a finding echoed in a recent review of dementia caregiver interventions (80). In a review of CT and CRT (81), the differences between these two psychosocial interventions were described using several dimensions such as the context, focus and goals of the intervention itself, the format and the proposed mechanism of action. The APA categorisation of PIs is also

a useful reference for clinicians (18), but it was developed at a time when PIs for people with dementia were in their infancy. Moreover, evidence was generated almost exclusively from use in residential settings and for people with severe dementia. This context influenced how these four categories were described and what interventions they included. Consequently, the categories do not fully reflect the new generation of PIs; which means that some of our listings under the APA headings are somewhat arbitrary. For example, the category 'stimulation-oriented approaches' may not adequately reflect physical exercise interventions, which are a more recent area of study. It is not clear where educational interventions might fit or how best to categorise multi-modal interventions. Therefore, based on the findings of this review, a number of possible dimensions for recalibrating the classification of psychosocial interventions are proposed and outlined in Table 4.

Table 4 about here: **Table 4: Possible dimensions for a classification framework for psychosocial interventions**

The recently published *Key questions on care interventions for people with dementia and their caregivers* (82) notes the urgent need for a summary of available evidence in this area and poses wide ranging questions. This review contributes to the knowledge base for a subset of the population (i.e. community dwelling people with mild to moderate dementia) and a subset of interventions (i.e. PIs). However, the long list of varied interventions in the *Key Questions* (82) points to the need for more consistent description and classification of interventions. Greater clarity on what exactly a PI aims to achieve and for whom, is necessary to ensure the most appropriate methods and measures are chosen to generate research evidence. We may need to approach creation of evidence for psychosocial interventions in a different way to that required for pharmacological treatments. It has been argued that the RCT may not be the most appropriate study design for psychosocial interventions

(83), particularly given the importance of the delivery context (84); and the lack of outcome measures which are sufficiently sensitive and specific (2). RCTs have failed to capture, admittedly hard to measure benefits, such as hope, connection to a service and option demand – the value of knowing support will be there when it is needed and it is now appreciated that an embedded qualitative component is essential to capture individual meaningful gains and to explain mechanisms of effect (85). Alternative study designs such as realist evaluation, which seeks to understand complexity and service delivery context, may be more appropriate (86). Pragmatic trials also offer a robust method for testing interventions in real-world contexts and work is progressing to create a framework for supporting pragmatic trials of psychosocial interventions (87).

We know that people with dementia want to be offered psychosocial treatment and support from the point of diagnosis (88) and that they also want interventions to meet their specific and individualised needs. More effort needs to be made to respond to what this patient group express that they both need and want after diagnosis. Ideally, patients should be more involved in the design of interventions to ensure relevance and feasibility. Public and patient involvement may yield significant benefits in terms of better designed studies and more relevant data and results (89).

Given the lack of curative treatments, psychosocial interventions are an important treatment and support option that can be offered now for people with dementia and family carers. The availability of such interventions may also affect the willingness of clinicians to diagnose dementia in the first place, as they now have something to offer following diagnosis (90). This may help alleviate the ‘therapeutic nihilism’ in relation to dementia (91) by making available relevant interventions which can provide a range of benefits to people with dementia and their carers. Classifying

potential psychosocial interventions correctly may help to encourage psychosocial prescribing that is both meaningful and beneficial to the recipient.

References

1. The Lancet: Dementia burden coming into focus. The Lancet 2017; 390:2606
2. Moniz-Cook E, Vernooij-Dassen M, Woods B, et al: Psychosocial interventions in dementia care research: The INTERDEM manifesto. Aging & Mental Health 2011; 15:283-290
3. Royal College of Psychiatrists: Memory Services National Accreditation Programme, London, 2018
4. World Health Organization: Global Action Plan on the Public Health Response to Dementia, Geneva, World Health Organization, 2017
5. US Department of Health and Human Services: National Plan to Address Alzheimer's Disease; 2017 Update, Washington, US Government, 2017
6. Bunn F, Goodman C, Sworn K, et al: Psychosocial Factors That Shape Patient and Carer Experiences of Dementia Diagnosis and Treatment: A Systematic Review of Qualitative Studies. PLoS Medicine 2012;
7. Moniz Cook E,Manthorpe j: Early Psychosocial Interventions in Dementia: Evidence Based Practice, London, Jessica Kingsley, 2009
8. Psychiatrists RCo: The English National Memory Clinics Audit Report, London, 2014
9. Fazio S, Pace D, Flinner J, et al: The Fundamentals of Person-Centered Care for Individuals With Dementia. The Gerontologist 2018; 58:S10-S19
10. Department of Health: Mid-term review of the implementation of the National Dementia Strategy, Dublin, Ireland, Deaprtmetn of Health, 2018
11. Winblad B, Amouyel P, Andrieu S, et al: Defeating Alzheimer's disease and other dementias: a priority for European science and society. The Lancet Neurology 2016; 15:455-532
12. McDermott O, Charlesworth G, Hogervorst E, et al: Psychosocial interventions for people with dementia: a synthesis of systematic reviews. Aging & Mental Health 2018; 1-11
13. Arksey H,O'Malley L: Scoping studies: towards a methodological framework. International Journal of Social Research Methodology 2005; 8:19-32
14. Peters MDJ, Godfrey CM, Khalil H, et al: Guidance for conducting systematic scoping reviews. International Journal of Evidence-Based Healthcare. 2015; 13:141-146
15. Amieva H, Robert PH, Grandoulier A-S, et al: Group and individual cognitive therapies in Alzheimer's disease: the ETNA3 randomized trial. International Psychogeriatrics 2015; 28:707-717
16. Quayhagen MP, Quayhagen M, Corbeil RR, et al: Coping With Dementia: Evaluation of Four Nonpharmacologic Interventions. International Psychogeriatrics 2000; 12:249-265
17. Tsantali E, Economidis D,Rigopoulou S: Testing the Benefits of Cognitive Training vs. Cognitive Stimulation in Mild Alzheimer's Disease: A Randomised Controlled Trial. Brain Impairment 2017; 18:188-196
18. American Psychiatric Association: Practice Guideline for the Treatment of Patients With Alzheimer’s Disease and Other Dementias, 1st Edition. 1997
19. Cipriani G, Bianchetti A,Trabucchi M: Outcomes of a computer-based cognitive rehabilitation program on Alzheimer's disease patients compared with those on patients affected by mild cognitive impairment. Archives of Gerontology and Geriatrics 2006; 43:327-335

20. Clare L, Linden DEJ, Woods RT, et al: Goal-Oriented Cognitive Rehabilitation for People With Early-Stage Alzheimer Disease: A Single-Blind Randomized Controlled Trial of Clinical Efficacy. The American Journal of Geriatric Psychiatry 2010; 18:928-939
21. Kim S: Cognitive rehabilitation for elderly people with early-stage Alzheimer's disease. Journal of Physical Therapy Science 2015; 27:543-546
22. Kurz A, Thöne-Otto A, Cramer B, et al: CORDIAL: Cognitive Rehabilitation and Cognitive-behavioral Treatment for Early Dementia in Alzheimer DiseaseA Multicenter, Randomized, Controlled Trial. Alzheimer Disease & Associated Disorders 2012; 26:246-253
23. Loewenstein DA, Acevedo A, Czaja SJ, et al: Cognitive Rehabilitation of Mildly Impaired Alzheimer Disease Patients on Cholinesterase Inhibitors. The American Journal of Geriatric Psychiatry 2004; 12:395-402
24. Talassi E, Guerreschi M, Feriani M, et al: Effectiveness of a cognitive rehabilitation program in mild dementia (MD) and mild cognitive impairment (MCI): A case control study. Archives of Gerontology and Geriatrics 2007; 44:391-399
25. Thivierge S, Jean L,Simard M: A Randomized Cross-over Controlled Study on Cognitive Rehabilitation of Instrumental Activities of Daily Living in Alzheimer Disease. The American Journal of Geriatric Psychiatry 2014; 22:1188-1199
26. Huntley JD, Hampshire A, Bor D, et al: Adaptive working memory strategy training in early Alzheimer's disease: Randomised controlled trial. British Journal of Psychiatry 2018; 210:61-66
27. Kanaan SF, McDowd JM, Colgrove Y, et al: Feasibility and Efficacy of Intensive Cognitive Training in Early-Stage Alzheimer's Disease. American Journal of Alzheimer's Disease & Other Dementias® 2014; 29:150-158
28. Lee G, Yip C, Yu E, et al: Evaluation of a computer-assisted errorless learning-based memory training program for patients with early Alzheimer's disease in Hong Kong: a pilot study. Clinical Interventions in Aging Volume 2013; 8:623-633
29. Moore S, Sandman CA, McGrady K, et al: Memory training improves cognitive ability in patients with dementia. Neuropsychological Rehabilitation 2001; 11:245-261
30. Neely AS, Vikström S,Josephsson S: Collaborative memory intervention in dementia: Caregiver participation matters. Neuropsychological Rehabilitation 2009; 19:696-715
31. Milders M, Bell S, Lorimer A, et al: Cognitive stimulation by caregivers for people with dementia. Geriatric Nursing 2013; 34:267-273
32. Olazarán J, Muñiz R, Reisberg B, et al: Benefits of cognitive-motor intervention in MCI and mild to moderate Alzheimer disease. Neurology 2004; 63:2348-2353
33. Orgeta V, Leung P, Yates L, et al: Individual cognitive stimulation therapy for dementia: a clinical effectiveness and cost-effectiveness pragmatic, multicentre, randomised controlled trial. Health Technology Assessment 2015; 19:
34. Quayhagen MP, Quayhagen M, Corbeil RR, et al: A dyadic remediation program for care recipients with dementia. Nursing Research 1995; 44:153-159
35. Fitzsimmons S,Buettner LL: Health Promotion for the Mind, Body, and Spirit: A college course for older adults with dementia. American Journal of Alzheimer's Disease & Other Dementias® 2003; 18:282-290
36. Laakkonen M-L, Kautiainen H, Hölttä E, et al: Effects of Self-Management Groups for People with Dementia and Their Spouses—Randomized Controlled Trial. Journal of the American Geriatrics Society 2016; 64:752-760

37. Quinn C, Toms G, Jones C, et al: A pilot randomized controlled trial of a self-management group intervention for people with early-stage dementia (The SMART study). International Psychogeriatrics 2015; 28:787-800
38. Richeson NE, Boyne S,Brady EM: Education for Older Adults with Early-Stage Dementia: Health Promotion for the Mind, Body, and Spirit. Educational Gerontology 2007; 33:723-736
39. Sprange K, Mountain GA, Shortland K, et al: Journeying through Dementia, a community-based self-management intervention for people aged 65 years and over: a feasibility study to inform a future trial. Pilot and Feasibility Studies 2015; 1:42
40. Curtin A: Individualized Skills Training Program for Community-Dwelling Adults with Mild Alzheimer's Disease. Journal of Gerontological Nursing 2011; 37:20-29
41. Gitlin LN, Arthur P, Piersol C, et al: Targeting Behavioral Symptoms and Functional Decline in Dementia: A Randomized Clinical Trial. Journal of the American Geriatrics Society 2018; 66:339-345
42. Graff MJL, Vernooij-Dassen MJM, Thijssen M, et al: Community based occupational therapy for patients with dementia and their care givers: randomised controlled trial. BMJ 2006; 333:1196
43. Voigt-Radloff S, Graff M, Leonhart R, et al: A multicentre RCT on community occupational therapy in Alzheimer's disease: 10 sessions are not better than one consultation. BMJ Open 2011; 1:
44. Galvin J, Tolea M, George N, et al: Public–private partnerships improve health outcomes in individuals with early stage Alzheimer's disease. Clinical Interventions in Aging 2014; 9:
45. Canonici AP, Andrade LPd, Gobbi S, et al: Functional dependence and caregiver burden in Alzheimer's disease: a controlled trial on the benefits of motor intervention. Psychogeriatrics 2012; 12:186-192
46. Holthoff V, Marschner K, Scharf M, et al: Effects of Physical Activity Training in Patients with Alzheimer's Dementia: Results of a Pilot RCT Study. PLOS One
47. Miu D, Szeto S,Mak Y: A randomised controlled trial on the effect of exercise on physical, cognitive and affective function in dementia subjects. Asian J Gerontol Geriatr 2008; 3:8-16
48. Pitkälä KH, Pöysti MM, Laakkonen M, et al: Effects of the finnish alzheimer disease exercise trial (finalex): A randomized controlled trial. JAMA Internal Medicine 2013; 173:894-901
49. Sobol NA, Hoffmann K, Frederiksen KS, et al: Effect of aerobic exercise on physical performance in patients with Alzheimer's disease. Alzheimer's & Dementia 2016; 12:1207-1215
50. Steinberg M, Leoutsakos J-MS, Podewils LJ, et al: Evaluation of a home-based exercise program in the treatment of Alzheimer's disease: The Maximizing Independence in Dementia (MIND) study. International Journal of Geriatric Psychiatry 2009; 24:680-685
51. Vreugdenhil A, Cannell J, Davies A, et al: A community-based exercise programme to improve functional ability in people with Alzheimer's disease: a randomized controlled trial. Scandinavian Journal of Caring Sciences 2011; 26:12-19
52. Yágüez L, Shaw KN, Morris R, et al: The effects on cognitive functions of a movement-based intervention in patients with Alzheimer's type dementia: a pilot study. International Journal of Geriatric Psychiatry 2011; 26:173-181

53. Camic PM, Tischler V,Pearman CH: Viewing and making art together: a multi-session art-gallery-based intervention for people with dementia and their carers. Aging & Mental Health 2014; 18:161-168
54. Petrescu I, MacFarlane K,Ranzijn R: Psychological effects of poetry workshops with people with early stage dementia: An exploratory study. Dementia 2012; 13:207-215
55. Ullán AM, Belver MH, Badía M, et al: Contributions of an artistic educational program for older people with early dementia: An exploratory qualitative study. Dementia 2012; 12:425-446
56. Auclair U, Epstein C,Mittelman M: Couples Counseling in Alzheimer's Disease: Additional Clinical Findings from a Novel Intervention Study. Clinical Gerontologist 2009; 32:130-146
57. Burns A, Guthrie E, Marino-Francis F, et al: Brief psychotherapy in Alzheimer's disease: Randomised controlled trial. British Journal of Psychiatry 2005; 187:143-147
58. Cheston R, Jones K,Gilliard J: Group psychotherapy and people with dementia. Aging & Mental Health 2003; 7:452-461
59. Spector A, Charlesworth G, King M, et al: Cognitive–behavioural therapy for anxiety in dementia: pilot randomised controlled trial. British Journal of Psychiatry 2015; 206:509-516
60. Stanley MA, Calleo J, Bush AL, et al: The Peaceful Mind Program: A Pilot Test of a Cognitive–Behavioral Therapy–Based Intervention for Anxious Patients with Dementia. The American Journal of Geriatric Psychiatry 2013; 21:696-708
61. Chung JCC: An intergenerational reminiscence programme for older adults with early dementia and youth volunteers: values and challenges. Scandinavian Journal of Caring Sciences 2009; 23:259-264
62. Jo H,Song E: The Effect of Reminiscence Therapy on Depression, Quality of Life, Ego-Integrity, Social Behavior Function, and Activies of Daily Living in Elderly Patients With Mild Dementia. Educational Gerontology 2015; 41:1-13
63. Johnston B, Lawton S, McCaw C, et al: Living well with dementia: enhancing dignity and quality of life, using a novel intervention, Dignity Therapy. International Journal of Older People Nursing 2015; 11:107-120
64. Tadaka E,Kanagawa K: Effects of reminiscence group in elderly people with Alzheimer disease and vascular dementia in a community setting. Geriatrics & Gerontology International 2007; 7:167-173
65. Woods RT, Orrell M, Bruce E, et al: REMCARE: Pragmatic Multi-Centre Randomised Trial of Reminiscence Groups for People with Dementia and their Family Carers: Effectiveness and Economic Analysis. PloS One 2016; 11:
66. Wu L-F,Koo M: Randomized controlled trial of a six-week spiritual reminiscence intervention on hope, life satisfaction, and spiritual well-being in elderly with mild and moderate dementia. International Journal of Geriatric Psychiatry 2016; 31:120-127
67. Cheston R,Howells L: A feasibility study of translating “Living Well with Dementia” groups into a Primary Care Improving Access to Psychological Therapy service (innovative practice). Dementia 2015; 15:273-278
68. Gaugler JE, Gallagher-Winker K, Kehrberg K, et al: The Memory Club: Providing Support to Persons with Early-Stage Dementia and Their Care Partners. American Journal of Alzheimer's Disease & Other Dementias® 2011; 26:218-226

69. Goldsilver PM,Gruneir MRB: Early stage dementia group: An innovative model of support for individuals in the early stages of dementia. American Journal of Alzheimer's Disease & Other Dementias® 2001; 16:109-114
70. Logsdon RG, Pike KC, McCurry SM, et al: Early-Stage Memory Loss Support Groups: Outcomes from a Randomized Controlled Clinical Trial. The Journals of Gerontology: Series B 2010; 65B:691-697
71. Burgener SC, Yang Y, Gilbert R, et al: The Effects of a Multimodal Intervention on Outcomes of Persons With Early-Stage Dementia. American Journal of Alzheimer's Disease & Other Dementias® 2008; 23:382-394
72. Charlesworth G, Burnell K, Crellin N, et al: Peer support and reminiscence therapy for people with dementia and their family carers: a factorial pragmatic randomised trial. Journal of Neurology, Neurosurgery & Psychiatry 2016; 87:1218-1228
73. Fischer-Terworth C,Probst P: Evaluation of a TEACCH- and Music Therapy-Based Psychological Intervention in Mild to Moderate Dementia: A Controlled Trial. The Journal of Gerontopsychology and Geriatric Psychiatry 2011; 24:93-101
74. Kim H-h: Effects of experience-based group therapy on cognitive and physical functions and psychological symptoms of elderly people with mild dementia. Journal of Physical Therapy Science 2015; 27:2069-2071
75. Marshall A, Spreadbury J, Cheston R, et al: A pilot randomised controlled trial to compare changes in quality of life for participants with early diagnosis dementia who attend a 'Living Well with Dementia' group compared to waiting-list control. Aging & Mental Health 2015; 19:526-535
76. Prick A-E, de Lange J, Scherder E, et al: The effects of a multicomponent dyadic intervention on the mood, behavior, and physical health of people with dementia: a randomized controlled trial. Clinical Interventions in Aging 2016; 11:383-395
77. Roberts JS,Silverio E: Evaluation of an Education and Support Program for Early-Stage Alzheimer's Disease. Journal of Applied Gerontology 2009; 28:419-435
78. Viola LF, Nunes PV, Yassuda MS, et al: Effects of a multidisciplinar cognitive rehabilitation program for patients with mild Alzheimer's disease. Clinics 2011; 66:1395-1400
79. Waldorff FB, Buss DV, Eckermann A, et al: Efficacy of psychosocial intervention in patients with mild Alzheimer's disease: the multicentre, rater blinded, randomised Danish Alzheimer Intervention Study (DAISY). BMJ : British Medical Journal 2012; 345:
80. Gaugler JE, Jutkowitz E, Shippee TP, et al: Consistency of dementia caregiver intervention classification: an evidence-based synthesis. International Psychogeriatrics 2016; 29:19-30
81. Bahar-Fuchs A, Clare L,Woods B: Cognitive training and cognitive rehabilitation for persons with mild to moderate dementia of the Alzheimer's or vascular type: a review. Alzheimer's research & therapy 2013; 5:35-35
82. Agency for Healthcare Research and Quality: Care Interventions for People With Dementia and Their Caregivers, 2018
83. de Medeiros K,Basting A: "Shall I Compare Thee to a Dose of Donepezil?": Cultural Arts Interventions in Dementia Care Research. The Gerontologist 2014; 54:344-353
84. Vernooij-Dassen M,Moniz-Cook E: Raising the standard of applied dementia care research: addressing the implementation error. Aging & Mental Health 2014; 18:809-814

85. Moore GF, Audrey S, Barker M, et al: Process evaluation of complex interventions: Medical Research Council guidance. BMJ : British Medical Journal 2015; 350:
86. Bonell C, Fletcher A, Morton M, et al: Realist randomised controlled trials: A new approach to evaluating complex public health interventions. Social Science & Medicine 2012; 75:2299-2306
87. Baier RR, Mitchell SL, Jutkowitz E, et al: Identifying and Supporting Nonpharmacological Dementia Interventions Ready for Pragmatic Trials: Results From an Expert Workshop. Journal of the American Medical Directors Association 2018; 19:560-562
88. Mitchell W: Somsed to Know, London, Bloomsbury, 2018
89. Iliffe S, McGrath T,Mitchell D: The impact of patient and public involvement in the work of the Dementias & Neurodegenerative Diseases Research Network (DeNDRoN): case studies. Health Expectations 2013; 16:351-361
90. Wilkinson D: Is there a double standard when it comes to dementia care? International Journal of Clinical Practice 2005; 59:3-7
91. Rockwood K: For how long should we use symptomatic therapies to treat people with Alzheimer disease? Canadian journal of psychiatry. Revue canadienne de psychiatrie 2014; 59:615-617

Figure

Figure 1: Flow chart describing data extraction

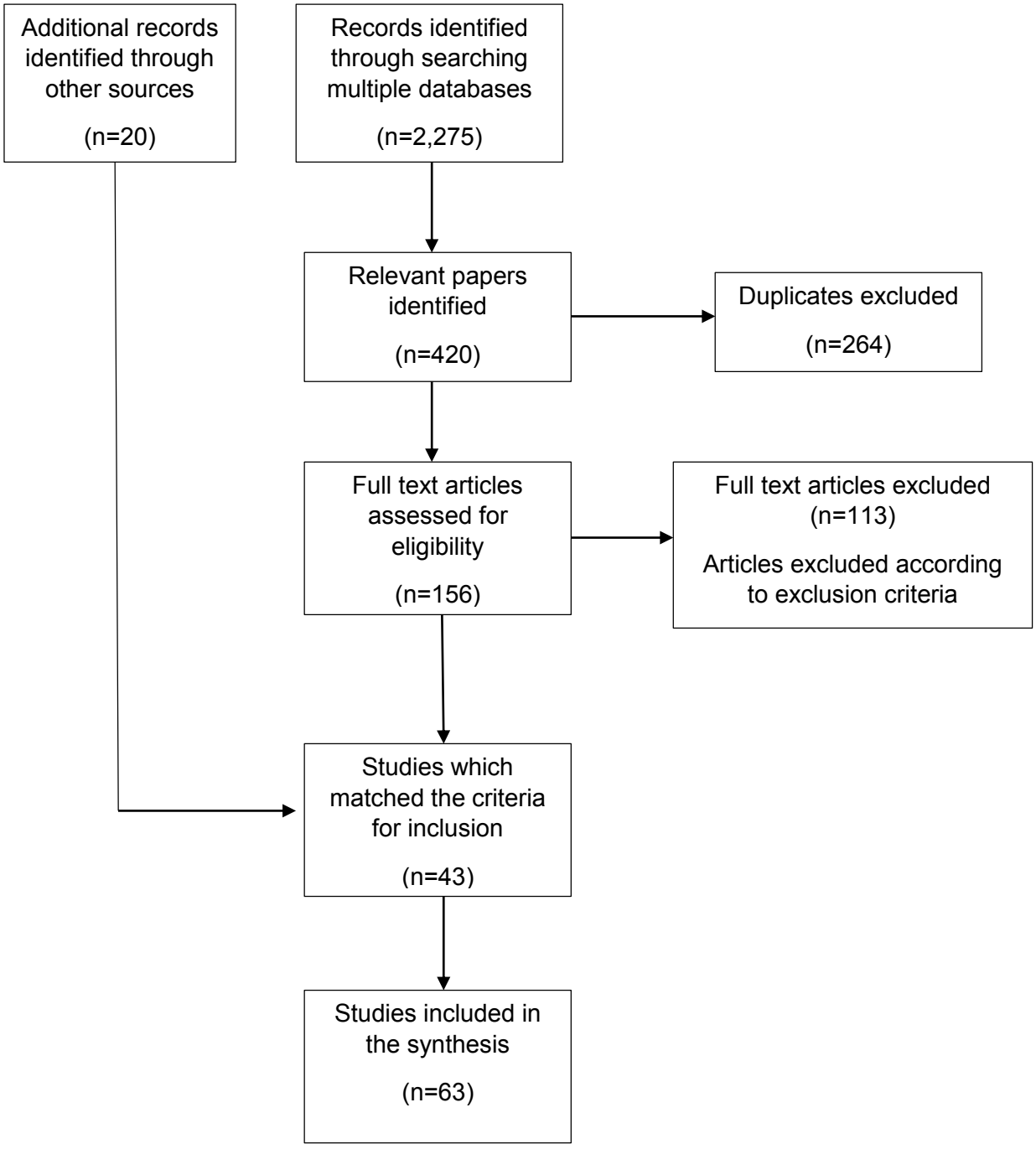

Table 1: Description of interventions identified in this review categorised by approach (adapted from APA 1997)

Approach or orientation	Types of psychosocial interventions (N=69 from 63 studies)
Cognition-oriented approaches n= 20	Cognitive Rehabilitation Therapy is tailored to the person and is delivered in their own home. A trained therapist works with the person with dementia and their carer to set personal goals; to plan how to meet these goals; and supports them in doing so.
	Cognitive Training or 'brain training' involves guided practice of a set of structured tasks, to train cognitive processes and abilities.
	Cognitive stimulation Therapy is typically delivered through group sessions, facilitated by a trained instructor/therapist over several weeks. Social interaction, engagement and stimulation are emphasised.
Emotion-oriented approaches n=13	Cognitive behaviour therapy
	Brief psychotherapy includes a range of therapeutic approaches, delivered by trained therapists, to individuals or groups.
	Reminiscence Therapy involves the discussion of past activities, events and experiences with another person or group of people, usually with the aid of visual and/or auditory materials.
Behavior-oriented approaches	Self-management programs include the provision of information and support to individuals or groups to encourage the development of self-efficacy.

n=11	Skills-maintenance programmes are mostly delivered by occupational therapists in the person's home, usually involving the family carer in some way.
Stimulation-oriented approaches	Physical activity and exercise programmes specifically developed for people with dementia which may or not may involve family carers.
n=11	Arts, music and recreation, usually in groups, facilitated by a therapist or trained instructor.
Social-oriented approaches n=5	Usually facilitated informal gatherings, support groups offer peer support (either carer to carer or person to person).
Multi-modal approaches n=9	A combination of two or more interventions such as support group, counselling, cognition-oriented approach, exercise and others.

Table 4: Possible dimensions for a classification framework for psychosocial interventions

Dimension	Examples of attributes for each dimension
General focus or approach	A high level description of the main area which the intervention address e.g. cognition, physical functioning, emotional wellbeing etc.
Purpose/ anticipated benefits	Improvements in specified areas of functioning, ability and/or wellbeing. Specification of outcomes.
Target beneficiary	Person with dementia only; family carer only; dyad only; other combination of person and carer; etc.
Stage of dementia	For example, early/mild
Setting for delivery	For example, home, day centre, community setting
Mode of delivery	Individual or group; type of therapist/instructor; technology facilitated (computer or phone).
Mechanism of action	Identification of possible mechanisms of action. For example, the repetition of tasks in CT may support maintenance of brain function.

Table 2: Identified interventions, mode of delivery and target groups.

Cognition oriented approaches (n= 20)			
Cognitive rehabilitation therapy (CRT) n= 8			
Author(s)	**Year**	**Mode of delivery**	**Target group Person/Carer/Dyad**
Amieva et al. (15)	2016	Individual dyad sessions	Dyad
Cipriani et al. (19)	2006	Individual computer-based program	Person
Clare et al. (20)	2010	Group	Person Carer joined end of sessions
Kim (Seyun) (21)	2015	Individual and group sessions	Person
Kurz et al. (22)	2012	Individual sessions with instructor	Person Information to carer to reinforce training
Loewenstein (23) et al.		Individual sessions with instructor	Person
Talassi et al.(24)	2007	Individual program; sessions with computer and sessions with therapist	Person

Thivierge et al. (25)	2015	Individual sessions with instructor.	Person Information to carer to reinforce training
Cognitive training (CT) n= 7			
Amieva et al. (15)	2016	Group	Joint and separate sessions for person and carer
Huntley et al. (26)	2016	Individual computer-based program	Person
Kanaanet al. (27)	2014	Individual sessions with instructor	Person
Lee et al. (28)	2013	Two interventions: individual with computer and individual with therapist	Person
Moore et al. (29)	2001	Group for dyads	Dyad
Neely et al. (30)		Two interventions: individual and caregiver with instructor and individual with instructor	Person alone and person with caregiver
Tsantali et al. (17)	2017	Individual sessions with instructor.	Person
Cognitive Stimulation Therapy (CST) n= 5			
Milders et al. (31)	2013	Caregiver-led sessions at home	Dyad Caregiver trained in program

Olazaran et al.(32)	2004	Group	Person
Orgeta et al. (33)	2015	Caregiver-led sessions at home	Dyad Caregiver trained in program
Quayhagen et al (34)	2000	Individual dyad	Dyad
Tsantali et al (17)	2017	Individual sessions with instructor.	Person
Behaviour-oriented approaches (n=11)			
Health promotion/Self-management interventions n=5			
Fitzsimmons & Buettner (35)	2003	Group	Person
Laakkonen et al. (36)	2016	Group	Person and carer in separate groups
Quinn et al. (37)	2015	Group	Person Carers attend first and final sessions
Richeson et al. (38)	2007	Group	Person
Sprange et al. (39)	2015	Person in group and four individual sessions with therapist	Person

Skills training n=4			
Curtin (40)	2011	Individual sessions with instructor.	Person Information to carer to reinforce training
Gitlin et al (41)	2018	Individual dyad with therapist	Dyad
Graff et al. (42)	2006	Individual dyad with therapist	Dyad
Voigt-Radloff et al. (43)	2011	Individual dyad with therapist	Dyad
Education n=2			
Galvin et al. (44)	2014	Dyad care consultation	Dyad
Quayhagen et al (16)	2000	Groups for dyads	Dyad
Stimulation-oriented approaches (n=11)			
Exercise and physical activity interventions n=8			
Canonici et al. (45)	2012	Group for dyads	Dyad
Holthoff et al. (46)	2015	Individual sessions with trainer	Person
Miu et al. (47)	2008	Group	Person

Pitkälä et al. (48)	2013	Two interventions: Group sessions; individual sessions with therapist	Person
Sobol et al. (49)	2016	Group	Person
Steinberg et al. (50)	2009	Individual program supervised by caregiver	Person Caregiver trained in exercise program
Vruegdenhil et al. (51)	2011	Individual program supervised by caregiver	Person Caregiver trained in exercise program
Yaguez et al. (52)	2011	Group for dyads	Dyad
Arts and recreation interventions n=3			
Camic et al. (53)	2014	Group	Dyad
Petrescu et al. (54)	2012	Group	Person
Ullan et al. (55)	2013	Group	Person
Emotion-oriented approaches (n=13)			
CBT and psychotherapies n=6			
Auclair et al. (56)	2009	Dyad counselling	Dyad
Burns et al. (57)	2005	Individual sessions with therapist	Person

Cheston et al. (58)	2003	Group	
Quayhagen et al. (16)	2000	Dyad counselling	Dyad
Spector et al. (59)	2015	Group	Person
Stanley et al. (60)	2013	Individual sessions with therapist. Telephone 'booster' sessions	Person Training to carer to reinforce skills
Reminiscence n=7			
Amieva et al. (15)	2016	Group	Person and carer separately
Chung (61)	2009	Group	Person
Jo & Song (62)	2015	Group	Person
Johnston et al. (63)	2015	Individual sessions with therapist	Person
Tadaka & Kanagawa (64)	2007	Group	Person
Woods et al. (65)	2016	Groups for dyads	Dyad
Wu & Koo (66)	2016	Group	Person
Social support approaches (n=5)			
Cheston & Howells (67)	2015	Group	Joint and separate sessions for person and carer

Gaugler et al. (68)	2011	Group	Joint and separate time in sessions
Goldsilver & Gruneir (69)	2001	Group	Person
Logsdon et al. (70)	2010	Group	Joint and separate sessions
Quayhagen et al. (16)	2000	Group	Person
Multi-modal approaches (n=9)			
Burgener et al. (71)	2008	Group	Person
Charlesworth et al. (72)	2016	Individual sessions for person and caregiver separately; groups for dyad	Carer separately Person separately Dyad
Fischer-Terworth & Probst (73)	2011	Group	Person
Kim (Hwan-hee) (74)	2015	Group	Person
Marshall et al. (75)	2015	Group	Person
Prick et al. (76)	2016	Individual dyad sessions	Dyad
Roberts & Silverio (77)	2009	Groups for each separately and for dyad	Person Carer Dyad

Viola et al. (78)	2011	Group sessions with therapists for dyads	Dyad
Waldorff et al. (79)	2012	Individual sessions for each alone. Separate groups for person and carer.	Person Carer Dyad

Table

Table 3: Main outcome domains measured and studies reporting significant effects

Outcome	**Number of studies which measured this domain**	**Studies reporting significant effects 53 (%)**
Person with dementia		
Cognitive functioning	40	16 (40%) (17,19, 21, 23, 24, 26-30, 34, 36, 46, 52, 64, 74)
Quality of life	27	5 (18%) (21, 61, 62, 70, 74)
ADL/physical functioning	28	13 (46%) (15, 21, 25, 42, 45-47, 49-51, 61, 62, 71)
Behavioural symptoms	1	0
Anxiety/depression/neuropsychiatric symptoms	37	6 (16%) (22-24, 29, 44, 70, 74)
Physical health	6	0
Other (e.g. self-efficacy, relationship quality, satisfaction, hope etc.)	20	7 (35%) (20, 21, 33, 37, 38, 44, 71)
Carer		
Caregiver burden/stress/distress	15	1 (6%) (45)
Coping/competence	8	1 (12%) (42)
Depression	6	1

		16%) (16)
Other (e.g. physical health, knowledge, quality of life etc.)	8	3 (37%) (33, 36, 44)