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## **Overview of systematic reviews: Effective Home Support in Dementia Care, components and impacts – Stage 1, psychosocial interventions for dementia**

**Running head: Systematic reviews for psychosocial interventions in dementia**

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### **Abstract**

**Aim.** To synthesise evidence to identify the components of effective psychosocial interventions in dementia care to inform clinical practice, policy and research.

**Background.** With population ageing dementia represents a significant care challenge with 60% of people with dementia living at home.

**Design.** Overview of systematic reviews with narrative summary.

**Data sources.** Electronic searches of published systematic reviews in English using Cochrane Database of Systematic Reviews, DARE, EPPI-Centre, between September 2013 - April 2014.

**Review methods.** Systematic reviews were appraised against Cochrane Collaboration levels of effectiveness. Components of psychosocial interventions were identified with their theoretical rationale. Findings were explored with a Patient, Public and Carer Involvement group.

**Results.** 36 systematic reviews were included. From interventions, 14 components were identified, nine for people with dementia and five for carers, mostly undertaken in nursing/care homes. For people with dementia, there was evidence of effectiveness for cognitive stimulation and cognitive training; but less evidence for sensory stimulation, reminiscence, staff education, behavioural therapy and ADL training. For carers, there was evidence of effectiveness for education and training, psychotherapy and counselling.

**Conclusion.** There was a lack of definitive evidence of effectiveness for most psychosocial interventions. Further studies with stronger methodology or replication of existing studies would strengthen the evidence base. Few interventions were undertaken with people with dementia and their carers living at home. Further work will investigate the extent to which components identified here are present in models of home support for people with dementia and carers and their effectiveness.

**Key words:** nursing, care homes, care at home, dementia, overview of reviews, psychosocial interventions

## **Summary statement**

### **Why is this research or review needed?**

- There is no cure for dementia currently and as people live longer the costs associated with its management will increase.
- Previous reviews are characterised by a lack of detailed information examining the application of multicomponent interventions for people with dementia and their carers.
- Little is known about the components of psychosocial interventions in dementia care and their relative effectiveness for service users and carers.

### **What are the key findings?**

- Multiple components of care for both older people and their carers were identified, which were provided in a multiplicity of settings.
- This overview confirms that there was insufficient evidence of effectiveness for psychosocial interventions for people with dementia and their carers in the home setting.

### **How should the findings be used to influence policy/practice/research/education?**

- This review informs the identification of different models of support for people with dementia and their carers provided at home in a subsequent literature review.

- Clinical practice and service commissioning will be informed by the evidence from this review relating to the components of effective support for people with dementia and their carers.

## **Introduction**

With population ageing dementia represents a significant public health and care challenge (Ferri *et al.* 2005). Dementia is a progressive disorder which leaves individuals less able to care for themselves, more prone to emotional and behavioural problems and more likely to have poor physical health (MacKnight & Rockwood 2001, Burns *et al.* 2005). Globally, it is a major cause of disability and high cost care in older people (Alzheimer's Disease International 2015). In the United Kingdom (UK), finding cost-effective ways to improve the care of people with dementia and their families has been termed the £20 billion question (House of Commons All-Party Parliamentary Group on Dementia 2011).

In England, about 60 per cent of people with dementia live in private households. Helping them to 'live well' (Department of Health 2009) necessitates establishing appropriate and effective forms of home or personal support. This includes specialist care to facilitate and augment existing coping skills of people with dementia and their informal carers (National Audit Office 2007). Many people can experience a good life in a care home or equivalent, but most prefer home life for its quality, self-determination and economy (Challis *et al.* 2002). Optimising support for people with dementia in their own homes has been prioritised (Department of Health 2009). Thus, investment in approaches that maintain life at home (avoiding nursing/care home admission) is required. Several reviews of psychosocial

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interventions for dementia, from various settings, have examined effectiveness but little information is available describing the essential ingredients of single or multicomponent interventions. Moreover, there is little information describing the effectiveness of such interventions. This paper presents findings from an extensive literature review designed to address this knowledge gap (Clarkson *et al.* 2016). It provides evidence to guide clinical practice in home support and assist in the commissioning and redesign of multidisciplinary approaches to the care of older people with dementia and their carers.

## Background

Psychosocial interventions for dementia are part of a wide range of non-pharmacological interventions available for people with long-term conditions that are delivered by several professionals, most notably nurses, occupational therapists and social workers (Reilly *et al.* 2010; Bökberg *et al.* 2015). Internationally, this is in the context of care delivered by family supported by community health and social care teams, comprising mental health nurses, district nurses, social workers, support workers and care assistants, among others (Lethin *et al.* 2016). In England, their relevance for clinical nursing has been reinforced by the policy goal of reducing antipsychotic drug prescribing due to lack of effectiveness and potential side-effects (Department of Health 2009). However, there is a paucity of robust scientific evidence on the effectiveness, implementation and feasibility of psychosocial interventions. Attempts to systematically review effectiveness of particular types or ranges of interventions in various settings are often inconclusive. Furthermore, meta-analyses of studies investigating home support to older people in general (Elkan *et al.* 2001) have argued that more precise descriptions of the actual *components* employed ('who, did what, where and how') are needed. Knowledge of such components in specialist support for dementia would

be particularly beneficial. Yet, the evidence regarding how particular components ('active ingredients') of these interventions could be combined into different approaches to home support and the likely effects of adopting these is relatively weak.

To respond to these challenges, this review draws on and extends previous UK government funded work (Challis *et al.* 2010). It is part of a wider research programme (National Institute for Health Research, Programme Grants for Applied Research No. DTC-RP-PG-0311-12003). The two-stage review appraises evidence of home support arrangements for people with dementia and their carers and particularly of their effectiveness. This paper presents an overview of systematic reviews evaluating evidence for the effectiveness of psychosocial support interventions in any setting (for example nursing/care homes, day centres and at home). It identifies the effective components of support in dementia both for early and later stages. Treatment approaches are reviewed, irrespective of the setting (for example, home and nursing or care homes) and personnel (for example nurses and occupational therapists) delivering them to elicit the components of effective dementia care.

### **The review**

#### **Aim**

To identify the components of effective psychosocial interventions in dementia care.

#### **Design**

The review followed established guidelines for conducting and reporting systematic reviews and overview of reviews (Becker & Oxman 2009; Centre for Reviews and Dissemination 2009; Moher *et al.* 2009). The protocol was registered with PROSPERO (Reference/ID No



CRD42014008890). A two-stage design was used (see protocol - Clarkson *et al.* 2016): (1) an overview of systematic reviews of psychosocial interventions for dementia from RCTs in various settings; (2) a systematic review of the effectiveness of home support interventions, identifying the extent to which components identified from stage 1 are present in different models of support (reported in a separate paper, Clarkson *et al.* 2017). The focus of the first stage reported in this paper was an overview of published systematic reviews of psychosocial (i.e. non-pharmacological) interventions for dementia in various settings to identify their active ingredients, or components (Teri *et al.* 2005).

### **Search methods**

Search terms were derived after discussion between the reviewers and piloted by an experienced systematic reviewer prior to the development of the protocol (see supplementary information File S1). Searches were not restricted by date parameters or year of publication and were conducted by three reviewers. This was a concurrent data collection with searches conducted between September 2013 and April 2014 with that for Stage 1 completed within a month. Additionally, recent systematic reviews known to the reviewers were included.

### **Search outcome**

Two researchers selected reviews for inclusion and agreed exclusions. One screened the titles and abstracts of all potentially relevant citations against the inclusion criteria, with a second reviewing these decisions. Where this was not clear, the full-text of the study was read and uncertainties resolved through discussion with comments by a third, independent reviewer. Subsequently, one researcher read the full text of each of the included reviews and extracted

data concerning their key characteristics. A second researcher confirmed the inclusion of these reviews and independently extracted data from all.

### **Quality appraisal**

Three reviewers, using a checklist of criteria, assessed the quality of the included studies independently using the AMSTAR tool (Shea *et al.* 2009; with more detailed notes/guidance at: [http://amstar.ca/Armstar\\_checklist.php](http://amstar.ca/Armstar_checklist.php), accessed 20/04/2015). The quality score ranged from 0-11, with a higher score indicating greater quality. Discrepancies were resolved by discussion. Table 1 shows the quality rating of each review. No review scored positively for the presence of information concerning conflict of interest in the primary studies (Shea *et al.* 2009); therefore, ratings were between 1 and 10. Non Cochrane reviews did not include lists of excluded studies and so tended to have lower scores. Most (n=30) provided detail on the characteristics of included studies. Of the 23 non-Cochrane reviews, only two scored positively on the AMSTAR criterion of a priori design, i.e. published or registered study protocol (Gallagher-Thompson & Coon 2007, Logsdon *et al.* 2007). There were six notably high scoring reviews (AMSTAR score=10) (Vink *et al.* 2004, Woods *et al.* 2005, 2012, Forbes *et al.* 2008, 2009, Vernooij-Dassen *et al.* 2011) and three very low scoring (AMSTAR score=1) (Lou 2001; Spira & Edelstein 2006, Sánchez *et al.* 2012).

### **Data abstraction**

To collate evidence, data were extracted into Excel databases using a proforma based on the PICOS (Population, Interventions, Comparators, Outcomes and Study designs framework, as per protocol) (Centre for Reviews and Dissemination 2009; Clarkson *et al.* 2016). Data

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extraction was based primarily on that contained in the reviews. However, occasionally, the abstracts or content of primary studies were checked, for information regarding study design and details of the intervention.

Data were extracted from included reviews according to named intervention categories with shared characteristics (for example, cognitive stimulation, music therapy, or exercise training) (Olazarán *et al.* 2010; Dickson *et al.* 2012). Each was described as precisely as possible, including definition, techniques and original references. Category descriptions were mutually exclusive and presented according to the amendment of an existing template (Davidson *et al.* 2003), as per protocol (Clarkson *et al.* 2016).

Four levels of statement were used to rate effectiveness evidence for the categories, based on a scheme developed by the Cochrane Collaboration (Ryan *et al.*, 2014) and similar to the Oxford Centre of Evidence-Based Medicine guidelines adopted by some included reviews (Livingston *et al.* 2005; Olazarán *et al.* 2010). The number and quality of reviews and that of primary studies were taken into consideration when making judgements about the level of evidence and more weight was given to high quality reviews of specific interventions:

- ‘Sufficient evidence’ (Level 1): Consistent evidence from high, moderate quality, or reviews of specific interventions;
- ‘Some evidence’ (Level 2): Less consistent, second level recommendation by high or moderate quality reviews, or with majority of reviews or studies in favour of intervention;
- ‘Insufficient evidence’ (Level 3): Conflicting results, or evidence suggesting ineffectiveness;

- ‘Insufficient evidence to determine’ (Level 4): Due to lack of primary studies or information.

## **Synthesis**

A narrative summary was undertaken to elicit the components to take forward into Stage 2 of the review derived from a framework used in the design of behavior change interventions (Michie *et al.* 2011). Five steps were used to synthesize the information (see supplementary information File S2). Following data extraction and data synthesis, preliminary findings on components were discussed in the ongoing Patient, Public and Carer Involvement (PPCI) collaboration in the programme.

## **Results**

### **Study selection**

A total of 279 reviews were initially extracted, of which 36 met the inclusion criteria (Figure 1). Over half (148; 53%) of excluded reviews were of pharmacological interventions. Of those included, 21 (58%) were of specific, named interventions (for example, physical activity programmes) – termed here ‘narrow reviews’, among which 13 were Cochrane reviews. Fifteen (42%) were reviews of a range of interventions – termed here ‘broad reviews’.

### **Study characteristics**

Table 1 provides descriptive data from each review. There were three ‘empty reviews’ (Yaffe *et al.* 2012); these were systematic reviews finding no studies eligible for inclusion (Price *et al.* 2001; Hermans *et al.* 2007; Martin *et al.* 2008). Included reviews often used several

research designs as inclusion criteria. However, only the numbers of randomised studies in each review are reported here. The systematic review reported by Basu and Brinson (2010) and not their overview, was reviewed here. Twenty-one (58%) reviews focused on people with dementia and seven (19%) on interventions to carers, with eight (22%) reviewing interventions to both. Very few specified severity of dementia as one of their inclusion criteria. Some (n=13) did not specify stage of dementia but required information from primary studies to enable this judgement to be made. Reviews contained a range of studies with different foci and a range of outcomes.

Olazarán *et al.* (2010) was used to categorise interventions for people with dementia (Table 2) and carers (Table 3). There were different typologies available from the reviews by which interventions could be grouped and sometimes there was no clear cut dividing line between categories. Some categories were more general (for example emotion oriented approaches) and some specific (for example light therapy). There was overlap between the cognitive stimulation and cognitive training/rehabilitation categories but these were considered sufficiently distinct to warrant inclusion separately. Cognitive stimulation generally stimulates information processing in the person with dementia whereas cognitive training/rehabilitation is more specific, entailing guided practice on cognitive functions using specific techniques and technologies (for example memory aids). Twenty intervention categories for people with dementia and six for carers with evidence of effectiveness were identified.

The detail available to describe each intervention was variable. Content was predominantly based on how interventions were described in the reviews and not in each of the primary studies. Details of provider were sometimes partial; but interventions were delivered by a

range of professionals, family carers and researchers. A mix of individual and group sessions was identified. The predominant settings for interventions were nursing/care homes (n=18 reviews) with 11 conducted at home (6 for the person with dementia and 5 for carers). There was variation in the intensity of interventions. Where reviews contained little information on the implementation of the interventions it was difficult to make judgements about their fidelity (the term only appeared in one review; Elvish *et al.* 2013). Where such data were absent, we report information on the methodological conduct of the studies as a proxy for this (for example risk of bias measures, such as assignment and assessment concealment). Some reviews described a process analysis, whereby studies included details on whether the intervention protocol was complied with. For example, one review found that two of the 11 included studies reported process analyses (Vernooij-Dassen *et al.* 2011). Overall there was a lack of evidence whether interventions were undertaken as intended.

### **Effectiveness evidence: people with dementia**

#### *Sufficient evidence (Level 1)*

There was sufficient evidence for the effectiveness of two intervention categories. The first suggested that cognitive stimulation benefits cognition in people with early stage dementia (Olazarán *et al.* 2010, Woods *et al.* 2012). Although less conclusive, its effect on quality of life was also promising (Cooper *et al.* 2012, Woods *et al.* 2012). There was also evidence for its effectiveness on behaviour and neuropsychiatric symptoms (Livingston *et al.* 2005, Olazarán *et al.* 2010). Although not consistent, evidence from the majority showed that reality orientation had positive effects on both cognition and behaviour (Spector *et al.* 2000, Livingston *et al.* 2005, Olazarán *et al.* 2010, Woods *et al.* 2012). In most studies, however, participants were resident in nursing/care homes. Second, cognitive training was effective for improving cognition (Sitzer *et al.* 2006, Olazarán *et al.* 2010). It was also viewed as

promising for activities of daily living and depression. Restorative strategies, improving functioning in specific domains with the goal of returning functioning to premorbid levels, demonstrated the greatest overall effect (Sitzer *et al.* 2006). Participants were people with early stage dementia living at home, in nursing/care homes or geriatric units; and individual sessions were more common than that for cognitive stimulation therapies.

#### *Some evidence (Level 2)*

There was some evidence for the effectiveness of four intervention categories: behavioural therapy; reminiscence; sensory stimulation; and activities of daily living (ADL) training. For behavioural therapy, evidence of effectiveness was noted for both people with dementia living at home and those in nursing homes (Livingston *et al.* 2005, Logsdon *et al.* 2007, Olazarán *et al.* 2010). However, evidence of its effectiveness for behaviour management was mixed (Livingston *et al.* 2005, Logsdon *et al.* 2007, Kong *et al.* 2009, Olazarán *et al.* 2010). Three reviews identified two trials on simulated presence, providing limited evidence of effectiveness in reducing agitation and withdrawn behaviour for people with later stage dementia (Livingston *et al.* 2005, Kong *et al.* 2009, Kverno *et al.* 2009).

Evidence of effectiveness of reminiscence was also mixed (Livingston *et al.* 2005, Woods *et al.* 2005, Olazarán *et al.* 2010, Sánchez *et al.* 2012, Subramaniam & Woods 2012). A Cochrane review found evidence of effectiveness on cognition, mood, behaviour, caregiver strain and staff knowledge (Woods *et al.* 2005) and a more recent review judged the intervention as potentially promising (Subramaniam & Woods 2012). However, other reviewers concluded that there was insufficient evidence (Livingston *et al.* 2005; Olazarán *et al.* 2010). Reminiscence therapy was conducted in both individual and group sessions, for

people with both early and later stage dementia. In a minority of trials the target population was people with dementia living at home.

There was some evidence to show that sensory stimulation was effective on the behaviour and mood of people with dementia (Kong *et al.* 2009, Kverno *et al.* 2009, Livingston *et al.* 2005, Kim *et al.* 2012, Sánchez *et al.* 2012). Evidence of effectiveness of multisensory stimulation/snoezelen to improve behaviour and reduce apathy was mixed (Livingston *et al.* 2005, Kverno *et al.* 2009, Olazarán *et al.* 2010, Kim *et al.* 2012, Sánchez *et al.* 2012). There was limited evidence to suggest that aromatherapies may have short-term effects in reducing agitation and apathy (Kverno *et al.* 2009). Whilst there was some evidence concerning acupressure, acupuncture, reflexology, thermal bath and white noise, it was difficult to draw conclusions of their value (Livingston *et al.* 2005, Basu & Brinson 2010, Olazarán *et al.* 2010, Pieper *et al.* 2013). The majority of trials in this category were conducted in nursing/care homes, for people with later stage dementia. Some evidence on the effectiveness of ADL training was identified by one review (Olazarán *et al.* 2010) with trials conducted for people with dementia in nursing/care homes, in both individual and group sessions.

#### *Insufficient evidence (Level 3)*

There was insufficient evidence of effectiveness for seven intervention categories: physical activity/exercise, music, light therapy, recreational activity, massage and touch, case management and validation therapy. Ten reviews identified 18 studies on physical exercise. Two of these concluded that there was no clear evidence of effectiveness with regard to a range of outcomes (Forbes *et al.* 2008, Olazarán *et al.* 2010). In a third, there was some evidence that physical exercise had beneficial effect on walking performance and activities of daily living (Littbrand *et al.* 2011). The majority were conducted in residential care.



Over 20 studies on the use of music for people with dementia were identified by six reviews.

There was some evidence of its effectiveness for treating neuropsychiatric symptoms (Kverno *et al.* 2009), or reducing agitation in the short-term (Livingston *et al.* 2005). However, two reviews concluded that there was insufficient evidence to recommend music therapy due to poor methodological quality of the included studies (Olazarán *et al.* 2010; Vink *et al.* 2004).

In all studies where information was available, participants resided in nursing/care homes.

Five reviews identified 11 studies examining the effect of light therapy on residents of nursing/care homes or geriatric units in psychiatric hospital. Three reviews concluded that there was insufficient evidence to assess the value of light therapy on behavioural disturbances, cognition, psychiatric disturbances and sleep, due to methodological weaknesses (Forbes *et al.* 2009, Basu & Brinson 2010, Olazarán *et al.* 2010).

The recreational activity category included 11 studies in six reviews. Evidence of effectiveness for reducing agitation was conflicting and that on apathy, depression and engagement was insufficient to determine. Participants were people with dementia living at home and in nursing/care homes.

Massage and touch were identified in a smaller number of studies. Whilst one review, concluded there was limited evidence for massage and touch for problems such as agitation (Hansen *et al.* 2006), another stated that evidence of effectiveness was lacking (Olazarán *et al.* 2010). Participants resided in nursing/care homes or other institutions.

The case management category was diverse and there was insufficient evidence of effectiveness. Limited evidence suggested that case management was ineffective for depression, psychosis and behavioural symptoms (Basu & Brinson 2010) and evidence on

reducing institutionalisation was conflicting (Livingston *et al.* 2005, Spijker *et al.* 2008). However, there was some evidence to suggest that personalised care plans could reduce pain or discomfort (Pieper *et al.* 2013) but were ineffective in improving quality of life (Cooper *et al.* 2012). Most studies in this category were, perhaps, surprisingly conducted in nursing/care homes.

Only five studies on validation therapy were identified, for people with dementia living in nursing/care homes. There was insufficient evidence to support the efficacy of validation therapy for people with dementia or cognitive impairment.

*Insufficient evidence to determine (Level 4)*

There was insufficient evidence to determine effectiveness of a range of interventions. These included animal/pet therapy, muscle relaxation, psychotherapy/counselling, transcutaneous electrical stimulation and transcranial magnetic stimulation, special care units and palliative care.

**Effectiveness evidence: carers**

*Some evidence (Level 2)*

The largest intervention category was caregiver education and training (Table 3). There was some evidence of effectiveness, with more reviews suggesting effective (Ayalon *et al.* 2006, Gallagher-Thompson & Coon 2007, Logsdon *et al.* 2007, Elvish *et al.* 2013) or mixed evidence (Livingston *et al.* 2005, Olazarán *et al.* 2010, Li *et al.* 2013) than ineffective (Cooper *et al.* 2007, 2012, Kong *et al.* 2009). Evidence of effectiveness of caregiver training based on behaviour management was reported in some reviews. There was also evidence of effectiveness of caregiver skills building, communication and interactions with patients and

technology based interventions. Psychotherapy and counselling was the second largest category of interventions delivered to carers with some evidence to support its effectiveness.

Most interventions focused on carers of people with dementia living at home. Most of reviews evaluated cognitive behaviour therapy. Counselling was sometimes used as part of an intervention.

#### *Insufficient evidence (Level 3)*

A Cochrane review concluded that evidence on respite care did not demonstrate any benefits or adverse effects for people with dementia and their carers (Lee & Cameron 2004).

#### *Insufficient to determine (Level 4)*

The evidence for caregiver support groups, case management and physical exercise were insufficient to determine effectiveness.

#### **Interventions for both people with dementia and carers**

Nine reviews evaluated multicomponent interventions to both people with dementia and carers. One intervention included adapting the home environment to the capacities of people with dementia and providing training, counselling and support, delivered by occupational therapists and psychologists. There was insufficient evidence of effectiveness (Level 3) for this intervention with only modest potential for quality of life. There was insufficient evidence to determine (Level 4) the effectiveness of four interventions. These were: caregiver training in behaviour management and exercise for the person with dementia; information and training on night-time insomnia for carers and daily walk and increased light exposure for the person with dementia; individual, family and ad hoc counselling; and support group attendance.

## Synthesis

Table S3 (supplementary information online) describes each component identified from the synthesis. Data on the mix of components in each review is available from the authors. There were specific theory-linked techniques that may have been responsible for an intervention's effects. For example, the provision of education or advice to carers about dementia is effective when delivered through the Information-Motivation-Behavioural Skills model. Providing information about dementia, for example through information leaflets or websites, has potential to change carers' behaviour, but information alone is insufficient to achieve this (Mazzuca 1982). The carer's motivation to engage with the information and the development of behavioural skills, such as 'how to respond', are crucial determinants of effectiveness (World Health Organisation 2003).

The provision of structured physical activity can improve learning and memory and slow down physical decline (Cotman & Berchtold 2007). Engaging in this as a group activity can also have an impact on well-being, through participants increasing their social networks (Bowes *et al.* 2013). Behaviour management for carers may also be an effective element of interventions. This is achieved by identifying, analysing and correcting maladaptive beliefs that may be contributing to caregiver strain in dealing with the behaviours of the person with dementia (Losada *et al.* 2011).

### *Observations from PPCI group*

The group likened the components of interventions to 'ingredients', like those involved in baking a cake, which could interact in different ways to produce the desired result, for example increased well-being of the carer or person with dementia. Similarly, a carers

support service might contain three ingredients: emotional support, information and advice.

Each might act differently to influence carer well-being, through increased competence in their role and less guilt about decision making on behalf of their relative (see Figure 2).

Tailoring interventions to the stage of dementia was identified as a critical success factor. For example, people with dementia in later stages may require assistance with the activities of daily living inappropriate for people in early stage of the condition. For carers, respite was signalled as important in the later stages of dementia.

## **Discussion**

The aim of Stage 1 of this systematic review of effective home support to people with dementia was to identify components and appraise the evidence for their effectiveness, irrespective of setting. There was sufficient evidence for the effectiveness of two interventions: cognitive stimulation and cognitive training for people with dementia. For carers, evidence of effectiveness for the interventions identified was insufficient. Nevertheless, from these interventions, 14 components were identified. Nine related to the person with dementia: behaviour management; care co-ordination; cognitive training; daily living assistance; emotional support; environmental modifications; physical activity; sensory enhancement/relaxation; and social engagement. Only five focused on the caregiver: behaviour management; education/advice; emotional support; respite; and social support.

However, there was insufficient evidence of effectiveness for non-pharmacological interventions for those living at home. Many of the interventions reported were undertaken in nursing/care homes and few undertaken with people with dementia and their carers at home. This could be associated with the human and financial resources required to deliver

these interventions to people with dementia at home. For example, whilst it was more common for cognitive training to be conducted in people's own homes in individual formats, cognitive stimulation interventions were usually conducted in nursing/care homes in group formats, possibly because the latter were delivered by specialists whereas the former could be delivered by family carers.

In particular, there was insufficient evidence for the effectiveness of case management (also known as care coordination) with its broad objective of tailoring support to identified need for older people requiring long-term care to enable them to live at home with one of its defining characteristics being the breadth of services required to achieve this goal (Applebaum & Austin 1990). However, a Cochrane review on case management approaches to home support for dementia, published after the study selection of this overview, has identified some evidence on its effectiveness in reducing admission to care homes and overall healthcare costs, but its effect on patient depression, functional abilities or cognition remains uncertain. It also noted the importance of specificity of case management content influencing effectiveness (Reilly *et al.* 2015).

Other research has demonstrated that specific forms of case management may provide effective support to carers, captured through measures of burden and general health (Challis *et al.* 2016; Venables *et al.* 2006). This contrasts with findings from this overview which provided some evidence to support the effectiveness of interventions based on education and training and psychotherapy and counselling, in terms of improving carers' psychological well-being which were where the person they cared for was living at home. Respite care, primarily regarded as way of relieving carers of the burden of looking after people with dementia, was not identified as showing sufficient evidence of effectiveness, as a component

of home support in this overview. Whilst it might be construed as being an element of a care plan in the component of care coordination its absence was commented on by the PPCI group, indicating the priority it is accorded by people currently caring for people with dementia.

Components identified from this overview were theory-linked, in that they contained specific mechanisms of action that may be responsible for their potential effects. For example, it may be that the component, cognitive training, was responsible for most of the effects of the intervention, cognitive training/rehabilitation, through improving neuronal functioning (Swaab *et al.* 2002). However, the intervention may also have contained emotional support or other components, particularly where provided by carers, trained to provide this intervention by specialist staff. Moreover, the consultation with the PPCI group highlighted both the complexity of needs and the challenge of meeting them. To advance knowledge and guide future clinical practice with regard to support provided to people with dementia and their carers at home only interventions delivered in this setting will be included in the second stage of the review.

### **Limitations**

This narrative summary has certain limitations. Importantly, some items of the AMSTAR tool focus on the quality of reporting of systematic reviews at the expense of their methodological quality (Faggion 2015). For example, none of the reviews scored positively on item 11 (conflict of interest statement included), despite some of them rated as of high quality (see Table 1). Furthermore, sometimes the primary studies did not provide enough information making it difficult for the systematic reviews to draw conclusions about certain

aspects of the studies such as the implementation process and fidelity (Spector *et al.* 2000, Vernooij-Dassen *et al.* 2011). This is even more the case for overviews due to the variations in reporting style of the systematic reviews.

Other limitations reflect the scope and objectives of this paper, which aimed to provide an overview of the range of interventions and their effectiveness and to identify common components, to be evaluated in more detail in the next stage. As such, the findings reported are necessarily largely limited to those contained in the reviews. Details of the primary studies in each category, such as the number of participants and control condition of studies, could not be reported here, although these might have been usefully contributed to judgements about the conclusions.

## **Conclusion**

This review provides an overview of the evidence regarding psychosocial interventions for people with dementia and their carers and their potential effectiveness, using a range of outcome measures. In terms of methodology, future research could benefit from reducing or minimising heterogeneity of the study sample, for example, by specifying the stage of dementia for which the intervention might be of benefit. Replication of existing small scale good quality studies could also be fruitful. Most people with dementia live at home. However, the majority of the reviews described here, report research undertaken in other settings. There is therefore an important gap in the evidence base required to guide practitioners – nurses, social workers and occupational therapists – coordinating long-term support to people with dementia at home. Nevertheless, evidence from this review will help to inform policy makers and service planners, assist in establishing the utility and



effectiveness of interventions in a variety of settings and inform clinical practice in care homes and other group living environments/settings. More generally, evidence is required as to what constitutes effective care for people with dementia living at home.

#### **Author Contributions:**

All authors have agreed on the final version and meet at least one of the following criteria (recommended by the ICMJE\*):

- 1) substantial contributions to conception and design, acquisition of data, or analysis and interpretation of data;
- 2) drafting the article or revising it critically for important intellectual content.

\* <http://www.icmje.org/recommendations/>

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**Table 1** Reviews of psychosocial interventions in dementia

Review & year	Date of last search	Number of studies <sup>1</sup>	Types of participants	Dementia stage <sup>2</sup>	Intervention categories	Foci of interventions	Outcome foci	Quality rating
<i>Narrow Reviews</i>								
Elvish <i>et al.</i> (2013)	Not stated	14 (9/4/1)	Carers	Not specified	CG EDU, CG PSY	Carer stress and well-being	Anxiety, attitudes, carer burden, depression, QoL, well-being	5
Forbes <i>et al.</i> (2008)	09/09/2007	4 (2/3/0)	People with dementia	Early and later stage	PHY	Cognition, function, behaviour, depression, and mortality	Behaviour, cognition, function, mood	10
Forbes <i>et al.</i> (2009)	04/03/2008	8 (6/2/0)	People with dementia	Early and later stage	LT	Cognitive, sleep, functional, behavioural, or psychiatric disturbances	ADL, agitation, cognition, depression, institutionalisation, sleep	10
Hall <i>et al.</i> (2011)	Not stated	2 (1/1/0)	People with dementia	Later stage	SCU	Palliative care	Behaviours, discomfort, physical complications, mortality, quality of care	7
Hansen <i>et al.</i> (2006)	12/07/2005	2 (0/2/0)	People with dementia	Not specified	MAT	Anxiety, agitation, depression	Agitation, emotional well-being, QoL, cognition, survival, medication use, caregiver burden	8
Hermans <i>et al.</i> (2007)	11/06/2009 <sup>3</sup>	0 <sup>4</sup>	People with dementia	Not specified	No interventions found	Wandering in the domestic setting	Not applicable	7
Lee & Cameron (2004)	10/12/2007 <sup>3</sup>	3 (0/2/1)	Carers	Early and later stage	RC	Carer stress and well-being	Carer burden, carer mood	8
Li <i>et al.</i> (2013)	07/2011	8 (3/1/4)	Carers	Not Specified	CG EDU, CG PSY	Coping skills, psychological morbidity	Coping style, psychological morbidity	5
Littbrand <i>et al.</i> (2011)	01/09/2010	10 (6/4/0)	People with dementia	Early and later stage	PHY	Physical and cognitive functions, ADL	Mobility, balance, muscle strength, cognitive function, ADL	5
Lou (2001)	Not stated	1 (0/1/0)	People with dementia	Later stage	MUT	Agitated/aggressive behaviour	Aggressive behaviour	1

Martin <i>et al.</i> (2008)	01/03/2007	0 <sup>4</sup>	People with dementia	Not specified	ENM	Health and social care needs	Not applicable	5
Neal & Barton Wright (2003)	05/08/2005 <sup>3</sup>	3 (1/3/0)	People with dementia	Not specified	VAL	Cognitive and behavioural features manifested by people with dementia	Cognition, agitation and social behaviour, mood, ADLs	7
Price <i>et al.</i> (2001)	09/03/2009 <sup>3</sup>	0 <sup>4</sup>	People with dementia	Not specified	ENM	Wandering	Number of exits or carer interventions, resource use, acceptability of the intervention and the effects on carer and wanderer	7
Sánchez <i>et al.</i> (2013)	Not stated	9 (5/4/0)	People with dementia	Later stage	SS(O)	Behaviour, mood	Behaviour, cognition, communication, functional status mood	1
Sitzer <i>et al.</i> (2006)	Not stated	12 (5/0/7)	People with dementia	Early stage	CT, CS	Cognition	Cognition; ADLs; QoL; Mood	4
Spector <i>et al.</i> (2000)	Not stated	8 (4/6/0)	People with dementia	Not specified	CS	Cognition	Cognition, behaviour	5
Subramaniam & Woods (2012)	12/2011	5 (2/3/0)	People with dementia	Early and later stage	REM	Psychosocial well-being	Cognition, Quality of Life	4
Vernooij-Dassen <i>et al.</i> (2011)	05/04/2009	11 (3/3/4)	Carers	Not specified	PSY	Psychological morbidity and stress	Anxiety, depression, carer burden and coping; QoL, healthcare utilisation (PWD)	10
Vink <i>et al.</i> (2004)	06/2010 <sup>3</sup>	10 (5/5/0)	People with dementia	Not specified	MUT	Behavioural, social, cognitive and emotional problems	Problem behaviours, cognition, emotional wellbeing and social behaviours	10
Woods <i>et al.</i> (2005)	04/05/2004	5 (3/5/0)	People with dementia	Early and later stage	REM	Mood, cognition, well-being	Well-being, mood, QoL, communication, cognition; caregiver strain	10
Woods <i>et al.</i> (2012)	06/12/2011	15 (4/11/0)	People with dementia	Early stage	CS	Cognition	Cognitive functioning, QoL, mood, well-being	10

<i>Broad reviews</i>								
Ayalon <i>et al.</i> (2006)	12/2005	3 (0/3/0)	Carers	Early and later stage	CG EDU	Neuropsychiatric symptoms in people with dementia	Neuropsychiatric symptoms (e.g. hallucination, delusion, agitation, aggression, wandering)	6
Basu & Brinson (2010)	06/08/2009	19 <sup>5</sup> (12/10/0)	People with dementia	Early and later stage	BT, CM, LT, MAT, MUT, REC, REM, SS(O), SE	Behavioural and psychological symptoms	Aggression, agitation, non-specific or multiple outcomes, anxiety, depression, apathy	8
Brodsky & Burns (2012)	Not stated	8 (4/3/1)	People with dementia	Early and later stage	CS, PHY, REM, SCU, SS(O), PWD & CG	Apathy	Outcomes relevant to apathy	5
Cooper (2007)	06/2005	11 (6/2/2)	Carers	Not specified	PHY, RC, CG EDU, CG PSY	Anxiety	Anxiety symptoms	5
Cooper <i>et al.</i> (2012)	01/2011	20 (7/13/2)	People with dementia & carers	Early and later stage	CG EDU, CM, CS, CT, PHY, REM, SS (O), MUL, PWD & CG	Quality of life	Quality of life	6
Gallagher-Thompson & Coon (2007)	Not stated	17 (7/5/5)	Carers	Early and later stage	CG Edu; CG PSY; CG SG	Distress in family carers	Carer depression, Carer QoL, carer burden	3
Kim <i>et al.</i> (2012)	30/03/2011	9 (0/9/0)	People with dementia & carers	Early and later stage	ADL, CT, SS, PWD & CG MUL	Behavioural problems and depression	Behavioural problems and depression	6
Kong <i>et al.</i> (2009)	Not stated	14 (6/9/0)	People with dementia	Early and later stage	ADL, BT, PHY, LT, MAT, MUT, REC, SS(O)	Agitation	Agitation and behaviour	7
Kverno <i>et al.</i> (2009)	09/2008	13 (8/6/1)	People with dementia	Later stage	BT, LT, MUT, PHY, SS (O), VAL, SE	Neuropsychiatric symptoms	Agitation; depression, behaviour, mood; affect; rest-activity rhythm, apathy	5
Livingston <i>et al.</i> (2005)	07/2003	22 (17/5/5) NI <sup>6</sup> : 28	People with dementia & carers	Not specified	BT, CS, MAT, MUT, PHY, REC, REL, REM, SCU, SS(O), VAL, SE, CG EDU, CG PSY	Neuropsychiatric Symptoms	Care costs, QoL, institutionalization, decreased medication or restraint	2

Logsdon <i>et al.</i> (2007)	01/01/2006	14 (8/6/1)	People with dementia & carers	Early and later stage	BT, CG EDU, PWD & CG	Disruptive behaviours	Memory, behaviour, agitation, depression, QoL, CG stress	3
Olazaran <i>et al.</i> (2010)	15/09/2008	179 (92/87/NI <sup>6</sup> )	People with dementia & carers	Early and later stage	ADL, BT, CT, CS, LT, MAT, MUT, PHY, PSY, REC, REL, REM, SCU, SE, SS (O), TES, TMS, VAL, MUL. CG CM, CG EDU; CG RC, CG SG, CG MUL; PWD & CG	Cognition, ADLs, behaviour, mood, physical, QoL, initialisation, restraints  CG mood, CG well-being, CG QoL, CG burden	Institutionalisation, Cognition, ADLs, Behaviour, mood, QoL, restraints, CG mood, CG well-being, CG QoL	5
Pieper <i>et al.</i> (2013)	03/2013	5 (1/4/0)	People with dementia & carers	Early and later stage	CM, PHY, SS(O)	Pain, challenging behaviour	Pain, behaviour (e.g. agitation), mood (e.g. depression, anxiety)	5
Spijker <i>et al.</i> (2008)	03/2006	8 (2/6/0)	People with dementia & carers	Early and later stage	CM, CG EDU, CG PSY, PWD & CG	Institutionalisation	Institutionalisation	6
Spira & Edelstein (2006)	Not stated	3 (1/1/0)	People with dementia & Carers	Not specified	BT, CG EDU, SE	Agitation	Agitation, orientation, behaviour	1

<sup>1</sup> Randomised controlled studies (Active/Usual care/Waiting list controls). Some studies had multiple control groups; some had no information on the control condition.

<sup>2</sup> Early stage: described as mild to moderate, mean Mini Mental State Examination (MMSE) reported of 26-16, mean Global Deterioration Scale (GDS) of >3<=5; later stage: described as moderate to severe, mean MMSE reported of 0-15, mean GDS of >5.

<sup>3</sup> Cochrane reviews where new searches had been conducted by the closing date of this overview but with no change to conclusions.

<sup>4</sup> 'Empty reviews': systematic (Cochrane) reviews that found no studies eligible for inclusion.

<sup>5</sup> Only RCTs within the 42 'unique primary studies' were considered by this overview.

<sup>6</sup> No information.

#### Abbreviations:

ADL: activities of daily living; APT: animal/pet therapy; BT: behavioural therapy; CG: caregiver; CM: case/care management; CS: cognitive stimulation; CT: cognitive training/rehabilitation; EDU: education (and training); ENM: environmental modification; LT: light therapy; MAT: massage and touch; MUL: multicomponent; MUT: music therapy; PHY: physical exercise/activity; PSY: psychotherapy/counselling; PWD: people with dementia; RC: respite care; REC: recreational activity; REL: Muscle relaxation; REM: reminiscence; SCU: special care unit; SE: staff education; SG: support group; SS (O): sensory stimulation (other); TES: Transcutaneous electrical stimulation; TMS: Transcranial magnetic stimulation; VAL: validation



**Table 2** Reviews of psychosocial interventions for dementia (stage 1) – ‘intervention categories’ person with dementia

Intervention category	No. of reviews	No. of primary studies	Description of category						Effectiveness evidence
			Content	Provider	Format	Setting	Intensity	Fidelity	
ADL training	4	6	ADL/Functional training	Occupational therapist (OT)	Individual	Nursing homes	30 min- 2.5 hour; 2-5/ week; 3 days to 20 weeks	Inadequate allocation concealment noted	Some evidence
Animal/pet therapy	1	1	Dog present	no information	no information	Care facility	Two 30 min sessions	No information	Insufficient evidence to determine
Behavioural therapy	6	20	Behaviour management, simulated presence	Professional or family care providers	Individual or group	Nursing homes, home	15 min - 3 hr; 4/week - 1/month; 1 week to 24 months	Delivery by researchers may represent optimal implementation. Allocation concealment unclear.	Some evidence
Case management	5	10	Psychiatric/nurse CM; identification of unmet needs and individualised care plans; person centred care, interdisciplinary teams	Geriatric psychiatrists, multi-disciplinary team, dementia family care coordinator, counsellor	Individual, and group	Nursing/care homes, home	Varied: e.g. 4 - 8 hours over 12 weeks, or team met 5 times over 8 weeks. Duration; 2 to 24 months	Methodological quality varied. One study acknowledged potential ‘leakage’ of intervention elements between groups.	Insufficient evidence
Cognitive stimulation	7	27	Reality orientation board, themed activities, drawing,	Psychologists, nurses, OT, trained facilitators, speech and	Groups, and individual	Nursing/care homes, hospitals, home	30–90 min , 1-5/week, 1 week to 24 months	Difficulty to totally blind participants and staff; possible ‘contamination’	Sufficient evidence

			psychomotor activation	language pathologist, specialist psychomotor therapists				between groups in some cases	
Cognitive training/rehabilitation	5	18	Memory training, problem solving, goal oriented CT, teaching a behavioral chain backward	Family CG; OT	Individual; group	Home; nursing home; geriatric unit	20-90 min; 1 - 7/week; 2 weeks to 6 months	Studies of mixed quality	Sufficient evidence
Light therapy	5	11	Bright light exposure, dawn-dusk simulation	Researchers, nursing home staff	Group	Nursing homes, geriatric units in psychiatric hospital	1-9 hours; most daily or Mon. to Fri.; 2 weeks to 3 years	Interactions between lighting condition and other factors noted. Most met risk of bias criteria.	Insufficient evidence
Massage/touch	5	5	Hand massage; therapeutic touch	No information	No clear description	Nursing homes	10 - 40 min; only once, or 1 - 2/day, for one week	Outcome assessment was non-blinded. Appropriateness of nutritional intake as an outcome variable questioned.	Insufficient evidence
Muscle relaxation	2	1	Sequential tension and relaxation of muscle groups	No information	No information	No information	No information	No information	Insufficient evidence to determine
Music therapy	6	22	Receptive and active music therapy	Music therapist	Individual, and group	Residential or nursing homes, hospital	10-30 min; 1-5/week; 4 weeks to 6 months.	Methodological quality of studies generally poor with potentially	Insufficient evidence

								high risk of bias	
Physical exercise	10	18	Walking; strength, balance, flexibility and mobility training; rocking chair therapy	Researchers, nursing staff	Individual, in pair, group sessions	Nursing homes, home, geriatric psychiatry facilities	20–120 min; 1-7/ week; 2 weeks to 12 months	Problems with participant adherence; some sample sizes small.	Insufficient evidence
Psychotherapy/ Counselling	1	2	Psychodynamic therapy; counselling	no information	no information	no information	no information	no information	Insufficient evidence to determine
Recreational activity (REC)	6	11	(Therapeutic) REC e.g. use of recreational items, group discussion and biking	No information	Individual; group	Nursing home/institution; home	20 min to 1.5 hr, daily - 2/week; 2 - >10 weeks	Some were small sample studies	Insufficient evidence
Reminiscence (REM)	11	15	Life story (e.g. the production of a life story book); REM focusing on a particular life phase	Researchers; social workers; trained care staff; OT; trained activity therapist; psychologists	Individual or group sessions	Nursing/care home (mostly), home	30 (mostly) - 90 min, 1-5/week (majority weekly), 2 to 12 weeks.	Although all RCTs, studies exploratory in nature	Some evidence
Sensory stimulation	10	21	Multisensory stimulation/ Snoezelen; aroma; thermal bath; reflexology; acupressure; acupuncture; white noise	Reflexologist; researcher with acupressure training credits; care assistants	Individual, and group	Nursing homes, psychogeriatric units; and home	10–45 min, weekly to twice daily, 2 weeks to 15 months	Studies of varied quality. Some small scale or inadequate rater blinding.	Some evidence
Specialised care units	5	4	Palliative care; stimulation retreat model of care; specialised	Physicians, care managers	Group and individual	Nursing / residential homes	No information	Studies of varied quality; diverse interventions	Insufficient evidence to determine

			design and group living						
Transcranial magnetic stimulation	1	1	Transcranial magnetic stimulation	No information	No information	No information	No information	No information	Insufficient evidence to determine
Transcutaneous electrical stimulation	1	10	Transcutaneous electrical stimulation (cranial or dorsal stimulation)	No information	No information	No information	No information	No information	Insufficient evidence to determine
Validation	5	5	Interaction about topics of interest; programme activity e.g. singing or movement activity	Nursing staff, social work staff, researcher	Groups	(Skilled) nursing homes; day care units	30 min, 2-5/week, 6 weeks to 1 year.	'Risk of bias' was reported by one review, and there appears to be no major concern over fidelity.	Insufficient evidence
Staff education	5	13	BM, PCC, validation and reminiscence into 24 hour care, avoiding use of restraints	Mental health clinicians, researchers, nurses, and care staff	Group	Residential care settings	30-90 min, 5 - 13 sessions	Insufficient information	Some evidence

**Table 3** Reviews of psychosocial interventions for dementia (stage 1) – intervention categories caregiver

Intervention category	No. of contributing reviews	No. of primary studies	Description of category						Effectiveness evidence
			Content	Provider	Format	Setting	Intensity	Fidelity	
CG Education and Training	12	58	BM, communication, increasing pleasant events, information, problem solving, skills training, technology based	Nurses, psychologists, social workers, OTs, community consultants	Individual or group sessions	Home, nursing homes, hospital	0.5 - 4 hr, weekly, 1-12 months	Insufficient information	Some evidence
CG Psychotherapy/ Counselling	8	25	CBT, individual/family/group counselling, befriending	Counsellors, specialised nurses, social workers, psychologists, 'home help'	Individual and/or group	Home	2 hrs, weekly, 'high intensity' (1); 2-10 months	Insufficient information	Some evidence
Respite care	3	3	Respite care; assistance and companionship	Trained staff or volunteer	Individual and/or group	Home, day care, institution	2.5 - 6 hrs, daily/weekly, 2 weeks – 1 year	No information	Insufficient evidence
CG support group	2	2	Structured discussion groups, peer or professionally led groups	Volunteer facilitators, peer counsellors, professionals	Group	Home	1.5 - 2.0 hrs; weekly; 8 - 9 weeks	Facilitators trained annually	Insufficient evidence to determine
Physical exercise/activity	2	2	Physical activity, exercise	No information	Individual	Home	4 - 12 months	No information	Insufficient evidence to determine
Case management	1	4	Medicare, Managed care, case management	No information	No information	No information	No information	Home, hospital	Insufficient evidence to determine

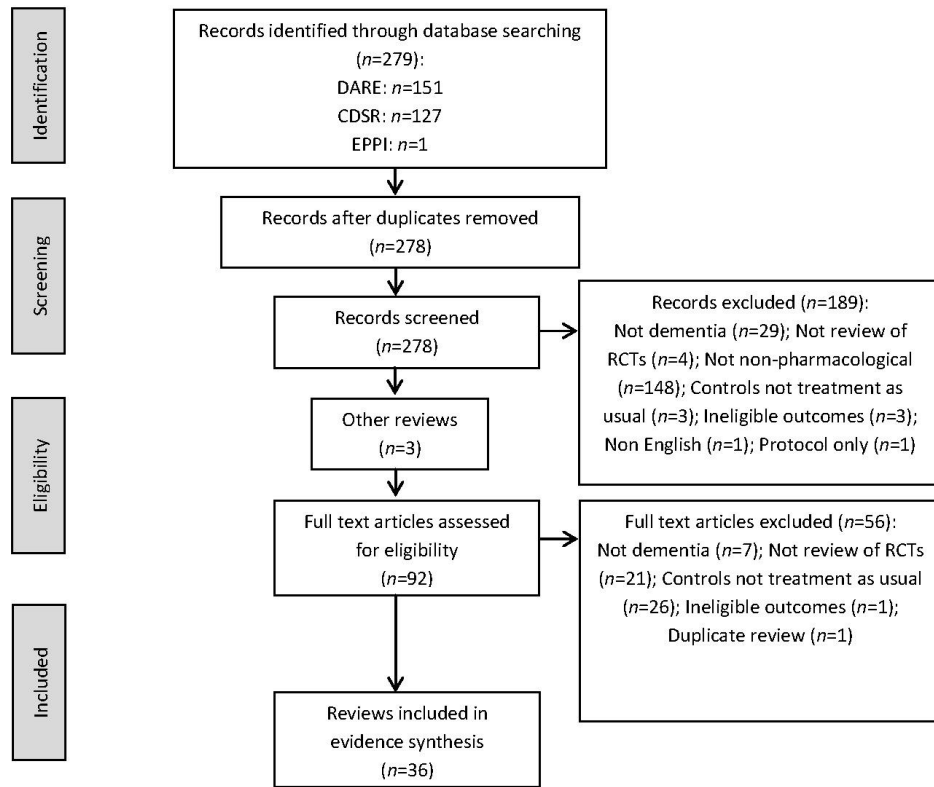


Figure 1 PRISMA flow diagram for included reviews

**Figure 2** Data synthesis – components of Carer Support service identified by Patient, Public and Carer Involvement Group

