

DR PAUL CLARKSON (Orcid ID : 0000-0002-0778-312X)

DR JANE HUGHES (Orcid ID : 0000-0001-5568-9659)

PROFESSOR BRENDA ROE (Orcid ID : 0000-0001-8227-0116)

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## **Systematic review: Effective Home Support in Dementia Care, components and impacts – Stage 2, effectiveness of home support interventions**

**Running head: Systematic review of effectiveness of dementia home support interventions**

Paul CLARKSON PhD, MSc, BA, Research Fellow  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

Jane HUGHES PhD, MSc, BA (econ), Senior Research Fellow  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

Brenda ROE RN, RHV, PhD, Professor of Health Research  
Edge Hill University  
Evidence-based Practice Research Centre  
Faculty of Health & Social Care  
Ormskirk, L39 4QP

Clarissa M. GIEBEL BSc, MSc, Research Assistant  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care

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School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

David JOLLEY MSc, MBBS Medicine, Honorary Reader  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

Fiona POLAND PGCHE, PhD, Professor of Social Research Methodology  
School of Health Sciences  
University of East Anglia,  
Norwich, UK

Michele ABENDSTERN PhD, BA, PG Dip, Research Associate  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

Helen CHESTER PhD, MSc, BA, Research Associate  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

David CHALLIS PhD, MSc, BA, Professor of Community Care Research  
Personal Social Services Research Unit  
Division of Population Health, Health Services Research and Primary Care  
School of Health Sciences  
Faculty of Biology, Medicine and Health  
University of Manchester  
Manchester Academic Health Science Centre  
Manchester, UK

& members of the HoSt-D (Home Support in Dementia) Programme Management Group.

*Corresponding author:* Dr Paul Clarkson, address above, Tel: +44 (0)161-275 5674; Fax: +44 (0)161 275 5790; E-mail: paul.clarkson@manchester.ac.uk.

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No conflict of interest was declared by the authors in relation to the study itself. Note that Brenda Roe is a *JAN* editor but, in line with usual practice, this paper was subjected to double blind peer review and was edited by another editor.

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## **Abstract**

**Aim.** To explicate the outcomes of home support interventions for older people with dementia and/or their carers to inform clinical practice, policy and research.

**Background.** Most people with dementia receive support at home. However, components and effectiveness of home support interventions have been little explored.

**Design.** Systematic review with narrative summary.

**Data sources.** Electronic searches of published studies in English using PubMed, Cochrane Central Register of Controlled Trials, PsychINFO, CINAHL, Applied Social Science Index and CSA Social Services Abstracts. Databases and sources were searched from inception to April 2014 with no date restrictions to locate studies.

**Review methods:** The PRISMA statement was followed and established systematic review methods used. Using 14 components of care for people with dementia and their carers, identified previously, data across studies were synthesized. Interventions were grouped and described and effectiveness ratings applied. Qualitative studies were synthesized using key themes.

**Results.** Seventy studies (four qualitative) were included. Most were directed to carers and of high quality. Seven interventions for carers and two for people with dementia were identified, covering 81% of studies. Those relating to daily living, cognitive training and physical activity for people with dementia were absent. Measures of effectiveness were influenced mainly by the intensity (duration and frequency) of interventions. Those containing education, social support and behaviour management appeared most effective.

**Conclusion.** These interventions reflect emergent patterns of home support. Research is required to identify effective interventions linked to the stage of dementia, which can be applied as part of routine clinical care.

**Keywords:** dementia, nursing, home support, carers, caregivers, systematic review, 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.
- Most studies report non-pharmacological interventions undertaken in nursing/care homes and not at home where most people with dementia live with their carers.
- Studies of non-pharmacological interventions for people with dementia and their carers often lack detailed descriptions of their components and effectiveness.

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

- Nine types of home support interventions were identified.
- Most interventions of home support for people with dementia were targeted on their carers and comprised more than one component.
- The effectiveness of particular interventions varied.

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

- This review informs clinical practice and service commissioning about effective support for people with dementia living at home with their carers.
- Further research is required to gather evidence about home support for people with dementia which can be replicated by practitioners in routine care.

## INTRODUCTION

Dementia is a major international public health concern with a growing number of people affected by the condition, either directly or indirectly through caring for someone with dementia, with associated high costs of treatment and care (Rosser & Knapp 2015). In 2015, worldwide, 9.9 million new cases of dementia were estimated each year, one case every 3.2 seconds, leading to a figure of 46.8 million people living with dementia. This figure is projected to reach 74.7 million in 2050 (Alzheimer's Disease International, 2015). It is estimated that over one million people were living with dementia in the United Kingdom (UK) by 2015, with currently over seven percent aged 65 or above having dementia (Prince *et al.* 2014). As the condition progresses, a reduction in independence leads to people with dementia being increasingly reliant on support, which, in conjunction with increased behavioural and cognitive difficulties, increases carer burden (Grau *et al.* 2015; Sutcliffe *et al.* 2016). Consequently, non-pharmacological interventions for people with dementia living at home are a critical element in improving dementia care.

### Background

An estimated 60 percent of people with dementia live in private households in the UK (Prince *et al.* 2014). Therefore, home support for these people and their carers is an important aspect of care. It includes the contribution of informal carers (spouses or children), estimated to provide about 40 percent of care (Schneider *et al.* 2003), a substantial amount of it unpaid (Department of Health 2009). Additionally, formal home support from professionals and support workers is available (Wilberforce *et al.* 2013). Many dementia home support interventions have been reported. For example care coordination by an interdisciplinary team including the provision of information about dementia, skill-building and regular monitoring by (Samus *et al.* 2014) and telephone-based support for family caregivers (Winter & Gitlin

2006). However, further investigation is required relating to the efficacy of such interventions in terms of effectiveness and outcomes. In particular, it is unknown which components of these interventions might offer the greatest benefits to people with dementia and their carers.

This paper is part of a two-stage synthesis to marshal evidence of home support arrangements for people with dementia and their carers, concerning their effectiveness (Clarkson *et al.* 2016). It presents a systematic review evaluating evidence for the effectiveness of home support interventions provided to people with dementia and their carers. This builds on an earlier review (stage 1), which evaluated evidence for the effectiveness of psychosocial support irrespective of setting, which identified several components both for people with dementia and their carers (Clarkson *et al.* 2017). The review is part of a wider research programme (National Institute for Health Research, Programme Grants for Applied Research No. DTC-RP-PG-0311-12003). Overall this review will provide 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.

## **THE REVIEW**

### **Aim**

The aim of this systematic review was to explicate the outcomes of home support interventions for older people with dementia and/or their carers that rely on one or more of the components identified previously (Clarkson *et al.* 2017). This includes whether there are differences in effectiveness between different stages of dementia.

## Design

A systematic review of primary studies with high external validity (that is, where the intervention had or could have been implemented in the routine practice of home support in the UK) was undertaken. Both qualitative and quantitative studies were included. The review followed the PRISMA statement and established guidelines for conducting and reporting systematic reviews (Centre for Reviews and Dissemination 2009; Moher *et al.* 2009; Liberati *et al.* 2009) PRISMA add references). Detailed information on the methodology of this review is in the published protocol, including the inclusion criteria for studies (Clarkson *et al.* 2016). In this, home support interventions were defined as those providing formal support and were categorized, as providing information, support, education or therapy. The review was registered with PROSPERO (Reference/ID No CRD42014008890).

## Search methods

Search strategies for identifying relevant studies were broad but subject to database-specific terms to enable appropriate studies to be identified. These terms were derived after discussion between the investigators, piloted and tested by an experienced systematic reviewer prior to the development of the protocol and included: dementia, Alzheimer Disease, home care services, social support (see Supplementary Information Table S1 for further information). Two reviewers searched electronic databases, PubMed, Cochrane Central Register of Controlled Trials, PsychINFO, CINAHL, Applied Social Science Index and CSA Social Services Abstracts (Clarkson *et al.* 2016). Reference lists of relevant citations were checked and hand searches of relevant journals known to the investigators were also undertaken to elicit additional references, including a previous literature review by the investigators (Challis *et al.* 2010). No date restrictions were applied and all databases and sources were searched from inception up to April 2014 to locate studies published in English.



### **Search outcome**

Two reviewers selected studies for inclusion and agreed exclusions. One researcher screened the titles and abstracts of all potentially relevant citations against the inclusion criteria, with a second reviewing these decisions. Where decisions were not clear, the full-text of the study was read and uncertainties resolved through discussion with a third, independent reviewer. The two reviewers then extracted data concerning the key characteristics of those studies meeting the inclusion criteria.

### **Quality appraisal**

Using checklists of criteria two reviewers assessed the quality of the included studies independently. For quantitative studies, the Quality Assessment Tool for Quantitative Studies was used (EPHPP 2003; Deeks *et al.* 2003). It assesses selection bias, study design, confounders, blinding, data collection methods and withdrawals and dropouts. Scores range from 1 (strong, with no weak ratings) to 3 (weak, with two or more weak ratings). For qualitative studies, the Critical Appraisal Skills Programme (CASP) checklist (Public Health Research Unit 2006) was employed with ratings provided by two reviewers. It comprises 10 questions designed to assist reviewers to appraise qualitative research by thinking systematically about the key issues of rigour, credibility and relevance. Discrepancies for both types of data were resolved through discussion.

### **Data abstraction**

A standardised electronic form, based on guidance was used to extract data about the interventions in the identified studies. This was based on the PICOS (Population, Interventions, Comparators, Outcomes and Study designs) Framework (Centre for Reviews and Dissemination 2009). The form comprised data on: study reference and setting; study

characteristics (aims/objectives, inclusion criteria, participant recruitment); study design; focus of intervention (e.g. carers, people with dementia); participant characteristics (number, age, gender, stage of dementia); the intervention description (how delivered, intensity – duration and frequency, by whom); relevant outcomes; and main findings. It was piloted and refined on a sample of five studies before full data extraction.

## **Synthesis**

Studies had a variety of objectives and research designs. A narrative summary was therefore undertaken to determine the extent to which home support interventions relied on the components identified previously (Clarkson *et al.* 2017) and to rate evidence concerning their effectiveness. Fourteen theory-linked components (nine for people with dementia and five for carers) were used. These were: for the person with dementia – sensory enhancement/relaxation, social engagement, cognitive training, emotional support, physical activity, environmental modification, behaviour management, daily living assistance and care coordination; for the carer – education/advice, social support, behaviour management, emotional support and respite. A coding manual was developed to enable reviewers to judge, independently, the presence or absence of each component in the published studies. A matrix (Teri *et al.*, 2005a) described the extent of the overlap of components in different studies.

Data were synthesized by grouping studies according to interventions, developed and agreed by the reviewers. In this review, interventions were defined as distinct, coherent and intentional acts of involvement aimed at alleviating difficulties. Thus, multiple studies reporting on the same intervention were grouped together to inform judgments of effectiveness (Carr *et al.* 2011). These were presented by their predominant component or component-mix. Effectiveness ratings were based on: statistically significant change (scored

as: non-significant = 0, significant = 1); effect size ('small'=0, 'medium'=1, 'large'=2); and intensity (the amount of exposure – duration and frequency – participants received from the intervention; scored as 'low intensity'=1, 'high intensity'=2.). Scores for each of these domains were summed to give an overall effectiveness score; see supplementary information, Table S2 for details of the calculation. The resulting synthesis comprised descriptions of the interventions in terms of context, their mechanisms (their theory of change), the role and type of staff involved in delivery and outcomes.

As detailed in the protocol, to synthesise data from qualitative studies, key themes were identified with which to determine how and to whom outcomes were generated. This followed Thomas & Harden's (2008) three stage approach: coding of text 'line-by-line'; the development of 'descriptive themes'; and the generation of 'analytical themes'. The analytical themes were generated from the 14 components above to provide an interpretive framework similar to that used in the quantitative summary. For example, studies were systematically appraised to establish the acceptability of interventions to people with dementia and their carers.

## **RESULTS**

### **Study selection**

A total of 603 citations were initially extracted, of which 160 were reviewed by title and abstract. Figure 1 shows the PRISMA (Moher *et al.* 2009) flow diagram for included studies. Seventy papers met the inclusion criteria. Three studies, where costs were the only outcome, were excluded.

## Study characteristics

Tables 1-3 describe the included studies reporting home support interventions. Most (N=37; 53%) were conducted in the United States (US), followed by the UK (N=13; 18%) and the remainder in other countries including Taiwan, Finland and China. Almost all were directed towards family carers: either as a primary focus (N=33; 47%) or with people with dementia (N=35; 50%). Two studies focused solely on people with dementia.

Twenty studies (29%) failed to specify the severity or stage of dementia. Of the remaining (N=50, 71%), most were directed towards carers or people with dementia in both early and later stages. A minority of studies addressed the needs of people exclusively in the early (N=7; 10%), or in the later (N=10; 14%), stages.

In terms of research design most studies (N= 57; 81%) were RCTs. Nine (13%) were quasi-experimental interventions and four (6%) were qualitative. Interventions lasted between one and 216 months (18 years). The largest one (Newcomer *et al.* (1999) included 2,731 (2,576) participants in the intervention (control) group, whilst the smallest (Sutcliffe & Lerner 1988) consisted of six participants in the intervention and five in the control group (see Tables 1, 2 and 3).

The quality rating for the quantitative studies (N=66) is also specified in the tables (Tables 1-3). The majority (N=37; 56%) were of high quality, with six (9%) categorized as weak. For the qualitative studies, two had low quality, one medium quality and one was rated of high quality. Overall, the 70 studies reported on 63 different interventions, with some studies reporting on different outcomes from the same intervention (e.g. Mittelman *et al.* 2004a; 2004b).

## Synthesis

The quantitative and qualitative studies are reported separately. In the first, the groupings of 14 components (5 for carers and 9 for people with dementia) identified previously (Clarkson *et al.* 2017) and detailed above, were employed. These are described as interventions and subsequently measures of effectiveness are applied to them (Table 4). Finally, findings from the qualitative data are reported, reflecting some of the 14 components referred to above.

### *Groupings of components*

There were 14 single-component and 52 multi-component carer studies and 21 single-component and 15 multi-component studies for people with dementia identified (see supplementary information Tables S3 and S4). The components identified in these studies were grouped together into interventions to capture the most prevalent approaches for both carers and people with dementia. This grouping included over four fifths (81%) of the studies in the review.

The interventions are described in Table 4. Seven interventions were identified for carers, based on five components. Education/advice and behaviour management were the most frequent components for carers and were often jointly employed. Information and advice was frequently provided alongside behavioural techniques, whereby carers were educated about the possible causes of their relative's behaviour problems. The interventions identified were a single-component approach, involving only behaviour management (N=8 studies); and a multicomponent intervention employing education/advice, emotional and social support (N=6 studies). The remainder employed: education/advice and behaviour management (N=11 studies); plus emotional support (N=5 studies); plus social support (N=5 studies); plus emotional and social support (N=6 studies). Finally, one approach involved all five

components: education/advice, behaviour management, emotional support, social support and respite (N=3 studies).

Two single component interventions were identified for people with dementia, from 9 possible components: one focusing on care coordination (N=7 studies) and the other on environmental modifications (N=6 studies). In describing the most prevalent groupings of components, seven components previously identified were not included (sensory enhancement/relaxation; social engagement; cognitive training; emotional support; physical activity; behaviour management; and daily living assistance) (Clarkson *et al.* 2017). The least represented components in this review of home support interventions were: sensory enhancement/relaxation, which was present in only one study (Torkomani *et al.* 2014); cognitive training in only three (Quayhagen *et al.* 2000; Davis *et al.* 2001; Graff *et al.* 2007) and physical activity in only four (Teri *et al.* 2003; Gitlin *et al.* 2008; Eloniemi-Sulkava *et al.* 2009; Steinberg *et al.* 2009). The inclusion of these studies would have reduced the number of interventions it was possible to categorise and therefore the evidence available (see supplementary information Table S4). As noted in Table 4, a range of staff were employed in undertaking the interventions, including professionally and non-professionally qualified personnel and researchers.

### ***Effectiveness***

The nine interventions, described above, comprising the most prevalent groupings of components, were selected to synthesise evidence relating to effectiveness. These are described in Table 4 with exemplars. Two criteria, effect size and intensity had most influence on the rating of effectiveness. Most studies reported statistically significant change in at least

one outcome. The statistics used for calculating the effectiveness rating for each study are in supplementary information, Table S4. The most salient findings are summarized below.

All interventions included studies with a range of effectiveness ratings. A larger number of components within an intervention did not necessarily increase effectiveness. Hence, the approach for carers containing all five components (C7, Table 4) was no more effective, in terms of the range of effectiveness ratings, than other approaches. However, there was a tendency for the approach containing education/advice, behaviour management and social support (C5, Table 4) to have a higher range of effectiveness than others.

Components were linked to a range of outcomes, including everyday functioning, behaviour, cognition and delaying nursing/care home admission. A number were multicomponent interventions. The mix of two components, education/advice and behaviour management (C3, Table 4), was the most frequent intervention approach, which effectively reduced carer burden, problem behaviour and improved well-being. This might reflect the fact that teaching carers to manage problem behaviours most often involves information and advice about the causes of such behaviours and about the condition as such. Another set of interventions comprised a different mix of components, providing education/advice, emotional and social support to carers (C2, Table 4). Often this consisted of face-to-face, telephone, or internet-based support groups and individual counselling, where carers were listened to and could exchange their experiences of caring for someone with dementia. The approach was used to reduce the rate of nursing/care home admissions and the promotion of carer well-being.

Measures of effectiveness were also captured in the two single component interventions for people with dementia (P1 and P2, Table 4). Six studies employing environmental

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modifications were rated low to moderately effective, although all reported significant improvements. These were based on the theory that removing stressors in the environment can reduce problem behaviour and increase everyday functioning of the person with dementia, such as transfers out of bed and enhance carer well-being. A range of effectiveness ratings were identified for care coordination. The primary goal of most was to delay or reduce nursing/care home admission (Lawton *et al.* 1989; Chien & Lee 2008, 2011; Challis *et al.* 2009). Most studies were RCTs and specifically designed to test the efficacy of a specific intervention. However, Tibaldi *et al.* (2004) compared the effectiveness of two different approaches to care. The care coordinated home hospitalisation service was effective in alleviating carer burden and reducing problem behaviours, compared with those admitted to a general medical ward.

### *Qualitative findings*

For qualitative studies, key themes were identified to determine how outcomes were generated. Three focused on carer skill building (Farran *et al.* 2003, 2004; Kelly *et al.* 2002). They all included the components of: education and advice, behaviour management, emotional support and the presence of social support. The remaining study focused on people with dementia and their carers (Rothera *et al.* 2008). Three components were also present in this: behaviour management, daily living and, for carers, emotional support.

Quality of life of the carer-person with dementia relationship was the main outcome focus of all qualitative studies, with carer burden being a specific element within it. Two linked studies (Farran *et al.* 2003, 2004) highlighted the need to support carers to come to an understanding of dementia as a condition and that how they manage their own feelings and behaviours can have an impact on both on the behaviour of the person with dementia and on their own well-



being. One carer commented that they had “finally realised that it’s me who has to change” (Farran *et al.* 2003, p. 371).

## **DISCUSSION**

In this section, the principal findings from this systematic review are appraised in terms of the principal findings, their logical coherence and implications for clinical practice. The aim of this review was to explicate the outcomes of home support interventions for older people with dementia and/or their carers, which relied on one or more of the components previously identified (Clarkson *et al.* 2017). However, the descriptions of the interventions were of variable quality. Nevertheless, in terms of influence, most studies reported positive outcomes, although these were derived from a disparate group of interventions, employing differing outcome measures and sometimes were based on small samples.

Reflecting the aim of the review, the principal finding was the identification of a range of potential approaches for delivering home support to people with dementia and their carers (Clarkson *et al.* 2016). This has been achieved by first identifying the components of the intervention irrespective of setting and second by investigating their presence in studies administered to people with dementia and their carers at home, with an assessment of their effectiveness. All 14 components identified previously (Clarkson *et al.* 2017) were present in the studies included in this review. The resulting interventions covered over four fifths of these. Many interventions targeted improving behavioural problems, with studies typically teaching carers techniques to address these. Behaviour management techniques focused on the person with dementia were rare. Only two of the nine components for people with dementia were included.

An interesting finding from this review was that most interventions addressed the needs of carers and not people with dementia. Their contribution to the care of people with more advanced dementia has been noted elsewhere (e.g. Starkstein *et al.* 2006). The management of problem behaviour by changing the response of carers was an important component of interventions in this literature review (see for example, Livingston *et al.* 2005). Interestingly, an intervention using this component together with education and social support revealed more evidence of effectiveness than other approaches (Chien & Lee 1998; Burgio *et al.* 2003; Belle *et al.* 2006; Finkel *et al.* 2007). However, effectiveness was unrelated to the number of components within an intervention.

To what extent does the logical coherence of the nine interventions identified constitute a taxonomy? This has been described as “a formal system for classifying multifaceted, complex phenomenon according to a set of common conceptual domains and dimensions” (Bradley *et al.* 2007, p. 1760). The approach has been used previously to describe approaches to information sharing and assessment in a demonstration program (Chester *et al.* 2015). Its value is in promoting “increased clarity in defining and hence comparing diverse, complex interventions” (Bradley *et al.* 2007, p. 1760) by using “a common language . . . that distils [them] into their essential components” (Bradley *et al.* 2007, p. 1766). The interventions described and appraised in Table 4 represent a synthesis of the 14 components, identified previously, in a variety of combinations (Clarkson *et al.* 2017). Critically, in this review they were delivered at home. Interventions within the taxonomy included studies with a range of effectiveness ratings based on multiple outcome measures. They differed in terms of their mechanisms for promoting change and the staff groups administering the interventions, together with measures of outcomes and effectiveness.

Furthermore, a taxonomy can be expanded and thus incorporate future interventions and evidence for them over time (Bazzoli *et al.* 1999). Thus, it provides a practical representation of the aim of this review by codifying home support interventions for older people with dementia and their carers together with evidence of effectiveness. For practitioners this could become a valuable resource. It could be expected, for example, that over time more evidence will be gathered relating to the components of interventions not captured in the taxonomy described above. These include three components of home support for people with dementia: daily living assistance, cognitive training and physical activity. However, to preserve its integrity as a taxonomy of home support, only interventions conducted in this setting should be included. This contrasts with previous research into home support for people with dementia which, whilst not a systematic review, categorised four approaches, case management, integrated care, consumer directed care and restorative care (Low & Fletcher 2015).

What are the implications of this review and the resultant taxonomy for clinical practice? The taxonomy provides a framework to guide practitioners. However, it is not a prescriptive tool and not all the interventions reported could be replicated and transferred into routine care administered by practitioners. Moreover, an intervention is unlikely to be effective if staff do not have the appropriate skills and training to deliver it. Of the nine interventions in the review, two thirds reported nurses or nurse therapists overseeing their administration. Furthermore, a judgement has to be made as to which interventions have the potential to be effective. This review suggested that approaches containing education, social support and behaviour management have the greatest potential. Finally, within this taxonomy no distinction is made about the stage of dementia in relation to judgements of effectiveness. Therefore, successful administration of an intervention requires an assessment of potential

utility to be made by the practitioner in the context of the progress of the condition for an individual.

## LIMITATIONS

This review was subject to certain limitations. One of the inclusion criteria for the review – the presence of a comparator of standard or usual care – may have excluded several qualitative studies. Typically, these tend to be small scale and of a case study design and less likely to have comparator data. Of the excluded qualitative papers (N=14), most (N=9) were excluded for this reason, illustrating the compromises inherent in the design of a systematic review with both qualitative and quantitative data. A further compromise inherent in the handling of qualitative data was that it did not explicitly follow established ENTREQ best practice guidance for qualitative research (Tong *et al.* 2012). Nevertheless, the majority of items documented in this (16 out of 21) were adhered to in the wider review process.

There were also limitations consequent on the use of review specific measures: the component rating manual and the effectiveness rating. More generally in term of effectiveness, the number of included studies (N=70) made it difficult to appraise the effectiveness of each intervention, particularly when there were multiple components. Furthermore, whilst the ratings of effectiveness captured statistically significant change in at least one outcome, one of their elements – effect size – could not be calculated for some due to data limitations. Finally, it was not possible to capture all the studies within the taxonomy. Notable omissions were daily living assistance, cognitive training and physical activity for people with dementia.

## CONCLUSION

This review has synthesised the evidence for home support approaches directed at tertiary prevention, to ameliorate difficulties and enhance well-being. The framework applied here, presented as a taxonomy of nine interventions combining these components in different ways, has enabled interventions to be compared and gaps in knowledge and understanding to be identified. It adds to existing knowledge and facilitates knowledge transfer from research into practice for both practitioners and service commissioners. In particular, the taxonomy highlights gaps in the understanding of the value of daily living assistance, cognitive training and physical activity for people with dementia. Two further general gaps in knowledge have been highlighted in this review. The first and arguably the more important, is the paucity of research relating to the care of people with dementia at home. Allied to this, many studies omitted information on the stage of the progression of dementia, a critical determinant of potential effectiveness. Future research should address these deficits by focussing on the care of people with dementia living at home and target interventions to distinguish between early and later stage dementia.

This review has also identified that research could usefully focus on care at home and support provided to carers. A further area of enquiry emerging from this review is a requirement for the systematic analysis of user and carer preference to gauge the most valuable components of support. There is also a need to investigate the effectiveness of interventions identified through our taxonomy using robust measures of effectiveness. In this there will be value in a clear distinction regarding early and later stage dementia. The care of people with dementia at home represents a global challenge and this review highlights both evidence to guide current packages of care and gaps in the evidence base from which tailored interventions could be designed and evaluated.

## 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/>

## References

- Afram B., Stephan A., Verbeek H., Bleijlevens M.H., Suhonen R., Sutcliffe C., Raamat K., Cabrera E., Soto M.E., Hallberg I.R., Meyer G, Hamers J.P. & RightTimePlaceCare Consortium (2014) Reasons for institutionalization of people with dementia: informal caregiver reports from 8 European countries. *Journal of the American Medical Directors Association* **15**(2), 108-116.
- Alzheimer's Disease International. (2015) *World Alzheimer's Report: The Global Impact of Dementia*. Alzheimer's Disease International, London.
- Askham J. & Thompson C. (1990) *Dementia and Home Care: A Research Report on a Home Support Scheme for Dementia Sufferers*. Age Concern Books, Mitcham.
- Bazzoli G., Shortell J., Dubbs N., Chan C. & Kralovec P. (1999) A taxonomy of health networks and systems: Bringing order out of chaos. *Health Services Research* **33**(6), 1683–1717.
- Belle S.H., Burgio L., Burns R., Coon D., Czaja S.J., Gallagher-Thompson D., Gitlin L.N., Klinger J., Koepke K.M., Lee C.C., Martindale-Adams J., Nichols L., Schulz R., Stahl S., Stevens A., Winter L. & Zhang S. (2006) Enhancing the quality of life of dementia

caregivers from different ethnic or racial groups: A randomized, controlled trial. *Annals of Internal Medicine* **145**(10), 727-738.

Bourgeois M.S., Burgio L.D., Schulz R., Beach S. & Palmer B. (1997) Modifying repetitive verbalizations of community-dwelling patients with AD. *Gerontologist* **37**, 30-39.

Bourgeois M.S., Schulz R., Burgio L. & Beach, S. (2002) Skills training for spouses of patients with Alzheimer's disease: outcomes of an intervention study. *Journal of Clinical Geropsychology* **8**, 53-73.

Bradley E., Curry L., & Devers K. (2007) Qualitative data analysis for health services research: Developing taxonomy, themes and theory. *Health Services Research* **42**(4), 1758-1772.

Buckwalter K.C., Gerdner L., Kohout F., Hall G.R., Kelly A., Richards B. & Sime M. (1999) A nursing intervention to decrease depression in family caregivers of persons with dementia. *Archives of Psychiatric Nursing* **13**, 80-88.

Burgener S.C., Bakas T., Murray C., Dunahee J. & Tossey S. (1998) Effective caregiving approaches for patients with Alzheimer's Disease. *Geriatric Nursing* **19**, 121-126.

Burgio L., Stevens A., Guy D., Roth D.L. & Haley W.E. (2003) Impact of two psychosocial interventions on white and African American family caregivers of individuals with dementia. *The Gerontologist* **43**(4), 568-579.

Carr S.M., Lhussier M., Forster N., Geddes L., Deane K., Pennington M., Visram S., White M., Michie S., Donaldson C. & Hildreth A. (2011) An evidence synthesis of qualitative and quantitative research on component intervention techniques, effectiveness, cost- effectiveness, equity and acceptability of different versions of health-related lifestyle advisor role in improving health. *Health Technology Assessment (Winch Eng)* **15**(9).

Centre for Reviews and Dissemination (2009) *Systematic Reviews: CRD's Guidance for Undertaking Reviews in Health Care*. University of York, York.

Challis D., Sutcliffe C., Hughes J., von Abendorff R., Brown P. & Chesterman J. (2009) *Supporting People with Dementia at Home*. Ashgate, Farnham.

Challis D., Clarkson P., Hughes J., Chester H., Davies S., Sutcliffe C., Xie C., Abendstern M., Jasper R., Jolley D., Roe B., Tucker S. & Wilberforce M. (2010) Community Support Services for People with Dementia: The Relative Costs and Benefits of Specialist and Generic Domiciliary Care Services. PSSRU, Manchester.

Chang B.L. (1999) Cognitive-behavioural intervention for homebound caregivers of persons with dementia. *Nursing Research* **48**(3), 173-182.

Chester H., Hughes J., Clarkson P., Davies S. & Challis, D. (2015) Approaches to information sharing and assessment: evidence from a demonstration program. *Care Management Journals* **16**(3), 150-158.

Chien W.T. & Lee Y.M. (2008) A Disease management program for families of persons in Hong Kong with dementia. *Psychiatric Services* **59**(4), 433-436.

Chien W.T. & Lee I.Y.M. (2011) Randomized controlled trial of a dementia care programme for families of home-resided older people with dementia. *Journal of Advanced Nursing* **67**(4), 774-787.

Chu P., Edwards J., Levin J. & Thompson J. (2000) The use of clinical case management for early stage Alzheimer's patients and their families. *American Journal of Alzheimer's Disease and Other Dementias* **15**, 284-292.

Clarkson P., Giebel C.M., Larbey M., Roe B., Challis D., Hughes J., Jolley D., Poland F. & Russell I. (2016) A protocol for a systematic review of effective home support to people with dementia and their carers: components and impacts. *Journal of Advanced Nursing* **72**, 186-196.



- Clarkson P., Hughes J., Xie C., Larbey M., Roe B., Giebel C.M., Jolley D., Challis D. & HoSt-D (Home Support in Dementia) Programme Management Group. (2017) Overview of systematic reviews: Effective home support in dementia care, components and impacts – Stage 1, psychosocial interventions for dementia. *Journal of Advanced Nursing* 2017;00:1–19. <https://doi.org/10.1111/jan.13362>.
- Cohen J. (1988) *Statistical Power Analysis for the Behavioral Sciences* (2nd edn.). Lawrence Erlbaum Associates, New York.
- Colvez A., Joël M.E., Ponton-Sanchez A. & Royer A.C. (2002) Health status and work burden of Alzheimer patients' informal caregivers: comparisons of five different care programs in the European Union. *Health Policy* **60**(3), 219-233.
- Davis R.N., Massman P.J. & Doody R.S. (2001) Cognitive intervention in Alzheimer disease: a randomized placebo-controlled study. *Alzheimer Disease and Associated Disorders* **15**, 1–9.
- Dias A., Dewey M.E., D'Souza J., Dhume R., Motghare D.D., Shaji K.S., Menon R., Prince M. & Patel V. (2008) The effectiveness of a home care program for supporting caregivers of persons with dementia in developing countries: a randomised controlled trial from Goa, India. *PloS one*, **3**(6), e2333.
- Deeks J.J., Dinnes J., D'Amico R., Sowden A.J., Sakarovitch C., Song F., Petticrew M. & Altman D.J. (2003) Evaluating non-randomised intervention studies. *Health Technology Assessment* **7**(27).
- Department of Health (2009) *Living Well with Dementia: A National Dementia Strategy*. The Stationery Office, London.
- Drentea P., Clay O.J., Roth D.L. & Mittelman M.S. (2006) Predictors of improvement in social support: Five-year effects of a structured intervention for caregivers of spouses with Alzheimer's Disease. *Social Science & Medicine* **63**(4), 957-967.

Effective Public Health Practice Project (EPHPP) (2003) *Quality Assessment Tool for Quantitative Studies*. Public Health Research, Education and Development Program (PHRED), ON, Canada.

Eisdorfer C., Szaja S.J., Loewenstein D.A., Rubert M.P., Argüelles S., Mitrani B.V. & Szapocznik J. (2003) The effect of a family therapy and technology based intervention on caregiver depression. *Gerontologist* **43**, 521–531.

Eloniemi-Sulkava U., Saarenheimo M., Laakkonen M.L., Pietilä M., Savikko N., Kautiainen H., Tilvis R.S. & Pitkälä K.H. (2009) Family care as collaboration: effectiveness of a multicomponent support program for elderly couples with dementia. Randomized controlled intervention study. *Journal of the American Geriatrics Society* **57**(12), 2200-2208.

Eloniemi-Sulkava U., Notkola I.L., Hentinen M., Kivelä S.L., Sivenius J. & Sulkava R. (2001) Effects of supporting community-living demented patients and their caregivers: A randomized trial. *Journal of the American Geriatrics Society* **49**(10), 1282–1287.

Engelhardt J.B., Kisiel T., Nicholson J., Mulichak L., DeMatteis J. & Tobin, D.R. (2008) Impact of a care coordination and support strategic partnership on clinical outcomes. *Home Healthcare Nursing* **26**(3), 166-172.

Farran C.J., Loukissa D., Perraud S. & Paun O. (2003) Alzheimer's disease caregiving information and skills. Part I: care recipient issues and concerns. *Research in Nursing & Health* **26**(5), 366-75.

Farran C.J., Loukissa D., Perraud S. & Paun O. (2004) Alzheimer's disease caregiving information and skills. Part II: family caregiver issues and concerns. *Research in Nursing & Health* **27**(1), 40-51.

- Farran C.J., Gilley D.W., McCann J.J., Bienias J.L., Lindeman D.A. & Evans D.A. (2007) Efficacy of behavioral interventions for dementia caregivers. *Western Journal of Nursing Research* **29**(8), 944-960.
- Finkel S., Czaja S.J., Schulz R., Martinovich Z., Harris C. & Pezzuto D. (2007) E-care: a telecommunications technology intervention for family caregivers of dementia patients. *American Journal of Geriatric Psychiatry* **15**, 443-448.
- Gallagher-Thompson D., Gray H.L., Tang P.C., Pu C.Y., Leung L.Y., Wang P.C., Tse C., Hsu S., Kwo E., Tong H.Q., Long J. & Thompson L.W. (2007) Impact of in-home behavioral management versus telephone support to reduce depressive symptoms and perceived stress in Chinese caregivers: results of a pilot study. *American Journal of Geriatric Psychiatry* **15**(5), 425-434.
- Gavrilova S.I., Ferri C.P., Mikhaylova N., Sokolova O., Banerjee S. & Prince M. (2009) Helping carers to care - the 10/66 dementia research group's randomized control trial of a caregiver intervention in Russia. *International Journal of Geriatric Psychiatry* **24**, 347-354.
- Gitlin L.N., Corcoran M., Winter L., Boyce A. & Hauck, W. (2001) A randomized, controlled trial of a home environmental intervention. *Gerontologist* **41**(1), 4-14.
- Gitlin L.N., Winter L., Corcoran M., Dennis M.P., Schinfeld S. & Hauck W.W. (2003) Effects of the home environmental skill-building program on the caregiver-care recipient dyad: 6-month outcomes from the Philadelphia REACH Initiative. *Gerontologist* **43**(4), 532-546.
- Gitlin L.N., Hauck W.W., Dennis M.P. & Winter L. (2005) Maintenance of effects of the Home Environmental Skill-Building Program for family caregivers and individuals with Alzheimer's Disease and related disorders. *Journal of Gerontological Sciences Series A: Biological Sciences and Medical Sciences* **60**(3), 368-374.

- Gitlin L.N., Winter L., Burke J., Chernett N., Dennis M.P. & Hauck W.W. (2008) Tailored activities to manage neuropsychiatric behaviors in persons with dementia and reduce caregiver burden: a randomized pilot study. *American Journal of Geriatric Psychiatry* **16**, 229–239.
- Gitlin L.N., Winter L., Dennis M.P., Hodgson N. & Hauck W.W. (2010a) A biobehavioral home-based intervention and the well-being of patients with dementia and their caregivers: the COPE randomized trial. *Journal of the American Medical Association* **304**, 983-991.
- Gitlin L.N., Winter L., Dennis M.P., Hodgson N. & Hauck W.W. (2010b) Targeting and managing behavioral symptoms in individuals with dementia: A randomized trial of a nonpharmacological intervention. *Journal of the American Geriatrics Society* **58**(8), 1465–1474.
- Graff M.J., Vernooij-Dassen M.J., Thijssen M., Dekker J., Hoefnagels W.H. & Rikkert M.G. (2006) Community based occupational therapy for patients with dementia and their caregivers: randomised controlled trial. *British Medical Journal* **333**, 1196-1201.
- Graff M.J., Vernooij-Dassen M.J., Thijssen M., Dekker J., Hoefnagels W.H. & Olderrikkert M.G. (2007) Effects of community occupational therapy on quality of life, mood and health status in dementia patients and their caregivers: a randomized controlled trial. *Journals of Gerontology Series A: Biological Sciences and Medical Sciences* **62**, 1002–1009.
- Grau H., Graessel E. & Berth H. (2015) The subjective burden of informal caregivers of persons with dementia: extended validation of the German language version of the Burden Scale for Family Caregivers (BSFC). *Aging & Mental Health* **19**(2), 159-168.

- Guerra M., Ferri C.P., Fonseca M., Banerjee S. & Prince, M. (2010) Helping carers to care: the 10/66 dementia research group's randomized control trial of a caregiver intervention in Peru. *Revista Brasileira de Psiquiatria* **33**, 47-54.
- Hinchliffe A.C., Hyman I.L., Blizard B. & Livingston G. (1995) Behavioral complications of dementia – can they be treated. *International Journal of Geriatric Psychiatry* **10**(10), 839-847.
- Horvath K.J., Trudeau S.A., Rudolph J.L., Trudeau P.A., Duffy M.E. & Berlowitz D. (2013) Clinical trial of a home safety toolkit for Alzheimer's disease. *International Journal of Alzheimer's Disease* 1-11, doi: 10.1155/2013/913606.
- Huang H.L., Lotus Shyu Y.I., Chen M.C., Chen S.T. & Lin L.C. (2003) A pilot study on a home-based caregiver training program for improving caregiver self-efficacy and decreasing the behavioral problems of elders with dementia in Taiwan. *International Journal of Geriatric Psychiatry* **18**, 337–345.
- Johnson D.K., Niedens M., Wilson J.R., Swartzendruber L., Yeager A. & Jones K. (2013) Treatment outcomes of a crisis intervention program for dementia with severe psychiatric complications: The Kansas Bridge Project. *Gerontologist* **53**(1), 102-112.
- Kelly A.W., Buckwalter K.C., Hall G., Weaver A.L. & Butcher H.K. (2002) The caregivers' story: Home caregiving for persons with dementia. *Home Health Care Management & Practice* **14**(2), 99-109.
- Kosloski K. & Montgomery R.J.V. (1993) The effects of respite on caregivers of Alzheimer's patients: one-year evaluation of the Michigan model respite programs. *The Journal of Applied Gerontology* **12**, 4-17.
- Kuo L-M., Huang H-L., Huang H-L., Liang J., Chiu Y-C., Chen S-T., Kwok Y-T., Hsu W-C., Shyu Y-I.L. (2013) A home-based training program improves Taiwanese family

caregivers' quality of life and decreases their risk for depression: a randomized controlled trial. *International Journal of Geriatric Psychiatry* **28**(5), 504-513.

Kwok T., Wong B., Ip I., Chui K., Young D. & Ho F. (2013) Telephone-delivered psychoeducational intervention for Hong Kong Chinese dementia caregivers: a single-blinded randomized controlled trial. *Clinical Interventions in Ageing* **8**, 1191-1197.

Lawton M.P., Brody E.M. & Saperstein A.R. (1989) A controlled study of respite service for caregivers of Alzheimer's patients. *Gerontologist* **29**(1), 8-16.

Liberati A., Altman D.G., Tetzlaff J., Mulrow C., Gotzsche P.C., Ioannidis J.P.A., Clarke M., Devereaux P.J., Kleijnen J. & Moher D. (2009) The PRISMA Statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. *PLoS Medicine*. **6**(7), e1000100.

Livingston G., Johnston K., Katona C., Paton J. & Lyketsos C.G. (2005) Systematic review of psychological approaches to the management of neuropsychiatric symptoms of dementia. *American Journal of Psychiatry* **162**, 1996–2021.

Livingston G., Barber J., Rapaport P., Knapp M., Griffin M., King D., Livingston D., Mummery C., Walker Z., Hoe J., Sampson E.L. & Cooper C. (2013) Clinical effectiveness of a manual based coping strategy programme (START, STRategies for RelaTives) in promoting the mental health of family carers of people with dementia: pragmatic randomised controlled trial. *British Medical Journal* **347**, f6276.

Low, L.F. & Fletcher, J. (2015) Models of home care services for persons with dementia: a narrative review. *International Psychogeriatrics* **27**(10), 1593-1600.

Mahoney D.F., Tarlow B.J. & Jones R.N. (2003) Effects of an automated telephone support system on caregiver burden and anxiety: findings from the REACH for TLC intervention study. *Gerontologist* **43**(4), 556-567.

- Mittelman M.S., Ferris S.H., Steinberg G, Shulman E., Mackell J.A., Ambinder A. & Cohen J. (1993) An intervention that delays institutionalization of Alzheimer's disease patients: treatment of spouse-caregivers. *Gerontologist* **33**, 730–740.
- Mittelman M.S., Roth D.L., Coon D.W. & Haley W.E. (2004a) Sustained benefit of supportive intervention for depressive symptoms in caregivers of patients with Alzheimer's disease. *American Journal of Psychiatry*, **161**(5), 850-856.
- Mittelman M.S., Roth D.L., Haley W.E. & Zarit S.H. (2004b) Effects of a caregiver intervention on negative caregiver appraisals of behaviour problems in patients with Alzheimer's Disease: Results of a randomized trial. *Journal of Gerontological Sciences Series B: Psychological Sciences and Social Science* **59**(1), 27-34.
- Mittelman M.S., Haley W.E., Clay O.J. & Roth D.L. (2006) Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology* **67**(9), 1592-1599.
- Moher D., Liberati A., Tetzlaff J. & Altman D.G. (2009) Preferred reporting items for systematic reviews and meta-analyses: the PRISMA Statement. *PLoS Medicine* **6**, e1000097. doi:10.1371/journal.pmed.1000097.
- Mohide E.A. (1990) A randomized trial of family caregiver support in the home management of dementia. *Journal of the American Geriatrics Society* **38**, 446-454.
- Moniz-Cook E., Elston C., Gardiner E., Agar S., Silver M., Win T. & Wang M. (2008) Can training community mental health nurses to support family carers reduce behavioural problems in dementia? An exploratory pragmatic randomised controlled trial. *International Journal of Geriatric Psychiatry* **23**(2), 185–191.
- Newcomer R., Yordi C., DuNah R., Fox P. & Wilkinson A. (1999) Effects of the Medicare Alzheimer's Disease demonstration on caregiver burden and depression. *Health Services Research* **34**, 669–689.

O'Connor D., Pollitt P., Brook C., Reiss B. & Roth, M. (1991) Does early intervention reduce the number of elderly people with dementia admitted to institutions for long term care? *British Medical Journal* **302**, 871-875.

Phung K.T., Waldorff F.B., Buss D.V., Eckermann A., Keiding N., Rishoj S., Siersma V., Sorensen J., Sogaard R., Sorensen L.V., Vogel A. & Waldemar G. (2013) A three-year follow-up on the efficacy of psychosocial interventions for patients with mild dementia and their caregivers: the multicentre, rater-blinded, randomised Danish Alzheimer Intervention Study (DAISY). *British Medical Journal Open* **3**(11), doi:10.1136/bmjopen-2013-003584.

Prince M., Knapp M., Guerchet M., McCrone P., Prina M., Comas-Herrera A., Wittenberg R., Adelaja B., Hu B., King D., Rehill A. & Salimkumar D. (2014) *Dementia UK: Update*. Alzheimer's Society, London.

Public Health Resource Unit (2006) Critical Appraisal Skills Programme. 10 Questions to help you make sense of qualitative research. Public Health Resource Unit, England.

Quayhagen M.P., Quayhagen M., Corbeil R.R., Hendrix R.C, Jackson J.E., Snyder L. & Bower D (2000) Coping with dementia: evaluation of four nonpharmacologic interventions. *International Psychogeriatrics* **12**(2), 249-265.

Riordan J.M. & Bennett A.V. (1998) An evaluation of an augmented domiciliary service to older people with dementia and their carers. *Aging & Mental Health* **2**(2), 137-143.

Rossor M. & Knapp M. (2015) Can we model a cognitive footprint of interventions and policies to help meet the global challenge of dementia? *The Lancet* **386** (9997), 1008-1010.

Rothera I., Jones R., Harwood R., Avery A., Fisher K., James V., Shaw I. & Waite J. (2008) An evaluation of a specialist multiagency home support service for older people with



dementia using qualitative methods. *International Journal of Geriatric Psychiatry* **23**, 65-72.

Samus Q.M., Johnston D., Black B.S., Hess E., Lyman C., Vavilikolanu A., Pollutra J., Leoutsakos J-M., Gitlin L.N., Rabins P.V. & Lyketsos C.G. (2014) A multidimensional home-based care coordination intervention for elders with memory disorders: the Maximizing Independence at Home (MIND) pilot randomized trial. *American Journal Geriatric Psychiatry* **22**(4), 398-414.

Schneider, J., Hallam, A., Islam, M.K., Murray, J., Foley, B., Atkins, L., Banerjee, S. & Mann, A. (2003) Formal and informal care for people with dementia: variations in costs over time. *Ageing and Society* **23**, 303-326.

Starkstein S.E., Jorge R., Mizrahi R. & Robinson R.G. (2006) A diagnostic formulation of anosognosia in Alzheimer's disease. *Journal of Neurology, Neurosurgery & Psychiatry* **77**(6), 719-725.

Steinberg M., Leoutsakos J.M., Podewils L.J. & Lyketsos C.G. (2009) 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* **24**, 680-685.

Sussman T. & Regehr C. (2009) The influence of community-based services on the burden of spouses caring for their partners with dementia. *Health & Social Work* **34**(1), 29-39.

Sutcliffe C. & Lerner S. (1988) Counselling carers of the elderly at home: a preliminary study. *British Journal of Clinical Psychology* **27**(2), 177-178.

Sutcliffe C.L., Giebel C.M., Jolley D. & Challis D.J. (2016) Experience of burden in carers of people with dementia on the margins of care. *International Journal of Geriatric Psychiatry* **31**(2), 101-108.

- Teri L., Gibbons L.E., McCurry S.M., Logsdon R.G., Buchner D.M., Barlow W.E., Kukull W.A., LaCroix A.Z., McCormick W. & Larson E.B. (2003) Exercise plus behavioral management in patients with Alzheimer disease: a randomized controlled trial. *Journal of the American Medical Association* **290**, 2015-2022.
- Teri L., McKenzie G. & LaFazia D. (2005a) Psychosocial treatment of depression in older adults with dementia. *Clinical Psychology: Science and Practice* **12**, 303-316.
- Teri L., McCurry S.M., Logsdon R. & Gibbons L.E. (2005b) Training community consultants to help family members improve dementia care: a randomized controlled trial. *Gerontologist* **45**, 802-811.
- Thomas J. & Harden A. (2008) Methods for the thematic analysis of qualitative research in systematic reviews. *BMC Medical Research Methodology* **8**, 45.
- Tibaldi V., Aimonino N., Ponzetto M., Stasi M.F., Amati D., Raspo S., Roglia D., Molaschi M. & Fabris F. (2004) A randomized controlled trial of a home hospital intervention for frail elderly demented patients: behavioral disturbances and caregiver's stress. *Archives of Gerontology & Geriatrics Suppl* **9**, 431-436.
- Tong, A., Flemming, K., McInnes, E., Oliver, S. & Craig, J. (2012) Enhancing transparency in reporting the synthesis of qualitative research: ENTREQ. *BMC Medical Research Methodology* **12**, 181.
- Torkamani M., McDonald L., Saez Aguayo I., Kanios C., Katsanou M.N., Madeley L., Limousin P.D., Lees A.J., Haritou M., Jahanshahi M. & ALADDIN Collaborative Group. (2014). A randomized controlled pilot study to evaluate a technology platform for the assisted living of people with dementia and their carers. *Journal of Alzheimer's Disease* **41**, 515-523.

Vernooij-Dassen M., Lamers C., Bor J., Felling A. & Grol, R. (2000) Prognostic factors of effectiveness of a support program for caregivers of dementia patients. *International Journal of Aging and Human Development* **51**(4), 259-274.

Vickrey B.G., Mittman B.S., Connor K.I., Pearson M.L., Della Penna R.D., Ganiats T.G., DeMonte R.W., Chodosh J., Cui X., Vassar S., Duan N., & Lee M. (2006) The effect of a disease management intervention on quality and outcomes of dementia care: a randomized, controlled trial. *Annals of Internal Medicine* **145**, 713–726.

Wilberforce, M., Tucker, S., Abendstern, M., Brand, C., Giebel, C.M. & Challis, D. (2013) Membership and management: structures of inter-professional working in community mental health teams for older people in England. *International Psychogeriatrics* **25**(9), 1485–1492.

Winter L. & Gitlin L.N. (2006) Evaluation of a telephone-based support group intervention for female caregivers of community-dwelling individuals with dementia. *American Journal of Alzheimer's Disease and other Dementias* **21**(6), 391-397.

Woods R.T., Wills W., Higginson I.J., Hobbins J. & Whitby, M. (2003) Support in the community for people with dementia and their carers: a comparative outcome study of specialist mental health service interventions. *International Journal of Geriatric Psychiatry* **18**, 298–307.

**Table 1** Review of home support interventions to carers

Author	Country	Intervention intensity; Duration <sup>1</sup> (Frequency) <sup>2</sup>	Study design	Sample size	Dementia stage <sup>3</sup>	Intervention description	Outcomes <sup>4</sup>	Quality rating
Belle <i>et al.</i> (2006)	US	6 m (12 sessions)	RCT	N <sub>I</sub> =261 & N <sub>C</sub> =257	Early and Later	Information, problem solving, telephone support, stress management techniques vs educational materials by post	Time to NH admission; <i>Carer burden</i> ; <i>Carer mood</i>	2
Bourgeois <i>et al.</i> (1997)	UK	3 m (13 sessions)	Q-Exp	N <sub>I</sub> =7 & N <sub>C</sub> =7	Later	Behaviour management intervention	<i>PwD behavior</i>	1
Bourgeois <i>et al.</i> (2002)	US	3 m (13 sessions)	RCT	N <sub>I1</sub> =22, N <sub>I2</sub> =21 & N <sub>C</sub> =20	Later	Two skills training approaches (change patient behaviour; change own (carer) coping behaviour)	<i>PwD behavior</i> ; <i>Carer mood</i>	1
Buckwalter <i>et al.</i> (1999)	US	6 m (13 sessions)	RCT	N <sub>I</sub> =132 & N <sub>C</sub> =108	nk	Teaching techniques to carers to reduce behavioural problems of PwD, i.e. environmental adaptations	<i>Carer mood</i>	2
Burgio <i>et al.</i> (2003)	US	12 m (16 sessions) <sup>5</sup>	RCT	N <sub>I</sub> =70 & N <sub>C</sub> =70	Early and Later	Information on behaviour management, problem solving skills, cognitive restructuring vs minimal support condition	<i>Carer mood</i> ; Time to NH admission; <i>PwD behavior</i>	1
Colvez <i>et al.</i> (2002)	Europe	Not specified	Q-Exp	N <sub>I1</sub> =36, N <sub>I2</sub> =50, N <sub>I3</sub> =99, N <sub>I4</sub> =100 & N <sub>I5</sub> =37	Early and Later	Home social services; day centres; expert centres; group-living; respite hospitalisation	<i>Carer burden [for group living and home social services]</i>	1
Drentea <i>et al.</i> (2006)	US	4 m (2 sessions)	RCT	N <sub>I</sub> =94 & N <sub>C</sub> =89	nk	Individual and family counselling, support group, ad hoc counselling	<i>Social support</i>	1
Eisdorfer <i>et al.</i> (2003)	US	12 m (26 sessions)	RCT	N <sub>I1</sub> =54, N <sub>I2</sub> =59 & N <sub>C</sub> =41	Early and Later	Structural ecosystems therapy; structural ecosystems therapy + computer-telephone integrated system; minimal support control	<i>Carer mood [for therapy + technology intervention]</i>	1
Farran <i>et al.</i> (2007)	US	12 m (14 sessions)	RCT	N <sub>I</sub> =143 & N <sub>C</sub> =153	Early and Later	Caregiver Skill Building Programme (5 weekly group session & 7 individual weekly telephone sessions + 2 groups session, one at 6 and one at 12 months + telephone contact when needed) vs. Information and Support Oriented Therapies	<i>Carer burden [for CSB]</i>	2
Finkel <i>et al.</i> (2007)	US	6 m (14 sessions)	RCT	N <sub>I</sub> =23 & N <sub>C</sub> =23	Early and Later	Technology-based psychoeducational intervention by community-based social service agency (information, strategies for safety enhancement, social support,	<i>Carer burden</i> ; <i>Carer mood</i>	1

						management of behaviors) vs information only		
Gallagher-Thompson <i>et al.</i> (2007)	US	4 m (7 sessions)	RCT	N <sub>I</sub> =22 & N <sub>C</sub> =23	nk	In-home behavioral management program (six modules: introduction, behaviour management, unhelpful thoughts, communication issues, end-of-life, pleasant events) vs. telephone-based comparison treatment	<i>Carer burden; PwD mood</i>	1
Gavrilova <i>et al.</i> (2009)	Russia	1 m (5 sessions)	RCT	N <sub>I</sub> =25 & N <sub>C</sub> =28	nk	Education about dementia and strategies for managing behaviour +usual medical care vs Usual medical care only (control)	<i>Carer burden; PwD mood; PwD behavior; PwD QoL</i>	1
Gitlin <i>et al.</i> (2003)	US	6 m (10 sessions)	RCT	N <sub>I</sub> =89 & N <sub>C</sub> =109	Early and Later	[Home Environmental Skill-Building Programme] five home contacts and 1 telephone contact (by OT, focusing on education, problem-solving, training and adaptive equipment)	<i>Carer burden; Carer QoL</i>	1
Guerra <i>et al.</i> (2010)	Peru	1 m (5 sessions)	RCT	N <sub>I</sub> =29 & N <sub>C</sub> =29	Early and Later	5 weekly home sessions about assessment, education and behaviour management	<i>Carer burden; Carer QoL; PwD QoL; PwD behavior</i>	1
Horvath <i>et al.</i> (2013)	US	6 m (1 session)	RCT	N <sub>I</sub> =60 & N <sub>C</sub> =48	Early and Later	Home Safety toolkit vs customary care	<i>Carer burden</i>	1
Kelly <i>et al.</i> (2002)	US	Not specified	Qual	Total N=226	Early and Later	Psychoeducational nursing/home care intervention vs comparison group (information only)	<i>Carer burden [themes]</i>	Medium quality <sup>6</sup>
Kosloski & Montgomery (1993)	US	6 m (Flexible)	Q-Exp	N <sub>I</sub> =45 & N <sub>C</sub> =25	nk	Carer respite	<i>Carer burden [on subjective burden]</i>	1
Kuo <i>et al.</i> (2013)	Taiwan	6 m (9 sessions)	RCT	N <sub>I</sub> =63 & N <sub>C</sub> =66	nk	Home-based training programme (based on Progressively Lowered Stress Threshold model, make adaptations to the environment to reduce PwD problematic behaviour and reduce carer stress) vs attention control	<i>Carer QoL; Carer mood</i>	3
Kwok <i>et al.</i> (2013)	China	3 m (12 sessions)	RCT	N <sub>I</sub> =18 & N <sub>C</sub> =20	nk	Telephone-based carer intervention (psychoeducation from social worker)	<i>Carer burden</i>	1
Lawton <i>et al.</i> (1989)	US	12 m (Flexible)	RCT	N <sub>I</sub> =317 & N <sub>C</sub> =315	nk	Carer respite	<i>Carer QoL; Carer burden; PwD mood; Time to NH admission</i>	1
Livingston <i>et al.</i> (2013)	UK	4 m (8 sessions)	RCT	N <sub>I</sub> =173 & N <sub>C</sub> =87	nk	Manual based coping strategies (psychoeducation about dementia, behaviour management, changing unhelpful thoughts, relaxation) vs treatment as usual	<i>Carer mood; Carer burden; PwD QoL</i>	2

Mahoney <i>et al.</i> (2003)	US	12 m (52 sessions)	RCT	N <sub>I</sub> =49 & N <sub>C</sub> =51	Early and Later	Integrated telephone network system support and weekly computer caregiver conversations (software)	<i>Carer burden; PwD mood</i>	2
Mittelman <i>et al.</i> (1993)	US	4 m (6 sessions + support groups/ counselling)	RCT	N <sub>I</sub> =103 & N <sub>C</sub> =103	nk	Individual and family counselling, support groups, ad hoc consultation vs routine support	<i>Time to NH admission</i>	2
Mittelman <i>et al.</i> (2004a)	US	4 m (6 sessions + support groups/ counselling)	RCT	N <sub>I</sub> =203 & N <sub>C</sub> =203	Early and Later	Counselling, support groups	<i>Carer mood</i>	2
Mittelman <i>et al.</i> (2004b)	US	4 m (6 sessions + support groups/ counselling)	RCT	N <sub>I</sub> =203 & N <sub>C</sub> =203	Early and Later	Counselling, support groups	<i>Carer burden</i>	1
Mohide (1990)	Canada	6 m (26 sessions)	RCT	N <sub>I</sub> =30 & N <sub>C</sub> =30	Later	Carer-focused health care, education, in- home respite, support group	<i>Carer QoL; NH admission</i>	1
Moniz-Cook <i>et al.</i> (2008)	UK	1 m (4 sessions + flexible contact)	RCT	N <sub>I</sub> =54 & N <sub>C</sub> =59	nk	Psychosocial intervention on managing behaviour from trained (experimental) CMHN or usual care (control) CMHN	<i>PwD behavior; Carer mood</i>	2
Sussman & Regehr (2009)	Canada	Not specified	Q-Exp	N <sub>I</sub> =85	Early and Later	Homemaking service vs adult day program services (respite) vs in-home professional support services	<i>Carer burden [for day centres]</i>	2
Sutcliffe & Lerner (1988)	UK	4.5 m (6 sessions)	RCT	N <sub>I1</sub> =6, N <sub>I2</sub> =4 & N <sub>C</sub> =5	nk	Emotional support; Information only	<i>Carer burden[for emotional support]; Carer mood</i>	2
Torkomani <i>et al.</i> (2014)	UK, Spain, Greece	6 m (1 session + flexible)	RCT	N <sub>I</sub> =30 & N <sub>C</sub> =30	Early and Later	Telemedicine system providing information/education, social networking, monitoring health, contact feature	<i>Carer QoL; Carer burden; PwD behavior; Carer mood</i>	2
Vernooij-Dassen <i>et al.</i> (2000)	Netherlands	10 m (not specified)	RCT	N <sub>I</sub> =73 & N <sub>C</sub> =63; but only N <sub>I</sub> =49 in admission analysis & N <sub>I</sub> =41 in carer competency analysis	Early and Later	Information about available support, offering listening, support positive contribution family makes to care (amongst others)	<i>Family carer skills</i>	2
Winter & Gitlin (2006)	US	6 m (26 sessions)	RCT	N <sub>I</sub> =58 & N <sub>C</sub> =45	Early and Later	Telephone support group (5 carers for an hour weekly)	<i>Carer mood; Carer burden</i>	1
Woods <i>et al.</i> (2003)	UK	Not specified	Q-Exp	N <sub>I</sub> =55 &	nk	Admiral Nurse Service vs. Conventional	<i>Carer burden</i>	3

				N <sub>C</sub> =73		services		
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<sup>1</sup> Duration of intervention is the length of time over which the active intervention was conducted (m = months), not the length of the study evaluation period; <sup>2</sup> Frequency of intervention is the number of sessions/visits over this period; <sup>3</sup> Dementia stage: early stage = described as mild to moderate, mean MMSE reported of 26-16, mean GDR of >3<=5; later stage = described as moderate to severe, mean MMSE reported of 0-15, mean GDR of >5; <sup>4</sup> All outcomes highlighted in *italics* indicate significant improvements post intervention; <sup>5</sup> Study only reports 6-months outcomes; <sup>6</sup> Quality ratings for qualitative studies based on the CASP assessment.

N<sub>i</sub>= Sample size for intervention group; N<sub>i1</sub>= Sample size for intervention 1; N<sub>i2</sub>= Sample size for intervention 2; N<sub>C</sub>= Sample size for control group; NH= Nursing home; nk=not known; Qual= Qualitative; Q-Exp= Quasi-Experimental; RCT = Randomised Controlled Trial

**Table 2** Review of home support interventions to carers and people with dementia

Author	Country	Intervention intensity; Duration <sup>1</sup> (Frequency) <sup>2</sup>	Study design	Sample size	Dementia stage <sup>3</sup>	Intervention description	Outcomes <sup>4</sup>	Quality rating
Askham & Thompson (1990)	UK	12 m (flexible)	RCT	N <sub>I</sub> =60 & N <sub>C</sub> =40 [at 6 months]; N <sub>I</sub> =47 & N <sub>C</sub> =44 [at 12 months]	nk	Different types of services provided depending on individual: no support; obtaining/increasing support from other services; providing continuing direct support; monitoring situation only; putting in support workers (help with ADLs, accompanying to social events, orientation to time and place, sitting service, companionship)	Time to NH admission	2
Burgener <i>et al.</i> (1998)	US	1 m (1 session)	RCT	N <sub>1</sub> =11, N <sub>2</sub> =12, N <sub>3</sub> =12 & N <sub>C</sub> =12	Later	Education + behaviour intervention; education intervention; behaviour intervention	<i>Person with dementia behavior [Intervention 1 and 2]; ADLs [Intervention 3]</i>	1
Challis <i>et al.</i> (2009)	UK	12 m (not specified)	Q-Exp	N <sub>I</sub> =43 & N <sub>C</sub> =43	Later	Case management	<i>NH admission</i>	2
Chang (1999)	US	2 m (not specified)	RCT	N <sub>I</sub> =31 & N <sub>C</sub> =34	Early and Later	Cognitive-behavioural intervention	<i>Carer mood</i>	2
Chien & Lee (2008)	China	6 m (12 sessions)	RCT	N <sub>I</sub> =44 & N <sub>C</sub> =44	Early and Later	Education and support group + home visits by case managers for education and family health	<i>Time to NH admission; Carer QoL; Carer burden</i>	1
Chien & Lee (2011)	China	6 m (14 sessions)	RCT	N <sub>I</sub> =46 & N <sub>C</sub> =46	nk	Weekly home visits, education for assessment, then intervention with individual families: fortnightly sessions (in total 10 2-hour sessions) involving education, problem-solving, psychological support	<i>Time to NH admission; Carer QoL</i>	1
Chu <i>et al.</i> (2000)	Canada	18 m (Flexible)	RCT	N <sub>I</sub> =37 & N <sub>C</sub> =38	Early	Early Home Care Programme (case management, OT, physical therapy, social work, respite, etc.) vs. information only	<i>Time to NH admission; Carer burden</i>	1
Dias <i>et al.</i> (2008)	India	6 m (13 sessions)	RCT	N <sub>I</sub> =41 & N <sub>C</sub> =40	nk	Intervention (education about dementia and behaviour, support for carers, psychiatrist referrals, networking, advice) vs. waiting list (receiving intervention after 6 months)	<i>Carer burden; Person with dementia behavior; ADLs</i>	1
Eloniemi-Sulkava <i>et al.</i> (2001)	Finland	24 m (Flexible + 20 days training)	RCT	N <sub>I</sub> =53 & N <sub>C</sub> =47	Early and Later	Dementia family care coordinator (advocacy, training, counselling, in-home visits, etc.) vs usual care	NH admission	1
Eloniemi-Sulkava <i>et</i>	Finland	24 m	RCT	N <sub>I</sub> =63 &	Early and	Home visits (initial support plan), geriatric	<i>Time to NH</i>	2



<i>al. (2009)</i>		(6 sessions)		N <sub>C</sub> =62	Later	assessments, education, individually tailored and need-based activities by trained public health registered nurse, support groups for carers, information sessions	<i>admission</i>	
Engelhardt <i>et al.</i> (2008)	US	Not specified	Q-Exp	N <sub>I</sub> =36 & N <sub>C</sub> =113	nk	Telephone health counselling	<i>Hospital admission</i>	2
Farran <i>et al.</i> (2003)	US	12 m (14 sessions)	Qual	Total N=177	Early and Later	Caregiver Skill Building Programme	<i>Carer perceptions of Person with dementia behaviors, ADLs &amp; cognitive decline</i>	low quality <sup>5</sup>
Farran <i>et al.</i> (2004)	US	12 m (14 sessions)	Qual	Total N=177	Early and Later	Caregiver Skill Building Programme	Carer burden	low quality <sup>5</sup>
Gitlin <i>et al.</i> (2001)	US	3 m (5 sessions)	RCT	N <sub>I</sub> =93 & N <sub>C</sub> =78	Early and Later	Home environmental intervention (caregiver education about environmental impact on behaviour, breaking down tasks, involving other family members)	<i>IADLs; ADLs; Person with dementia behavior; Carer burden</i>	1
Gitlin <i>et al.</i> (2005)	US	6 m (10 sessions)	RCT	N <sub>I</sub> =65 & N <sub>C</sub> =65	Early and Later	Carer intervention for modifying home environment	<i>Carer burden; ADLs</i>	3
Gitlin <i>et al.</i> (2008)	US	4 m (8 sessions)	RCT	N <sub>I</sub> =30 & N <sub>C</sub> =30	Later	Six home visits and two telephone chats with OT; training of different activities (not really IADLs)	<i>Person with dementia behavior; Person with dementia mood; Person with dementia QoL; Carer mood</i>	1
Gitlin <i>et al.</i> (2010a)	US	4 m (8 sessions)	RCT	N <sub>I</sub> =102 & N <sub>C</sub> =107	Later	12 home or telephone contacts (reducing environmental stressors and improving carer skills; education and carer training) vs 3 telephone calls and education	<i>IADLs; ADLs; Carer QoL; Person with dementia QoL</i>	1
Gitlin <i>et al.</i> (2010b)	US	4 m (8 sessions)	RCT	N <sub>I</sub> =117 & N <sub>C</sub> =122	Early and Later	Problem behaviour management skills	<i>Person with dementia behavior; Carer burden; Carer mood</i>	1
Graff <i>et al.</i> (2006)	Netherlands	1 m (10 sessions)	RCT	N <sub>I</sub> =68 & N <sub>C</sub> =67	Early	OT (cognitive and behavioural interventions, i.e. training Person with dementia to use aids)	<i>IADLs; Carer burden</i>	1
Graff <i>et al.</i> (2007)	Netherlands	1 m (10 sessions)	RCT	N <sub>I</sub> =68 & N <sub>C</sub> =67	Early	Occupational therapy sessions (10), including cognitive and behavioural interventions with problem solving, etc.	<i>Person with dementia QoL; Person with dementia mood; Carer burden; Carer mood</i>	1

Hinchliffe <i>et al.</i> (1995)	UK	4 m (6 -19 sessions)	RCT	N <sub>I</sub> =20 & N <sub>C</sub> =13	Early and Later	Medication, psychological measures, and social measures, such as daytime activities to reduce night-time disturbances	<i>Person with dementia behavior; Carer burden</i>	1
Huang <i>et al.</i> (2003)	Taiwan	0.5 m (2 sessions)	RCT	N <sub>I</sub> =24 & N <sub>C</sub> =24	Early and Later	Based on Progressively Lowered Threshold Model, reducing problem behaviour, vs educational information	<i>Person with dementia behavior</i>	1
Johnson <i>et al.</i> (2013)	US	Not specified	Q-Exp	N <sub>I</sub> =77 & N <sub>C</sub> =52	nk	Information, education, counselling	<i>Carer burden; Person with dementia behavior; Person with dementia mood; NH admission</i>	2
Mittelman <i>et al.</i> (2006)	US	max 216 m (6 sessions + support groups/ counselling)	RCT	N <sub>I</sub> =203 & N <sub>C</sub> =203	Early and Later	Counselling, support groups, ad hoc telephone counselling	<i>NH admission; Carer burden</i>	2
Newcomer <i>et al.</i> (1999)	US	36 m (not specified)	RCT	N <sub>I</sub> =2731 & N <sub>C</sub> =2576	Early and Later	Carer education, training, support groups, carer and client case management	<i>Carer burden; Carer mood</i>	1
O'Connor <i>et al.</i> (1991)	UK	24 m (not specified)	RCT	N <sub>I</sub> =86 & N <sub>C</sub> =73	Early and Later	Advice, family counselling, liaison, support groups, respite	<i>Time to NH admission</i>	2
Phung <i>et al.</i> (2013)	Denmark	8-12 m (17-20 sessions)	RCT	N <sub>I</sub> =163 & N <sub>C</sub> =167	Early	Counselling, information, support, telephone counselling, log books	<i>Cognition; Person with dementia QoL; Person with dementia mood &amp; Carer mood [only at 1 y, not at 2 y]</i>	2
Quayhagen <i>et al.</i> (2000)	UK	2 m (10 sessions)	RCT	N <sub>1</sub> =21, N <sub>2</sub> =29, N <sub>3</sub> =22, N <sub>4</sub> =16 & N <sub>C</sub> =15	Early	Cognitive stimulation; dyadic counselling; dual supportive seminars; early-stage day care	<i>Cognition [Cognitive stimulation]; Person with dementia behavior [Early-stage day care]; Carer mood [Cognitive stimulation]</i>	3
Riordan & Bennett (1998)	UK	12 m (Daily sessions)	Q-Exp	N <sub>I</sub> =19 & N <sub>C</sub> =19	Later	Practical and emotional help, information, advice	<i>Time to NH admission</i>	2
Rothera <i>et al.</i> (2008)	UK	Not specified	Qual	not specified, but for both intervention	Early and Later	Multiagency home support service	<i>Better quality care of service; time to NH admission</i>	high quality <sup>5</sup>

				service & standard service N=82				
Samus <i>et al.</i> (2014)	US	18 m (not specified)	RCT	N <sub>1</sub> =74 & N <sub>C</sub> =114	Early and Later	Care coordination; service referral; education; skill-building; care monitoring	<i>Time to NH admission; Person with dementia QoL</i>	1
Teri <i>et al.</i> (2003)	US	3 m (12 sessions + daily exercise)	RCT	N <sub>1</sub> =76 & N <sub>C</sub> =77	Early and Later	Exercise at home programme for Person with dementia and carer training in managing behavior	<i>Time to NH admission; Person with dementia mood</i>	2
Teri <i>et al.</i> (2005b)	US	6 m (8 sessions + 4 monthly follow-up calls)	RCT	N <sub>1</sub> =47 & N <sub>C</sub> =48	Later	Behaviour and mood management skills training (in home sessions and afterwards telephone calls) vs routine medical care	<i>Carer burden; Carer mood; Person with dementia behavior; Person with dementia QoL</i>	1
Tibaldi <i>et al.</i> (2004)	Italy	Not specified	RCT	N <sub>1</sub> =56 & N <sub>C</sub> =53	Later	Geriatric Home Hospitalization Service vs. General Medical Ward	<i>Person with dementia behavior; Carer burden</i>	3
Vickrey <i>et al.</i> (2006)	US	12 m (5 sessions)	RCT	N <sub>1</sub> =238 & N <sub>C</sub> =170	nk	Care management, in-home assessment, interactive seminars in care issues for carers	<i>Person with dementia QoL</i>	3

<sup>1</sup> Duration of intervention is the length of time over which the active intervention was conducted (m = months), not the length of the study evaluation period; <sup>2</sup> Frequency of intervention is the number of sessions/visits over this period; <sup>3</sup> Dementia stage: early stage = described as mild to moderate, mean MMSE reported of 26-16, mean GDR of >3<=5; later stage = described as moderate to severe, mean MMSE reported of 0-15, mean GDR of >5; <sup>4</sup> All outcomes highlighted in *italics* indicate significant improvements post intervention; <sup>5</sup> Quality ratings for qualitative studies based on the CASP assessment.

N<sub>1</sub>= Sample size for intervention group; N<sub>11</sub>= Sample size for intervention 1; N<sub>12</sub>= Sample size for intervention 2; N<sub>C</sub>= Sample size for control group; NH= Nursing home; nk=not known; Qual= Qualitative; Q-Exp= Quasi-Experimental; RCT = Randomised Controlled Trial

**Table 3** Review of home support interventions to people with dementia

Author	Country	Intervention intensity; Duration <sup>1</sup> (Frequency) <sup>2</sup>	Study design	Sample size	Dementia stage <sup>3</sup>	Intervention description	Outcomes <sup>4</sup>	Quality rating
Davis <i>et al.</i> (2001)	US	1 m (5 sessions + 6 home exercises weekly)	RCT	N <sub>I</sub> =19 & N <sub>C</sub> =18	Early	Testing recall, cognitive stimulation	Person with dementia QoL; Person with dementia mood; <i>Cognition</i>	1
Steinberg <i>et al.</i> (2009)	US	1.5-3 m (10 sessions)	RCT	N <sub>I</sub> =14 & N <sub>C</sub> =13	Early	Exercise programme vs home safety	Cognition; <i>ADLs</i> ; Person with dementia QoL; Person with dementia behavior; Person with dementia mood; Carer burden	1

<sup>1</sup> Duration of intervention is the length of time over which the active intervention was conducted (m = months), not the length of the study evaluation period; <sup>2</sup> Frequency of intervention is the number of sessions/visits over this period; <sup>3</sup> Dementia stage: early stage = described as mild to moderate, mean MMSE reported of 26-16, mean GDR of >3<=5; later stage = described as moderate to severe, mean MMSE reported of 0-15, mean GDR of >5; <sup>4</sup> All outcomes highlighted in *italics* indicate significant improvements post intervention.  
 N<sub>I</sub>= Sample size for intervention group; N<sub>I1</sub>= Sample size for intervention 1; N<sub>I2</sub>= Sample size for intervention 2; N<sub>C</sub>= Sample size for control group; NH= Nursing home; nk=not known; Qual= Qualitative; Q-Exp= Quasi-Experimental; RCT = Randomised Controlled Trial.

**Table 4** Synthesis of home support interventions

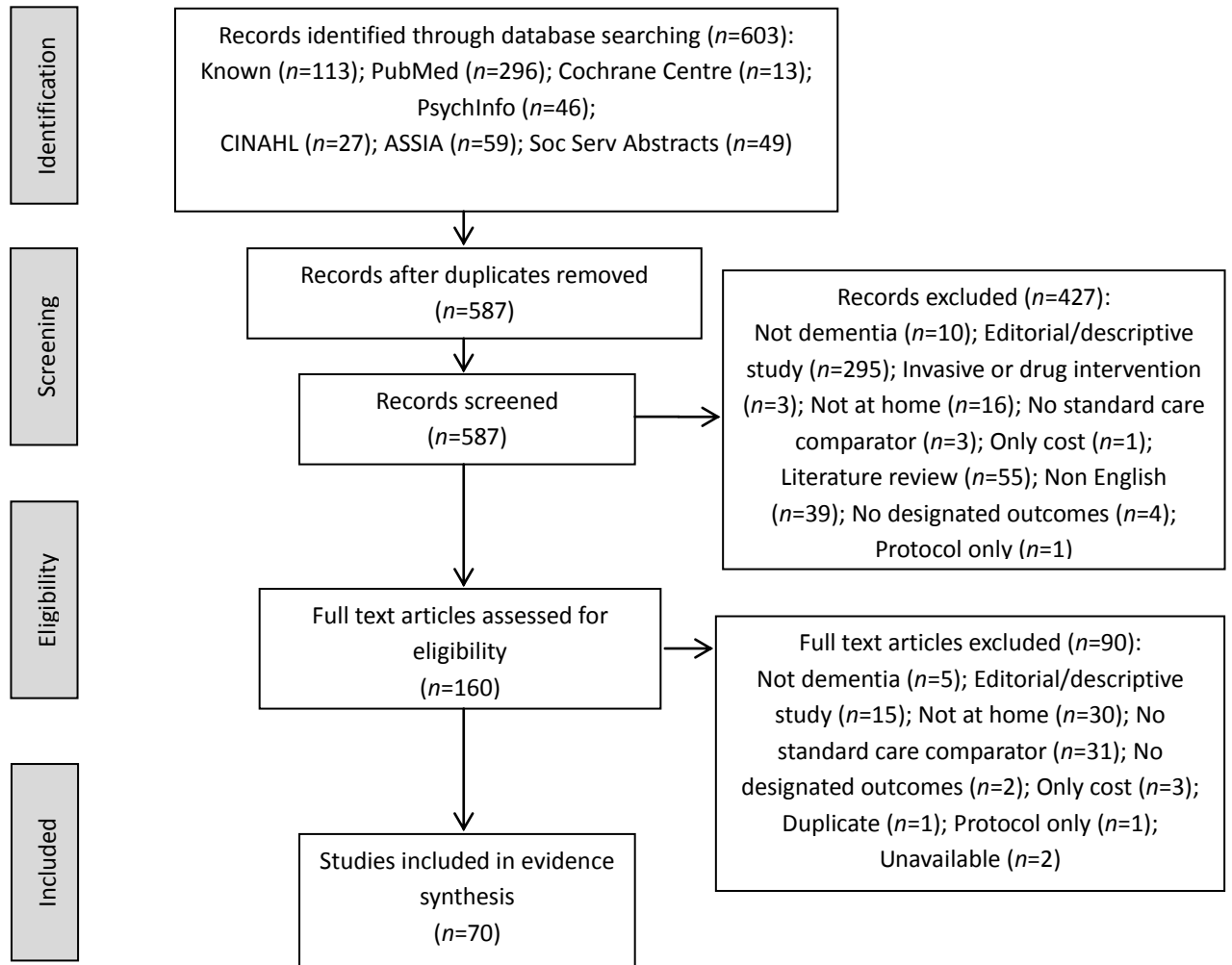
Home support intervention (single or multiple components)	Exemplar Intervention	Mechanisms/theory of change	Staff group	Outcomes	Effectiveness rating
Primarily to carers					
C1 – Behaviour management	Caregivers taught to identify and modify behavioural problems of their relatives through instruction on how to reduce occurrence of problems and teaching in skills to modify precipitants of distress (Teri <i>et al.</i> 2003)	CR	Nurse therapists; occupational therapists; physical therapists; psychologists; researcher	Physical health and functioning; affective symptoms/mood; behavioural problems, frequency of repetitive verbalization, ADLs (person with dementia);	2 – 5 (8 studies)

				caregiver's self-efficacy/perceived stress; QoL	
C2 – Education/ advice, emotional & social support	A support program, four hours a week over 10 months, offered opportunities for carers to express feelings and problems and provided practical support concerning feasible solutions to problems (Vernooij-Dassen <i>et al.</i> 2000)	IMB; SS/SNT; EOCS	case managers; home helps; specialist nurse	Carers' sense of competence/well-being; caregiver burden; admissions to care homes; behavioural problems, ADLs; dementia severity (person with dementia); caregiver neuroticism; social support/social network	1 – 4 (6 studies)
C3 - Education/ advice & behaviour management	Caregivers offered home contacts and one telephone contact and provided with skills to effectively manipulate the home environment to manage daily problems associated with dementia care (Gitlin <i>et al.</i> 2003)	IMB; CR; CEPF	Multi-purpose health workers; nurses; occupational therapists; psychologists; researcher; social workers	Caregiver objective and subjective burden; caregiver well-being and mood; care recipient problem behaviours and physical function; caregiver skills/efficacy	1 – 4 (11 studies)
C4 – Education/ advice, behaviour management & emotional support	Caregivers offered education about dementia, carers' stress, and sources of emotional support; understanding behaviours of the family member and behavioural management techniques; changing unhelpful thoughts; promoting acceptance; assertive communication; relaxation etc. Carers practised techniques at home, using a manual and relaxation CDs (Livingston <i>et al.</i> 2013)	IMB; CR; EOCS	community workers; home care nurses; psychiatrist; psychology graduates; social workers	Affective symptoms and behaviour (person with dementia); time at community tenure; depression and anxiety; quality of life of carer and care recipient; potentially abusive behaviour by carer towards care recipient; carer self-efficacy	1 – 4 (5 studies)
C5 – Education/ advice, behaviour management & social support	Education and support group for carers with home visits (Chien & Lee, 1998) or electronic versions providing individual and support group sessions to carers involving information, safety strategies	CR; IMB; SS/SNT	community nurses; psychiatrist; respite workers; social workers	Carer burden; carer mood; behaviour; NH admission; carer QoL	3 – 5 (5 studies)

	and social support (Finkel <i>et al.</i> 2007)				
C6 – Education/ advice, behaviour management, emotional support & social support	Telephone support groups (Winter & Gitlin, 2007) or face-to-face support groups with ad hoc telephone counselling (Mittelman <i>et al.</i> 2006)	CR; EOCS; IMB; SS/SNT	Counsellors	Carer mood; carer burden; Person with dementia mood; NH admission	1 – 3 (6 studies)
C7 – Education/ advice, behaviour management, emotional support, social support & respite	Providing information to reduce problem behaviours (such as increasing activity) and improving carer coping skills, whilst also providing options for respite (Hinchliffe <i>et al.</i> 1995)	CR; EOCS; HN; IMB; SS/SNT	Automated conversation system; counsellor; psychiatrist	Carer burden; behaviour; Person with dementia mood; ADLs	2 – 4 (3 studies)
Primarily to persons with dementia					
P1 – Environmental modifications	Carers and people with dementia received a home safety toolkit, containing simple home safety tips. Carers also received supportive phone calls (Horvarth <i>et al.</i> 2013).	CEPF	Occupational therapists	Carer burden, carer mood, carer QoL, IADLs/ADLs	2 – 3 (6 studies)
P2 – Care coordination	Providing a specialist geriatric team at home and directing to services, with flexible use targeted at the individual (Dias <i>et al.</i> 2008; Tibaldi <i>et al.</i> 2004)	CIC	Counsellors; geriatricians; nurses; occupational therapists; psychiatrists; physiotherapists; social workers;	Carer burden; behavior; NH admission; Carer QoL; Carer burden	1 – 5 (7 studies)

<sup>†</sup> Rated taking into account: statistically significant change, effect size and intervention intensity; effectiveness rating range = 1 – 5, see supplementary information, File S2.

CEPF = Competence-Environmental Press Framework; CIC = Continuity and Integration of Care; CR = Cognitive Restructuring; EOCS = Emotion Oriented Coping Strategies; HN = Hierarchy of Needs; IMB = Information-Motivation-Behavioural Skills model; SS/SNT = Social Support/Social Network Theory



**Figure 1** PRISMA flow diagram for included studies