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

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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

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Conflict of interest statement

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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
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 & Larner 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
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


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


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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.


### Table 1: Review of home support interventions to carers

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th><strong>Intervention intensity: Duration</strong>&lt;sup&gt;1&lt;/sup&gt; (Frequency)&lt;sup&gt;2&lt;/sup&gt;</th>
<th>Study design</th>
<th>Sample size</th>
<th>Dementia stage&lt;sup&gt;3&lt;/sup&gt;</th>
<th>Intervention description</th>
<th>Outcomes&lt;sup&gt;4&lt;/sup&gt;</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Belle <em>et al.</em> (2006)</td>
<td>US</td>
<td>6 m (12 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=261 &amp; N&lt;sub&gt;C&lt;/sub&gt;=257</td>
<td>Early and Later</td>
<td>Information, problem solving, telephone support, stress management techniques vs educational materials by post</td>
<td>Time to NH admission; Carer burden; Carer mood</td>
<td>2</td>
</tr>
<tr>
<td>Bourgeois <em>et al.</em> (1997)</td>
<td>UK</td>
<td>3 m (13 sessions)</td>
<td>Q-Exp</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=7 &amp; N&lt;sub&gt;C&lt;/sub&gt;=7</td>
<td>Later</td>
<td>Behaviour management intervention</td>
<td>PwD behavior</td>
<td>1</td>
</tr>
<tr>
<td>Bourgeois <em>et al.</em> (2002)</td>
<td>US</td>
<td>3 m (13 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=22, N&lt;sub&gt;C&lt;/sub&gt;=21 &amp; N&lt;sub&gt;C&lt;/sub&gt;=20</td>
<td>Later</td>
<td>Two skills training approaches (change patient behaviour; change own (carer) coping behaviour)</td>
<td>PwD behavior; Carer mood</td>
<td>1</td>
</tr>
<tr>
<td>Buckwalter <em>et al.</em> (1999)</td>
<td>US</td>
<td>6 m (13 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=132 &amp; N&lt;sub&gt;C&lt;/sub&gt;=108</td>
<td>nk</td>
<td>Teaching techniques to carers to reduce behavioural problems of PwD, i.e. environmental adaptations</td>
<td>Carer mood</td>
<td>2</td>
</tr>
<tr>
<td>Burgio <em>et al.</em> (2003)</td>
<td>US</td>
<td>12 m (16 sessions)&lt;sup&gt;6&lt;/sup&gt;</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=70 &amp; N&lt;sub&gt;C&lt;/sub&gt;=70</td>
<td>Early and Later</td>
<td>Information on behaviour management, problem solving skills, cognitive restructuring vs minimal support condition</td>
<td>Carer mood; Time to NH admission; PwD behavior</td>
<td>1</td>
</tr>
<tr>
<td>Colvez <em>et al.</em> (2002)</td>
<td>Europe</td>
<td>Not specified</td>
<td>Q-Exp</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=36, N&lt;sub&gt;I&lt;/sub&gt;=50, N&lt;sub&gt;I&lt;/sub&gt;=99, N&lt;sub&gt;I&lt;/sub&gt;=100 &amp; N&lt;sub&gt;I&lt;/sub&gt;=37</td>
<td>Early and Later</td>
<td>Home social services; day centres; expert centres; group-living; respite hospitalisation</td>
<td>Carer burden [for group living and home social services]</td>
<td>1</td>
</tr>
<tr>
<td>Drentea <em>et al.</em> (2006)</td>
<td>US</td>
<td>4 m (2 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=94 &amp; N&lt;sub&gt;C&lt;/sub&gt;=89</td>
<td>nk</td>
<td>Individual and family counselling, support group, ad hoc counselling</td>
<td>Social support</td>
<td>1</td>
</tr>
<tr>
<td>Eisdorfer <em>et al.</em> (2003)</td>
<td>US</td>
<td>12 m (26 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=54, N&lt;sub&gt;I&lt;/sub&gt;=59 &amp; N&lt;sub&gt;I&lt;/sub&gt;=41</td>
<td>Early and Later</td>
<td>Structural ecosystems therapy; structural ecosystems therapy + computer-telephone integrated system; minimal support control</td>
<td>Carer mood [for therapy + technology intervention]</td>
<td>1</td>
</tr>
<tr>
<td>Farran <em>et al.</em> (2007)</td>
<td>US</td>
<td>12 m (14 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=143 &amp; N&lt;sub&gt;C&lt;/sub&gt;=153</td>
<td>Early and Later</td>
<td>Caregiver Skill Building Programme (5 weekly group session &amp; 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</td>
<td>Carer burden [for CSB]</td>
<td>2</td>
</tr>
<tr>
<td>Finkel <em>et al.</em> (2007)</td>
<td>US</td>
<td>6 m (14 sessions)</td>
<td>RCT</td>
<td>N&lt;sub&gt;I&lt;/sub&gt;=23 &amp; N&lt;sub&gt;C&lt;/sub&gt;=23</td>
<td>Early and Later</td>
<td>Technology-based psychoeducational intervention by community-based social service agency (information, strategies for safety enhancement, social support)</td>
<td>Carer burden; Carer mood</td>
<td>1</td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Duration</td>
<td>Design</td>
<td>Sample Size</td>
<td>Intervention</td>
<td>Comparison</td>
<td>Measures</td>
<td>Ratings</td>
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<tr>
<td>Gallagher-Thompson et al. (2007)</td>
<td>US</td>
<td>4 m (7 sessions)</td>
<td>RCT</td>
<td>N_I=22 &amp; N_C=23</td>
<td>In-home behavioral management program (six modules: introduction, behaviour management, unhelpful thoughts, communication issues, end-of-life, pleasant events) vs. telephone-based comparison treatment</td>
<td>Carer burden; PwD mood</td>
<td>1</td>
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<tr>
<td>Gavrilo et al. (2009)</td>
<td>Russia</td>
<td>1 m (5 sessions)</td>
<td>RCT</td>
<td>N_I=25 &amp; N_C=28</td>
<td>Education about dementia and strategies for managing behaviour +usual medical care vs Usual medical care only (control)</td>
<td>Carer burden; PwD mood; PwD behavior; PwD QoL</td>
<td>1</td>
<td></td>
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<tr>
<td>Gitlin et al. (2003)</td>
<td>US</td>
<td>6 m (10 sessions)</td>
<td>RCT</td>
<td>N_I=89 &amp; N_C=109</td>
<td>[Home Environmental Skill-Building Programme] five home contacts and 1 telephone contact (by OT, focusing on education, problem-solving, training and adaptive equipment)</td>
<td>Carer burden; Carer QoL</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Guerra et al. (2010)</td>
<td>Peru</td>
<td>1 m (5 sessions)</td>
<td>RCT</td>
<td>N_I=29 &amp; N_C=29</td>
<td>5 weekly home sessions about assessment, education and behaviour management</td>
<td>Carer burden; Carer QoL; PwD QoL; PwD behavior</td>
<td>1</td>
<td></td>
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<tr>
<td>Horvath et al. (2013)</td>
<td>US</td>
<td>6 m (1 session)</td>
<td>RCT</td>
<td>N_I=60 &amp; N_C=48</td>
<td>Home Safety toolkit vs customary care</td>
<td>Carer burden</td>
<td>1</td>
<td></td>
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<tr>
<td>Kuo et al. (2013)</td>
<td>Taiwan</td>
<td>6 m (9 sessions)</td>
<td>RCT</td>
<td>N_I=83 &amp; N_C=66</td>
<td>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</td>
<td>Carer QoL; Carer mood</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Kwok et al. (2013)</td>
<td>China</td>
<td>3 m (12 sessions)</td>
<td>RCT</td>
<td>N_I=18 &amp; N_C=20</td>
<td>Telephone-based carer intervention (psychoeducation from social worker)</td>
<td>Carer burden</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Lawton et al. (1989)</td>
<td>US</td>
<td>12 m (Flexible)</td>
<td>RCT</td>
<td>N_I=317 &amp; N_C=315</td>
<td>Carer respite</td>
<td>Carer QoL; Carer burden; PwD mood; Time to NH admission</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Livingston et al. (2013)</td>
<td>UK</td>
<td>4 m (8 sessions)</td>
<td>RCT</td>
<td>N_I=173 &amp; N_C=87</td>
<td>Manual based coping strategies (psychoeducation about dementia, behaviour management, changing unhelpful thoughts, relaxation) vs treatment as usual</td>
<td>Carer mood; Carer burden; PwD QoL</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Study</td>
<td>Country</td>
<td>Duration/ Sessions</td>
<td>Study Design</td>
<td>N Int</td>
<td>N Control</td>
<td>Study Intervention</td>
<td>Outcomes</td>
<td>Outcome Measures</td>
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<tr>
<td>Mahoney et al. (2003)</td>
<td>US</td>
<td>12 m (52 sessions)</td>
<td>RCT</td>
<td>N=49</td>
<td>N=51</td>
<td>Integrated telephone network system support and weekly computer caregiver conversations (software)</td>
<td>Carer burden; PwD mood</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Mittelman et al. (1993)</td>
<td>US</td>
<td>4 m (6 sessions + support groups/ counselling)</td>
<td>RCT</td>
<td>N=103</td>
<td>N=103</td>
<td>Individual and family counselling, support groups, ad hoc consultation vs routine support</td>
<td>Time to NH admission</td>
<td>nk</td>
</tr>
<tr>
<td>Mittelman et al. (2004a)</td>
<td>US</td>
<td>4 m (6 sessions + support groups/ counselling)</td>
<td>RCT</td>
<td>N=203</td>
<td>N=203</td>
<td>Counselling, support groups</td>
<td>Carer mood</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Mittelman et al. (2004b)</td>
<td>US</td>
<td>4 m (6 sessions + support groups/ counselling)</td>
<td>RCT</td>
<td>N=203</td>
<td>N=203</td>
<td>Counselling, support groups</td>
<td>Carer burden</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Mohide (1990)</td>
<td>Canada</td>
<td>6 m (26 sessions)</td>
<td>RCT</td>
<td>N=30</td>
<td>N=30</td>
<td>Carer-focused health care, education, in-home respite, support group</td>
<td>Carer QoL; NH admission</td>
<td>Later</td>
</tr>
<tr>
<td>Moniz-Cook et al. (2008)</td>
<td>UK</td>
<td>1 m (4 sessions + flexible contact)</td>
<td>RCT</td>
<td>N=54</td>
<td>N=59</td>
<td>Psychosocial intervention on managing behaviour from trained (experimental) CMHN or usual care (control) CMHN</td>
<td>PwD behavior; Carer mood</td>
<td>nk</td>
</tr>
<tr>
<td>Sussman &amp; Regehr (2009)</td>
<td>Canada</td>
<td>Not specified</td>
<td>Q-Exp</td>
<td>N=85</td>
<td></td>
<td>Homemaking service vs adult day program services (respite) vs in-home professional support services</td>
<td>Carer burden [for day centres]</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Sutcliffe &amp; Larner (1988)</td>
<td>UK</td>
<td>4.5 m (6 sessions)</td>
<td>RCT</td>
<td>N=6</td>
<td>N=5</td>
<td>Emotional support; Information only</td>
<td>Carer burden[for emotional support]; Carer mood</td>
<td>nk</td>
</tr>
<tr>
<td>Torkomani et al. (2014)</td>
<td>UK, Spain, Greece</td>
<td>6 m (1 session + flexible)</td>
<td>RCT</td>
<td>N=30</td>
<td>N=30</td>
<td>Telemedicine system providing information/education, social networking, monitoring health, contact feature</td>
<td>Carer QoL; Carer burden; PwD behavior; Carer mood</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Vernooij-Dassen et al. (2000)</td>
<td>Netherlands</td>
<td>10 m (not specified)</td>
<td>RCT</td>
<td>N=73</td>
<td>N=63</td>
<td>Information about available support, offering listening, support positive contribution family makes to care (amongst others)</td>
<td>Family carer skills</td>
<td>Early and Later</td>
</tr>
<tr>
<td>Winter &amp; Gitlin (2006)</td>
<td>US</td>
<td>6 m (26 sessions)</td>
<td>RCT</td>
<td>N=58</td>
<td>N=45</td>
<td>Telephone support group (5 carers for an hour weekly)</td>
<td>Carer mood; Carer burden</td>
<td>Early and Later</td>
</tr>
<tr>
<td>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;</td>
<td>&quot;Frequency of intervention is the number of sessions/visits over this period;&quot; Dementia stage: early stage = described as mild to moderate, mean MMSE reported of 26-16, mean GDR of &gt;3&lt;=5; later stage = described as moderate to severe, mean MMSE reported of 0-15, mean GDR of &gt;5; All outcomes highlighted in <em>italics</em> indicate significant improvements post intervention; Study only reports 6-months outcomes; Quality ratings for qualitative studies based on the CASP assessment.</td>
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<tr>
<td>N&lt;sub&gt;I&lt;/sub&gt; = Sample size for intervention group; N&lt;sub&gt;I1&lt;/sub&gt; = Sample size for intervention 1; N&lt;sub&gt;I2&lt;/sub&gt; = Sample size for intervention 2; N&lt;sub&gt;C&lt;/sub&gt; = Sample size for control group; NH = Nursing home; nk = not known; Qual = Qualitative; Q-Exp = Quasi-Experimental; RCT = Randomised Controlled Trial</td>
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</tbody>
</table>
### Table 2: Review of home support interventions to carers and people with dementia

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Intervention intensity: Duration (^1) (Frequency) (^2)</th>
<th>Study design</th>
<th>Sample size</th>
<th>Dementia stage (^3)</th>
<th>Intervention description</th>
<th>Outcomes (^4)</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Askham &amp; Thompson (1990)</td>
<td>UK</td>
<td>12 m (flexible)</td>
<td>RCT</td>
<td>N(_I)=60 &amp; N(_C)=40 [at 6 months]; N(_I)=47 &amp; N(_C)=44 [at 12 months]</td>
<td>nk</td>
<td>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)</td>
<td>Time to NH admission</td>
<td>2</td>
</tr>
<tr>
<td>Burgener et al. (1998)</td>
<td>US</td>
<td>1 m (1 session)</td>
<td>RCT</td>
<td>N(_I)=11, N(_I)=12, N(_I)=12 &amp; N(_C)=12</td>
<td>Later</td>
<td>Education + behaviour intervention; education intervention; behaviour intervention</td>
<td>Person with dementia behavior [Intervention 1 and 2]; ADLs [Intervention 3]</td>
<td>1</td>
</tr>
<tr>
<td>Challis et al. (2009)</td>
<td>UK</td>
<td>12 m (not specified)</td>
<td>Q-Exp</td>
<td>N(_I)=43 &amp; N(_C)=43</td>
<td>Later</td>
<td>Case management</td>
<td>NH admission</td>
<td>2</td>
</tr>
<tr>
<td>Chang (1999)</td>
<td>US</td>
<td>2 m (not specified)</td>
<td>RCT</td>
<td>N(_I)=31 &amp; N(_C)=34</td>
<td>Early and Later</td>
<td>Cognitive-behavioural intervention</td>
<td></td>
<td>2</td>
</tr>
<tr>
<td>Chien &amp; Lee (2008)</td>
<td>China</td>
<td>6 m (12 sessions)</td>
<td>RCT</td>
<td>N(_I)=44 &amp; N(_C)=44</td>
<td>Early and Later</td>
<td>Education and support group + home visits by case managers for education and family health</td>
<td>Time to NH admission; Carer QoL; Carer burden</td>
<td>1</td>
</tr>
<tr>
<td>Chien &amp; Lee (2011)</td>
<td>China</td>
<td>6 m (14 sessions)</td>
<td>RCT</td>
<td>N(_I)=46 &amp; N(_C)=46</td>
<td>nk</td>
<td>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</td>
<td>Time to NH admission; Carer QoL</td>
<td>1</td>
</tr>
<tr>
<td>Chu et al. (2000)</td>
<td>Canada</td>
<td>18 m (Flexible)</td>
<td>RCT</td>
<td>N(_I)=37 &amp; N(_C)=38</td>
<td>Early</td>
<td>Early Home Care Programme (case management, OT, physical therapy, social work, respite, etc.) vs. information only</td>
<td>Time to NH admission; Carer burden</td>
<td>1</td>
</tr>
<tr>
<td>Dias et al. (2008)</td>
<td>India</td>
<td>6 m (13 sessions)</td>
<td>RCT</td>
<td>N(_I)=41 &amp; N(_C)=40</td>
<td>nk</td>
<td>Intervention (education about dementia and behaviour, support for carers, psychiatrist referrals, networking, advice) vs. waiting list (receiving intervention after 6 months)</td>
<td>Carer burden; Person with dementia behavior; ADLs</td>
<td>1</td>
</tr>
<tr>
<td>Eloniemi-Sulkava et al. (2001)</td>
<td>Finland</td>
<td>24 m (Flexible + 20 days training)</td>
<td>RCT</td>
<td>N(_I)=53 &amp; N(_C)=47</td>
<td>Early and Later</td>
<td>Dementia family care coordinator (advocacy, training, counselling, in-home visits, etc.) vs usual care</td>
<td>NH admission</td>
<td>1</td>
</tr>
<tr>
<td>Eloniemi-Sulkava et</td>
<td>Finland</td>
<td>24 m</td>
<td>RCT</td>
<td>N(_I)=63 &amp;</td>
<td>Early and</td>
<td>Home visits (initial support plan), geriatric</td>
<td>Time to NH admission</td>
<td>2</td>
</tr>
<tr>
<td>Study (Year)</td>
<td>Country</td>
<td>Duration</td>
<td>Randomization</td>
<td>N_I &amp; N_C</td>
<td>Intervention Details</td>
<td>Follow-up</td>
<td>Primary Outcomes</td>
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<tr>
<td>Engelhardt et al.</td>
<td>US</td>
<td>12 m</td>
<td>Qual</td>
<td>Total N=177</td>
<td>Caregiver Skill Building Programme</td>
<td>Early and Later</td>
<td>Career perceptions of Person with dementia behaviors, ADLs &amp; cognitive decline</td>
<td></td>
</tr>
<tr>
<td>Farran et al. (2003)</td>
<td>US</td>
<td>12 m</td>
<td>Qual</td>
<td>Total N=177</td>
<td>Caregiver Skill Building Programme</td>
<td>Early and Later</td>
<td>Carer burden</td>
<td></td>
</tr>
<tr>
<td>Gitlin et al. (2001)</td>
<td>US</td>
<td>3 m</td>
<td>RCT</td>
<td>N_I=93 &amp; N_C=78</td>
<td>Home environmental intervention (caregiver education about environmental impact on behaviour, breaking down tasks, involving other family members)</td>
<td>Early and Later</td>
<td>IADLs; ADLs; Person with dementia behavior; Carer burden</td>
<td></td>
</tr>
<tr>
<td>Gitlin et al. (2005)</td>
<td>US</td>
<td>6 m</td>
<td>RCT</td>
<td>N_I=65 &amp; N_C=65</td>
<td>Carer intervention for modifying home environment</td>
<td>Early and Later</td>
<td>Carer burden; ADLs</td>
<td></td>
</tr>
<tr>
<td>Gitlin et al. (2008)</td>
<td>US</td>
<td>4 m</td>
<td>RCT</td>
<td>N_I=30 &amp; N_C=30</td>
<td>Six home visits and two telephone chats with OT; training of different activities (not really IADLs)</td>
<td>Later</td>
<td>Person with dementia behavior; Person with dementia mood; Person with dementia QoL; Carer burden</td>
<td></td>
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<tr>
<td>Gitlin et al. (2010a)</td>
<td>US</td>
<td>4 m</td>
<td>RCT</td>
<td>N_I=102 &amp; N_C=107</td>
<td>12 home or telephone contacts (reducing environmental stressors and improving carer skills; education and carer training) vs 3 telephone calls and education</td>
<td>Later</td>
<td>IADLs; ADLs; Carer QoL; Person with dementia QoL</td>
<td></td>
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<tr>
<td>Gitlin et al. (2010b)</td>
<td>US</td>
<td>4 m</td>
<td>RCT</td>
<td>N_I=117 &amp; N_C=122</td>
<td>Problem behaviour management skills</td>
<td>Early and Later</td>
<td>Person with dementia behavior; Carer burden</td>
<td></td>
</tr>
<tr>
<td>Graff et al. (2006)</td>
<td>Netherlands</td>
<td>1 m</td>
<td>RCT</td>
<td>N_I=68 &amp; N_C=67</td>
<td>OT (cognitive and behavioural interventions, i.e. training Person with dementia to use aids)</td>
<td>Early</td>
<td>IADLs; Carer burden</td>
<td></td>
</tr>
<tr>
<td>Graff et al. (2007)</td>
<td>Netherlands</td>
<td>1 m</td>
<td>RCT</td>
<td>N_I=68 &amp; N_C=67</td>
<td>Occupational therapy sessions (10), including cognitive and behavioural interventions with problem solving, etc.</td>
<td>Early</td>
<td>Person with dementia QoL; Person with dementia QoL; Carer burden</td>
<td></td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th>Study</th>
<th>Country</th>
<th>Duration</th>
<th>Study Design</th>
<th>N_I &amp; N_C</th>
<th>Early/Late</th>
<th>Intervention Details</th>
<th>Outcome Measures</th>
<th>Notes</th>
</tr>
</thead>
<tbody>
<tr>
<td>Hinchliffe et al.</td>
<td>UK</td>
<td>4 m (6-19 sessions) RCT</td>
<td>N_I=20 &amp; N_C=13</td>
<td>Early and Later</td>
<td>Medication, psychological measures, and social measures, such as daytime activities to reduce night-time disturbances</td>
<td>Person with dementia behavior; Carer burden</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Huang et al. (2003)</td>
<td>Taiwan</td>
<td>0.5 m (2 sessions) RCT</td>
<td>N_I=24 &amp; N_C=24</td>
<td>Early and Later</td>
<td>Based on Progressively Lowered Threshold Model, reducing problem behaviour, vs educational information</td>
<td>Person with dementia behavior</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>Johnson et al. (2013)</td>
<td>US</td>
<td>Not specified Q-Exp</td>
<td>N_I=77 &amp; N_C=52</td>
<td>nk</td>
<td>Information, education, counselling</td>
<td>Carer burden; Person with dementia behavior; Person with dementia mood; NH admission</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Mittelman et al.</td>
<td>US</td>
<td>max 216 m (6 sessions + support groups/ counselling) RCT</td>
<td>N_I=203 &amp; N_C=203</td>
<td>Early and Later</td>
<td>Counselling, support groups, ad hoc telephone counselling</td>
<td>NH admission; Carer burden</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Newcomer et al. (1999)</td>
<td>US</td>
<td>36 m (not specified) RCT</td>
<td>N_I=2731 &amp; N_C=2576</td>
<td>Early and Later</td>
<td>Carer education, training, support groups, carer and client case management</td>
<td>Carer burden; Carer mood</td>
<td>1</td>
<td></td>
</tr>
<tr>
<td>O'Connor et al. (1991)</td>
<td>UK</td>
<td>24 m (not specified) RCT</td>
<td>N_I=86 &amp; N_C=73</td>
<td>Early and Later</td>
<td>Advice, family counselling, liaison, support groups, respite</td>
<td>Time to NH admission</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Phung et al. (2013)</td>
<td>Denmark</td>
<td>8-12 m (17-20 sessions) RCT</td>
<td>N_I=163 &amp; N_C=167</td>
<td>Early</td>
<td>Counselling, information, support, telephone counselling, log books</td>
<td>Cognition; Person with dementia QoL; Person with dementia mood &amp; Carer mood (only at 1 y, not at 2 y)</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Quayhagen et al. (2000)</td>
<td>UK</td>
<td>2 m (10 sessions) RCT</td>
<td>N_I=21, N_I2=29, N_I3=22, N_I4=16 &amp; N_C=15</td>
<td>Early</td>
<td>Cognitive stimulation; dyadic counselling; dual supportive seminars; early-stage day care</td>
<td>Cognition [Cognitive stimulation]; Person with dementia behavior [Early-stage day care], Carer mood [Cognitive stimulation]</td>
<td>3</td>
<td></td>
</tr>
<tr>
<td>Riordan &amp; Bennett (1998)</td>
<td>UK</td>
<td>12 m (Daily sessions) Q-Exp</td>
<td>N_I=19 &amp; N_C=19</td>
<td>Later</td>
<td>Practical and emotional help, information, advice</td>
<td>Time to NH admission</td>
<td>2</td>
<td></td>
</tr>
<tr>
<td>Rothera et al. (2008)</td>
<td>UK</td>
<td>Not specified Qual</td>
<td>not specified, but for both intervention</td>
<td>Early and Later</td>
<td>Multiagency home support service</td>
<td>Better quality care of service; time to NH admission</td>
<td>high quality²</td>
<td></td>
</tr>
<tr>
<td>Source</td>
<td>Location</td>
<td>Duration</td>
<td>Study Type</td>
<td>N_I</td>
<td>N_C</td>
<td>Time to NH admission</td>
<td>Person with dementia QoL</td>
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<tr>
<td>Samus et al. (2014)</td>
<td>US</td>
<td>18 m (not specified)</td>
<td>RCT</td>
<td>N_I = 74 &amp; N_C = 114</td>
<td>Early and Later</td>
<td>Care coordination; service referral; education; skill-building; care monitoring</td>
<td>Time to NH admission; Person with dementia QoL</td>
<td></td>
</tr>
<tr>
<td>Teri et al. (2003)</td>
<td>US</td>
<td>3 m (12 sessions + daily exercise)</td>
<td>RCT</td>
<td>N_I = 76 &amp; N_C = 77</td>
<td>Early and Later</td>
<td>Exercise at home programme for Person with dementia and carer training in managing behavior</td>
<td>Time to NH admission; Person with dementia mood</td>
<td></td>
</tr>
<tr>
<td>Teri et al. (2005b)</td>
<td>US</td>
<td>6 m (8 sessions + 4 monthly follow-up calls)</td>
<td>RCT</td>
<td>N_I = 47 &amp; N_C = 48</td>
<td>Later</td>
<td>Behaviour and mood management skills training (in home sessions and afterwards telephone calls) vs routine medical care</td>
<td>Carer burden; Person with dementia behavior; Person with dementia mood</td>
<td></td>
</tr>
<tr>
<td>Tibaldi et al. (2004)</td>
<td>Italy</td>
<td>Not specified</td>
<td>RCT</td>
<td>N_I = 56 &amp; N_C = 53</td>
<td>Later</td>
<td>Geriatric Home Hospitalization Service vs. General Medical Ward</td>
<td>Person with dementia behavior; Carer burden</td>
<td></td>
</tr>
<tr>
<td>Vickrey et al. (2006)</td>
<td>US</td>
<td>12 m (5 sessions)</td>
<td>RCT</td>
<td>N_I = 238 &amp; N_C = 170</td>
<td>nk</td>
<td>Care management, in-home assessment, interactive seminars in care issues for carers</td>
<td>Person with dementia QoL</td>
<td></td>
</tr>
</tbody>
</table>

1 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.  
2 Frequency of intervention is the number of sessions/visits over this period. 
3 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; 
4 All outcomes highlighted in *italics* indicate significant improvements post intervention; 
5 Quality ratings for qualitative studies based on the CASP assessment.

N_I = Sample size for intervention group; N_i = Sample size for intervention 1; N_a= Sample size for intervention 2; N_C = 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

<table>
<thead>
<tr>
<th>Author</th>
<th>Country</th>
<th>Intervention intensity: Duration (Frequency)</th>
<th>Study design</th>
<th>Sample size</th>
<th>Dementia stage</th>
<th>Intervention description</th>
<th>Outcomes*</th>
<th>Quality rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Davis et al. (2001)</td>
<td>US</td>
<td>1 m (5 sessions + 6 home exercises weekly)</td>
<td>RCT</td>
<td>N_I=19 &amp; N_C=18</td>
<td>Early</td>
<td>Testing recall, cognitive stimulation</td>
<td>Person with dementia QoL; Person with dementia mood; Cognition</td>
<td>1</td>
</tr>
<tr>
<td>Steinberg et al. (2009)</td>
<td>US</td>
<td>1.5-3 m (10 sessions)</td>
<td>RCT</td>
<td>N_I=14 &amp; N_C=13</td>
<td>Early</td>
<td>Exercise programme vs home safety</td>
<td>Cognition; ADLs; Person with dementia QoL; Person with dementia behavior; Person with dementia mood; Carer burden</td>
<td>1</td>
</tr>
</tbody>
</table>

1. 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;  
2. Frequency of intervention is the number of sessions/visits over this period;  
3. 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;  
4. All outcomes highlighted in italics indicate significant improvements post intervention.  

N_I= Sample size for intervention group; N_I1= Sample size for intervention 1; N_I2= Sample size for intervention 2; N_C= 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

<table>
<thead>
<tr>
<th>Home support intervention (single or multiple components)</th>
<th>Exemplar Intervention</th>
<th>Mechanisms/ theory of change</th>
<th>Staff group</th>
<th>Outcomes</th>
<th>Effectiveness rating</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primarily to carers</td>
<td>C1 – Behaviour management</td>
<td>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 et al. 2003)</td>
<td>CR</td>
<td>Nurse therapists; occupational therapists; physical therapists; psychologists; researcher</td>
<td>Physical health and functioning; affective symptoms/mood; behavioural problems, frequency of repetitive verbalization, ADLs (person with dementia);</td>
</tr>
</tbody>
</table>

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<table>
<thead>
<tr>
<th></th>
<th>Education/advise, emotional &amp; social support</th>
<th>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 et al. 2000)</th>
<th>IMB; SS/SNT; EOCS</th>
<th>case managers; home helps; specialist nurse</th>
<th>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</th>
<th>1–4 (6 studies)</th>
</tr>
</thead>
<tbody>
<tr>
<td>C2 – Education/ advice, emotional &amp; social support</td>
<td>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 et al. 2003)</td>
<td>IMB; CR; CEPF</td>
<td>Multi-purpose health workers; nurses; occupational therapists; psychologists; researcher; social workers</td>
<td>Caregiver objective and subjective burden; caregiver well-being and mood; care recipient problem behaviours and physical function; caregiver skills/efficacy</td>
<td>1–4 (11 studies)</td>
<td></td>
</tr>
<tr>
<td>C3 – Education/ advise &amp; behaviour management</td>
<td>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 et al. 2013)</td>
<td>IMB; CR; EOCS</td>
<td>Community workers; home care nurses; psychiatrist; psychology graduates; social workers</td>
<td>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</td>
<td>1–4 (5 studies)</td>
<td></td>
</tr>
<tr>
<td>C4 – Education/ advice, behaviour management &amp; emotional support</td>
<td>Education and support group for carers with home visits (Chien &amp; Lee, 1998) or electronic versions providing individual and support group sessions to carers involving information, safety strategies</td>
<td>CR; IMB; SS/SNT</td>
<td>Community nurses; psychiatrist; respite workers; social workers</td>
<td>Carer burden; carer mood; behaviour; NH admission; carer QoL</td>
<td>3–5 (5 studies)</td>
<td></td>
</tr>
<tr>
<td>C6 – Education/advice, behaviour management, emotional support &amp; social support</td>
<td>Telephone support groups (Winter &amp; Gitlin, 2007) or face-to-face support groups with ad hoc telephone counselling (Mittelmann et al. 2006)</td>
<td>CR; EOCS; IMB; SS/SNT</td>
<td>Counsellors</td>
<td>Carer mood; carer burden; Person with dementia mood; NH admission</td>
<td>1 – 3 (6 studies)</td>
<td></td>
</tr>
<tr>
<td>C7 – Education/advice, behaviour management, emotional support, social support &amp; respite</td>
<td>Providing information to reduce problem behaviours (such as increasing activity) and improving carer coping skills, whilst also providing options for respite (Hinchliffe et al. 1995)</td>
<td>CR; EOCS; HN; IMB; SS/SNT</td>
<td>Automated conversation system; counsellor; psychiatrist</td>
<td>Carer burden; behaviour; Person with dementia mood; ADLs</td>
<td>2 – 4 (3 studies)</td>
<td></td>
</tr>
</tbody>
</table>

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 et al. 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 et al. 2008; Tibaldi et al. 2004) | CIC | Counsellors; geriatricians; nurses; occupational therapists; psychiatrists; physiotherapists; social workers | Carer burden; behavior; NH admission; Carer QoL; Carer burden | 1 – 5 (7 studies) |

1 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; EOCR = Emotion Oriented Coping Strategies; HN = Hierarchy of Needs; IMB = Information-Motivation-Behavioural Skills model; SS/SNT = Social Support/Social Network Theory
Records identified through database searching (n=603): Known (n=113); PubMed (n=296); Cochrane Centre (n=13); PsychInfo (n=46); CINAHL (n=27); ASSIA (n=59); Soc Serv Abstracts (n=49)

Records after duplicates removed (n=587)

Records excluded (n=427):
- Not dementia (n=10);
- Editorial/descriptive study (n=295);
- Invasive or drug intervention (n=3);
- Not at home (n=16);
- No standard care comparator (n=3);
- Only cost (n=1);
- Literature review (n=55);
- Non English (n=39);
- No designated outcomes (n=4);
- Protocol only (n=1)

Records screened (n=587)

Full text articles assessed for eligibility (n=160)

Full text articles excluded (n=90):
- Not dementia (n=5);
- Editorial/descriptive study (n=15);
- Not at home (n=30);
- No standard care comparator (n=31);
- No designated outcomes (n=2);
- Only cost (n=3);
- Duplicate (n=1);
- Protocol only (n=1);
- Unavailable (n=2)

Studies included in evidence synthesis (n=70)

Figure 1 PRISMA flow diagram for included studies