

REVIEW

Psychosocial intervention for carers of people with dementia: What components are most effective and when? A systematic review of systematic reviews

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ABSTRACT

Background: Psychosocial interventions for carers of people with dementia are increasingly recognized as playing an important role in dementia care. We aim to systematically review the evidence from existing systematic reviews of psychosocial interventions for informal carers of people with dementia.

Methods: Thirty-one systematic reviews were identified; following quality appraisal, data from 13 reviews, rated as high or moderate quality, were extracted.

Results: Well-designed, clearly structured multi-component interventions can help maintain the psychological health of carers of people with dementia and delay institutionalization of the latter. To be most effective, such interventions should include both an educational and a therapeutic component; delivery through a support group format may further enhance their effectiveness.

Conclusions: Successful translation of evidence into practice in this area remains a challenge. Future research should focus on determining the most cost-effective means of delivering effective multi-component interventions in real-world settings; the cost-effective potential of technology-based interventions is considerable.

Key words: mental health, carers, dementia, psychosocial interventions

Introduction

The number of people diagnosed with dementia is increasing worldwide; it is predicted that by 2050, there will be 100 million people with dementia (World Health Organization, 2012). The vast majority of people living with dementia are supported, in their own homes, by family members. This has obvious implications for health and social services in terms of supporting not only the person with dementia (PwD) but also their informal/family carer. In England, it is estimated that there are

more than 500,000 family members caring for a PwD providing unpaid care estimated to be worth more than £6 billion a year (Department of Health, 2009). Caring for people with dementia can be challenging and undoubtedly has wide ranging implications on carers' psychological, physical, and financial well-being (Grasel, 2002; Brodaty *et al.*, 2003; Burns and Illiffe, 2009). Carers of people with dementia experience more burden than carers of other people with chronic illness (Draper *et al.*, 1992; Ory *et al.*, 1999). Informal carers play a crucial role helping people with dementia to live at home, usually their preferred place of care, thus avoiding expensive residential or nursing care. The need to support carers has been recognized nationally and internationally (Stoltz *et al.*, 2004; Prince *et al.*, 2011).

Psychosocial interventions are derived from wide-ranging theories and concepts and as such

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have disparate targets (Moniz-Cook *et al.*, 2008). A review of evidence-based psychological treatments for family carers of older people (Gallagher-Thompson and Coon, 2007) found the most common theoretical models used in the caregiving literature have been grounded in stress-coping perspectives (Lazarus and Folkman, 1984; Schulz and Martire, 2004) and cognitive and behavioral theoretical frameworks (Lewinsohn *et al.*, 1978; Beck *et al.*, 1979). There has been criticisms that interventions grounded in these frameworks have led to a dominance of negative outcome measures such as stress, depression, and burden. However, the last two decades have seen the introduction of the concept of positive aspects of caregiving (Grant and Nolan, 1993; Kramer, 1997). It has been suggested that psychosocial interventions should stress the positive aspects of caring and increase positive events in order to maintain and improve carers' involvement. As a result, outcome measures focusing on self-efficacy, satisfactions, and self-esteem have been incorporated into studies. However, the conceptual framework of positive aspects of caregiving in dementia also has limitations for example, it has been suggested it may lead to carers maintaining their caregiving role for longer than is desirable (Carbonneau *et al.*, 2010).

It is believed that there is now good evidence that psychosocial interventions for carers of people with dementia can reduce carers' psychological morbidity and delay relatives' entry into a formal care setting. Numerous psychosocial interventions that seek to support carers in their caring role have been developed, including peer support, befriending, cognitive behavioral therapy (CBT), and education and training (Hulstaert *et al.*, 2009). The range and types of interventions available and differences in their delivery methods, in addition to a wide range of possible outcome measures to evaluate their effectiveness, has produced a complex evidence base. Well-conducted systematic reviews have concluded that multi-component interventions are effective; however, despite numerous evidence syntheses, it is not clear which elements are important, and why. Clarity on these issues is needed in order to facilitate practical translation into real-world settings.

Systematic reviews of systematic reviews have been used to summarize and evaluate the literature on psychosocial interventions in a range of conditions such as cancer and heart disease (Rodgers *et al.*, 2005) and autism (Seida *et al.*, 2009) but, as yet, not for carers of people with dementia. Our aim was to systematically review evidence from existing systematic reviews and meta-analyses of psychosocial interventions directly

targeted at informal carers of people with dementia, in order to clarify the current evidence base, and determine which aspects are the most effective at maintaining carer health, and also identify priorities for future research.

Methods

Search strategy

The search strategy was developed by the information specialist (SR) in conjunction with the research team. Searches were conducted in a broad range of databases covering health and the social sciences: MEDLINE, CINAHL, EMBASE, PsycInfo, ASSIA: Applied Social Sciences Index and Abstracts, Scopus, Web of Science, Social Services Abstracts, Sociological Abstracts, SCIE: Social Care Online, Cochrane Database of Systematic Reviews, and DARE. Search terms were gathered into four facets: the disorder (dementia), the population (carers of people with dementia), non-pharmacological interventions, and health and well-being. Terms were coupled with relevant MeSH/thesaurus terms and were truncated as appropriate. Appropriate search filters were used to extract reviews and meta-analyses. Variant spellings (e.g. British vs. American English) of terms were also catered for. No time or language limits were set within the search strategy. A sample search strategy for MEDLINE is available (Supplementary Information 1).

Other sources of information were investigated using a hand search; including bibliographies of related review papers, reference lists of key papers, conference proceedings, and the output of key journals in the field (e.g. *Dementia*, *International Psychogeriatrics*, *Aging and Mental Health*, *Age and Ageing*, *International Journal of Geriatric Psychiatry*) as well as NICE/SCIE guideline and policy reports.

INCLUSION AND EXCLUSION CRITERIA

Study design. Systematic reviews and meta-analyses were included. The criteria for inclusion as a systematic review were: a statement of review, a documented search strategy of at least two databases with search terms stated, and stated inclusion/exclusion criteria. A broad approach was taken to ensure all relevant reviews were captured.

Participants. Participants had to be caregivers of people with dementia who lived in the community. The term caregiver was interpreted as family, informal, and unpaid carers of people with dementia.

Reviews that examined caregivers of multiple conditions were excluded unless they presented

their findings separately for carers of people with dementia. Reviews of carers of people with mild cognitive impairment were excluded.

Interventions. The intervention studied must have been directed at family and/or informal and unpaid caregivers of people with dementia and attempt to increase their knowledge (education), improve skills, and/or coping strategies and/or to provide support. Interventions could include CBT, psychotherapy, family therapy, counseling, anxiety/depression management, stress management, education or psychoeducation, health education, and social support among others.

Respite interventions and interventions which were formal approaches to care designed to support carers (e.g. care planning, care management, dementia nurse specialists) were excluded.

Outcomes. Reviews were included if they examined: (i) psychological outcomes such as depression or anxiety, (ii) healthcare usage, and (iii) quality of life.

Procedure

INITIAL ASSESSMENT

All titles and abstracts were independently assessed by two reviewers (CD and GG). Full paper copies of potentially relevant reviews were then obtained and assessed for inclusion by two reviewers independently. Disagreements regarding initial assessment were discussed and resolved with a third reviewer (LR).

DATA EXTRACTION AND SYNTHESIS

Data extraction was undertaken by two reviewers independently (CD and GG). A customized data extraction form was used to extract the following information: review authors, year, search strategy, inclusion/ exclusion criteria, methods, results, and conclusions/interpretations. The included reviews were combined in a narrative synthesis. Results were grouped, where possible, by type of intervention.

QUALITY ASSESSMENT

Two review authors (CD and LH) assessed the methodological quality of the included reviews independently using the “Assessment of Multiple Systematic Reviews” (AMSTAR) measurement tool (Shea *et al.*, 2009). The AMSTAR tool identifies 11 items which may affect quality. A score of 0–4 indicated low quality, 5–8 indicated moderate quality, and 9–11 indicated high quality. Disagreements were resolved by discussion or by the involvement of a third author (LR).

Results

A total of 954 references were identified from the main searches (Figure 1). On the basis of screening titles and abstracts, 144 papers were identified that met the criteria for full paper review. Two reviewers independently screened all 144 full publications. A total of 31 eligible reviews were identified as fitting the inclusion criteria of this review.

The AMSTAR tool was applied to all 31 reviews: two were rated as high quality, 11 were rated as moderate quality, and 18 were rated as low quality (Supplementary information 2). Only high- or moderate-quality reviews ($n = 13$) were included in the formal data analysis in order to ensure evidence of sufficient quality was used to inform practice (Table 1).

All reviews identified through the search were published after 2000 (Supplementary information 3). Interventions studied varied considerably and as such results are classified into six categories: psychosocial, therapeutic, multicomponent, information and support, educational/psychoeducational, and technology-based. These six categories were selected as they had been used in previous literature (Pinquart and Sorensen, 2006) and also comprehensively cover the range of interventions evaluated. Allocation to our categories in this review were determined by the terms used to describe the interventions by the original review authors. Notwithstanding categories frequently overlapped and where this occurred this is highlighted in the following narrative.

Reviews differed in the level of detail they provided about study participants. Generally, they reported the gender and mean age of carers, their relationship to the PwD and the length of time they had been providing care. Carers were usually female and aged over 55 years (although the range varied. Vernooji-Dassen *et al.* (2011) had the widest age range from 19 to 84 years). Reporting of the relationship of the carer to the PwD was often limited to spouse and adult child. Where reported carers were often predominantly spouses (Brodsky *et al.*, 2003; Pinquart and Sorensen, 2006; Parker *et al.*, 2008; Chien *et al.*, 2011), however, this did vary between studies with one review reporting that in five studies more than half of carers were spouses but in three studies less than half were caring for a spouse (Lins *et al.*, 2014). Four reviews (Pinquart and Sorensen, 2006; Parker *et al.*, 2008; Chien *et al.*, 2011; Lins *et al.*, 2014) reported on the length of time carers had provided care. This ranged from 20 months to 70 months. Few reviews reported details about the PwD who was the recipient of care. Chien *et al.* (2011) reported disease severity and found that one-third of included studies did

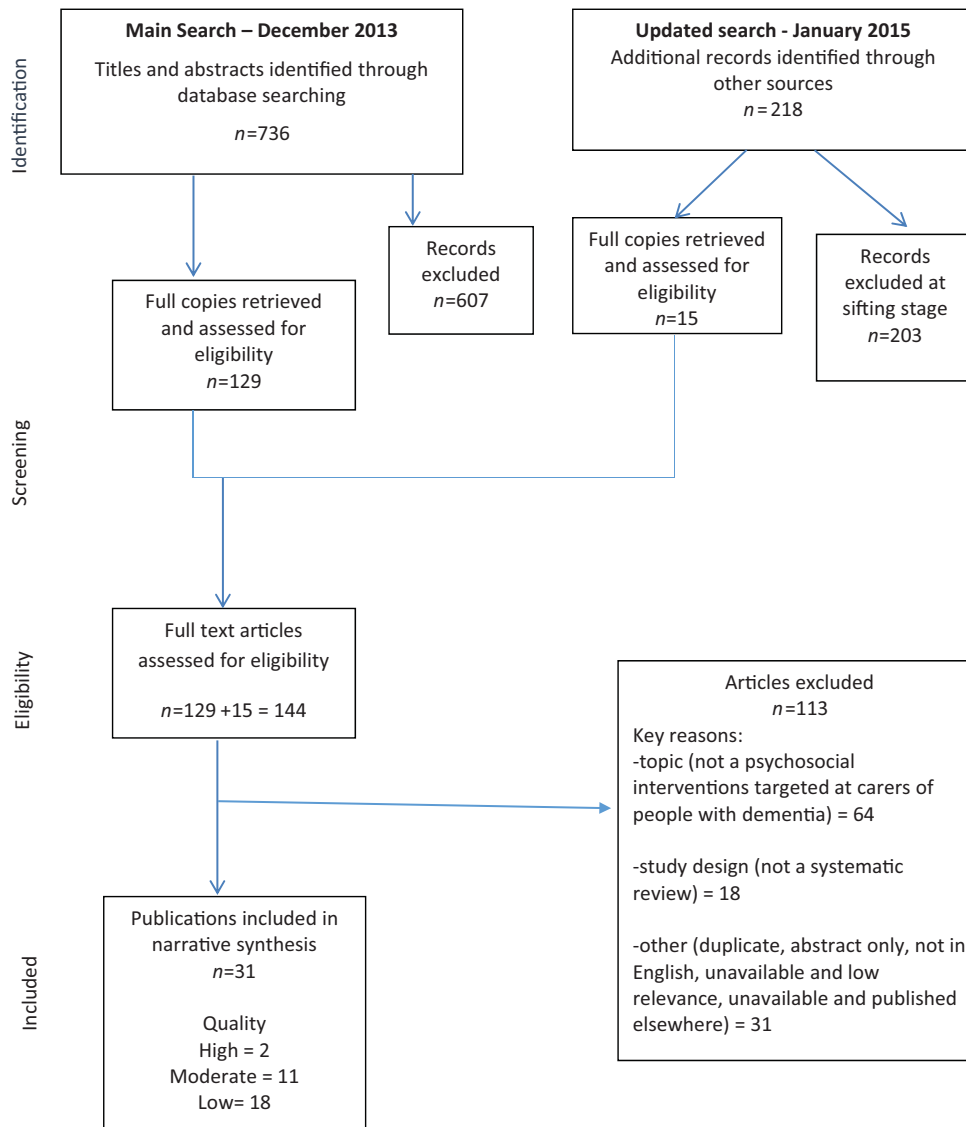


Figure 1. (Colour online) Flow chart showing the number of potentially relevant references identified by searches and number meeting inclusion criteria and included in the narrative review of systematic reviews.

not report this information. Of those studies that did 16.7% included people with mild dementia (MMSE 21–24) and 50% related to people with moderate dementia (MMSE 10–20).

Psychosocial interventions

NATURE OF THE INTERVENTION

This category was only used if it was used by the authors and when there was not enough detail to use a more specific category. Two of the included systematic reviews (Pusey and Richards, 2001; Brodaty *et al.*, 2003) used this broad umbrella term. One review (Brodaty *et al.*, 2003) did not explicitly define psychosocial interventions but employed a wide range of search terms: self-help groups, support groups, training, skills training, counseling,

psychotherapy. The second review (Pusey and Richards, 2001) defined psychosocial interventions as “interpersonal interventions concerned with the provision of information, education, or emotional support together with individual psychological interventions addressing a specific health and social care outcome.”

OUTCOME MEASURES

Brodaty *et al.* (2003) identified their primary outcome measure as psychological morbidity and burden. Secondary measures included: carers’ coping skills, social support, carers’ knowledge of Alzheimer’s disease, patient’s mood, and nursing home placement. Pusey and Richards (2001) did not identify a primary outcome measure but included outcomes of psychological health

Table 1. Summary of included reviews rated as high or moderate quality

LEAD AUTHOR (YEAR)	HOW STUDIES COMBINED	CATEGORIES OF INTERVENTIONS REPORTED					QUALITY	
		PSI ^a	TI	MCI	I & S	ED		TECH
1. Boots <i>et al.</i> , 2014	Narrative summary						✓	Moderate
2. Brodaty <i>et al.</i> , 2003	Meta-analysis	✓						Moderate
3. Chien <i>et al.</i> , 2011	Meta-analysis				✓			Moderate
4. Elvish <i>et al.</i> , 2013	Narrative summary		✓	✓		✓	✓	Moderate
5. Lins <i>et al.</i> , 2014	Meta-analysis and narrative summary						✓	High
6. Marim <i>et al.</i> , 2013	Meta-analysis					✓		Moderate
7. Olazaran <i>et al.</i> , 2010	Meta-analysis			✓		✓	✓	Moderate
8. Parker <i>et al.</i> , 2008	Meta-analysis and narrative summary			✓	✓	✓		Moderate
9. Peacock, 2003	Narrative summary		✓			✓	✓	Moderate
10. Pinquart and Sorensen, 2006	Meta-analysis		✓	✓	✓	✓		Moderate
11. Pusey and Richards, 2001	Narrative summary	✓					✓	Moderate
12. Thompson <i>et al.</i> , 2007	Meta-analysis				✓	✓	✓	Moderate
13. Vernooij-Dassen <i>et al.</i> , 2011	Meta-analysis		✓					High
		2	4	4	4	7	7	

^aPSI= psychosocial interventions, TI= therapeutic interventions, MCI= multicomponent interventions, I & S = information and support interventions, Ed= educational interventions (including psychoeducational), Tech= technology-based interventions.

(e.g. depression, guilt, anger, stress, and anxiety), physical health, and quality of life (including perception of burden).

KEY FINDINGS

Brodaty *et al.* (2003) included 30 studies ($n = 2,040$) in the analysis of psychosocial interventions. They reported significant benefits in caregiver psychological distress (22 trials; ES = 0.31; 95% CI: 0.13–0.50). No significant difference was shown in caregiver burden, with statistically significant small to moderate effect sizes shown for carer knowledge and patient mood. Pusey and Richards (2001) investigated the effect of psychosocial interventions by the method of delivery; individually based ($n = 9$) or group-based ($n = 14$). They concluded the evidence of the effectiveness of both group-based interventions and individually based was fairly weak due to inherent methodological weaknesses of the included studies.

Summary: The evidence for psychosocial interventions reported by these two reviews contrasted markedly. This is probably due to the wide variety of interventions included in the individual reviews.

Therapeutic interventions

NATURE OF THE INTERVENTIONS

This category was used for interventions that included counseling and psychotherapeutic interventions delivered in either an individual or

group format. Four reviews presented results from studies evaluating psychotherapeutic interventions for carers of people with dementia (Peacock and Forbes, 2003; Pinquart and Sorensen, 2006; Vernooij-Dassen *et al.*, 2011; Elvish *et al.*, 2013). One review was rated as high quality (Vernooij-Dassen *et al.*, 2011), the other three were of moderate quality. Elvish *et al.* (2013) and Peacock and Forbes (2003) used the categories of psychotherapy or psychotherapy/counseling to classify included studies. Pinquart and Sorensen (2006) focused on techniques based on CBT and Vernooij-Dassen *et al.* (2011) reported on cognitive reframing, a component of CBT.

OUTCOME MEASURES

Outcomes measures defined by review authors varied. Elvish *et al.* (2013) was the only systematic review which identified a primary outcome measure: psychosocial measures of carer well-being. The other three reviews included a wide range of measures. Vernooij-Dassen *et al.* (2011) included measures of psychological morbidity and distress (including depression and anxiety, quality of life, appraisal of role performance for carers) in addition to healthcare utilization for people with dementia (including admission to residential care, number of GP visits). Peacock and Forbes (2003) included measures of carer well-being along with measures of institutionalization and healthcare expenditure. Finally, Pinquart and Sorensen (2006) included

measures of burden, depression, subjective well-being, and ability/knowledge for carers in addition to symptoms of people with dementia and institutionalization.

KEY FINDINGS

In the only high-quality review, Vernooji-Dassen *et al.* (2011) pooled data from studies on cognitive reframing for carers. They found evidence of a beneficial effect of cognitive reframing on carers' psychological morbidity, specifically anxiety (standardized mean difference (SMD) -0.21 ; 95% confidence interval (CI) -0.39 to -0.04), depression (SMD -0.66 ; 95% CI -1.27 to -0.05), and subjective stress (SMD -0.23 ; 95% CI -0.43 to -0.04). However, no effects were found for appraisals of burden, reactions to relatives' behaviors, or institutionalization of the PwD. The authors concluded that cognitive reframing may be an effective component of individualized, multi-component interventions for carers. Pinguart and Sorensen (2006) pooled data from studies on CBT and found evidence it was associated with improvement in burden (nine studies; ES -0.36 , 95% CI: -0.73 , -0.01 , $p < 0.01$) and depression (11 studies; ES -0.70 , 95% CI: -1.10 , -0.30 , $p < 0.01$) but not with any other outcomes. They stated the lack of effects on subjective well-being and ability/knowledge should be interpreted with caution because only one and three studies, respectively, were available for these variables.

Peacock and Forbes (2003) identified two studies, both from the same intervention utilizing psychotherapy but reporting different outcomes. They reported evidence that the intervention delayed institutionalization of the PwD, even at follow-up 3.5 years later. Elvish *et al.* (2013) identified only one study which fitted their criteria for psychotherapy-counseling studies. This was a mixed methods study which reported clinicians' views of delivering a counseling intervention for older couples confronting Alzheimer's disease. Findings included a shift in participants' attitudes toward becoming more accepting and non-judgmental along with a more optimistic and collaborative view of the future. Elvish *et al.* (2013) concluded that results from this study were undermined by a lack of detail on data analysis.

Summary: There is evidence of a beneficial effect of cognitive reframing on carers' psychological well-being and for CBT in terms of improving depression and burden. Few studies were identified that investigated the effects of psychotherapy and/or counseling.

Information and support

NATURE OF THE INTERVENTIONS

This category included interventions that involved the provision of information to carers in a variety of formats and/or support interventions that provided opportunities to share personal feelings, overcome social isolation, and provide support for problems of caregiving. Four reviews, all rated as moderate quality, reported on information and support interventions (Pinguart and Sorensen, 2006; Thompson *et al.*, 2007; Parker *et al.*, 2008; Chien *et al.*, 2011). Three reviews (Pinguart and Sorensen, 2006; Parker *et al.*, 2008; Chien *et al.*, 2011) examined support only interventions. The definition of support groups used by Chien *et al.* (2011) included mutual support groups, educational psychology groups, and educational training groups but excluded groups organized on the internet, by telephone or in the community. Parker *et al.* (2008) defined support interventions as those that provide support for problems that inhibit caregiving and provide opportunities for sharing personal feelings and overcome social isolation. Pinguart and Sorensen (2006) used a similar definition of "general support." They specified that general support was less structured than psychoeducational and therapeutic interventions and again highlighted that the key to these interventions was to provide an opportunity to share feeling and which overcome social isolation. Thompson *et al.* (2007) aimed to review information and support interventions. They did not define either term, but their results are presented in terms of support and psychoeducational interventions (results for the psychoeducational interventions are presented in the psychoeducational section of this review).

OUTCOME MEASURES

The four reviews reported a range of outcome measures; none identified a primary outcome measure. Outcome measures for carers included depressive symptoms, subjective well-being, ability and knowledge, burden, and self-efficacy. Health service utilization of people with dementia was also included as an outcome measure. Thompson *et al.* (2007) was the only review to include economic outcomes.

KEY FINDINGS

All four reviews included meta-analyses. Chien *et al.* (2011) reported that support groups showed a significant positive effect on carers' psychological well-being (Hedge's $g = -0.44$, 95% CI = -0.73 , -0.15), depression (Hedge's $g = -0.40$, 95% CI = -0.72 , -0.08), burden (Hedge's $g = -0.23$, 95% CI = -0.33 , -0.13), and social outcomes (Hedge's

$g = -0.40$, 95% CI = $-0.09, 0.71$). They reported that the use of theoretical models, and the length and intensity of group sessions had a significant impact on effect sizes for carer psychological well-being and depression.

Parker *et al.* (2008) identified seven studies that evaluated support only interventions. Two studies were suitable for meta-analysis and demonstrated a small but significant improvement in carer burden (SMD -0.41 ; 95% CI $-0.80, -0.02$). Pinquart and Sorensen (2006) reported that supportive interventions improved subjective well-being, although this effect was based on only one study (one study; ES 2.03, 95% CI: 1.36, 2.70, $p < 0.001$). Thompson *et al.* (2007) reported a meta-analysis of two studies of support interventions (119 participants). This revealed no significant differences in carer burden between the intervention and control groups (effect estimate -0.40 , 95% CI -5.69 to 4.90).

Summary: The evidence for support interventions (no reviews actually reported on interventions providing information only) is mixed, with some positive evidence for improvements in carers' psychological well-being, depression, burden, and social outcomes. The mixed evidence of outcomes may be due to the variable nature of the support groups which may differ in their use of theoretical models and the length and intensity of group sessions.

Educational and psychoeducational interventions

NATURE OF THE INTERVENTION

This category included interventions that involved the structured presentation of information about dementia and caregiving issues. Seven reviews, all rated as moderate quality, reported on educational/ psychoeducational interventions (Peacock and Forbes, 2003; Pinquart and Sorensen, 2006; Thompson *et al.*, 2007; Parker *et al.*, 2008; Olazaran *et al.*, 2010; Elvish *et al.*, 2013; Marim *et al.*, 2013). Four reviews used the term "psychoeducational" to classify interventions. There was a consensus that such interventions aimed to increase knowledge of dementia and caregiving issues. Elvish *et al.* (2013) also included the aim of exploration of coping skills for managing emotional difficulties arising as a primary consequence of dementia. Parker *et al.* (2008) and Pinquart and Sorensen (2006) both specified that support may be part of psychoeducational interventions but that it was secondary to educational content. Pinquart and Sorensen (2006) also specified that psychoeducational interventions may include an active role by participants (e.g. role play).

Thompson *et al.* (2007) differentiated between psychoeducational interventions that were group-based and those that were individual-based. Marim *et al.* (2013) used the criterion that interventions provided interdisciplinary education and support for carers of people with dementia. Olazaran *et al.* (2010) included coping skills in individual or group sessions in their definition of carer education.

OUTCOME MEASURES

The seven reviews differed in the range of outcomes included. The review by Marim *et al.* (2013) focused on carer burden and only included studies which used the Zarit Burden Interview tool. Elvish *et al.* (2013) was the only review to identify a primary outcome measure. This was any measure of carer psychosocial well-being. The other five reviews were wider in focus and, in addition to including outcomes for carers, also included measures of health service utilization (Parker *et al.*, 2008), outcomes for people with dementia and cost-effectiveness (Olazaran *et al.*, 2010), symptoms of the PwD and rates of institutionalization (Pinquart and Sorensen, 2006), healthcare expenditure and rates of institutionalization (Peacock and Forbes, 2003) and outcomes for people with dementia, health service utilization and economic outcomes (Thompson *et al.*, 2007).

KEY FINDINGS

Four of the reviews reported meta-analyses (Pinquart and Sorensen, 2006; Thompson *et al.*, 2007; Parker *et al.*, 2008; Marim *et al.*, 2013). In the most recent meta-analysis of psychoeducational interventions, Marim *et al.* (2013) investigated the effectiveness of educational and support programs for carers on reducing carer burden. Seven RCTs were included but there was no overall statistically significant difference in the Zarit Burden interview (MD -1.79 ; 95% CI $-4.27, 0.69$). However, after sensitivity analysis was performed, which resulted in the exclusion of three clinically heterogeneous RCTs, there was a statistically significant decrease in Zarit score favoring the educational intervention group (four studies; MD -1.62 ; 95% CI $-2.16, -1.08$). The authors concluded that educational interventions can reduce carer burden in comparison to usual care.

Parker *et al.* (2008) reported a meta-analysis of eight studies of psychoeducational interventions. They found no significant impact of psychoeducational interventions on subjective well-being, self-efficacy, or carer health. However, they did find small but significant results for the impact of these interventions on carer depression (four

studies; WMD -1.93 ; 95% CI $-3.79, -0.07$) and burden (seven studies; SMD 0.02 ; 95% CI $-0.37, 0.42$). Thompson *et al.* (2007) pooled data from group-based psychoeducational interventions and reported a statistically significant effect in favor of the intervention (five studies; -0.71 , 95% CI -0.95 to -0.46). They found only group interventions underpinned by psychoeducational theoretical foundations had a positive impact on depression in carers (five studies; ES -0.71 ; 95% CI $-0.95, -0.46$). Pooled results for individual-based interventions of psychoeducational interventions showed no statistically significant difference between intervention and control groups for carer depression (seven studies; ES -0.21 ; 95% CI $-0.61, 0.20$) or self-efficacy (two studies; ES 0.37 ; 95% CI $-0.28, 1.02$).

Pinquart and Sorensen (2006) found evidence that psychoeducational interventions reduce carer burden (42 studies; ES 0.15 , 95% CI: $-0.25, -0.04$, $p < 0.01$) and depression (32 studies; ES -0.27 , 95% CI: $-0.41, p < 0.001$) and improve subjective well-being (13 studies; ES 0.24 , 95% CI: $0.04, 0.44$, $p < 0.05$), ability of knowledge (34 studies; ES 0.46 , 95% CI: $0.28, 0.64$, $p < 0.001$; significant heterogeneity, $p < 0.001$) and symptoms of the care receiver (33 studies; ES -0.17 , 95% CI: $-0.29, -0.04$, $p < 0.01$). However, they found no effect on institutionalization. They also compared educational interventions that consisted solely of information provision to interventions that included a more participatory role for carers (e.g. role playing). Only those interventions with a participatory element had a significant effect on burden, depression, subjective well-being, and symptoms of the care recipient; however, both intervention types were associated with an increase in carer knowledge. Olazaran *et al.* (2010) found that carer education for coping skills in individual sessions was of particular success when delivered to carers displaying psychological morbidity or when an emotion-oriented approach was used.

Elvish *et al.* (2013) found that seven out of eight studies of psychoeducational interventions reported significant results, demonstrating impact on carer depression, emotional well-being, quality of life, attitudes toward caregiving, and anxiety. They found that the majority of interventions in this category drew on cognitive-behavioral theory and principles and also theoretical models of stress and coping. Peacock and Forbes (2003) identified four studies utilizing an educational intervention which were rated as strong. They concluded that the results suggest that educational interventions are insufficient to improve overall carer psychological well-being, such as decreasing strain and depression or reducing disruptive behaviors by the care recipient.

Summary: Results from systematic reviews of psychoeducational interventions were mixed; however, there appear to be certain key components which increase the effectiveness of such interventions: an underpinning theoretical foundation, group delivery as opposed to individual sessions and carers having a participatory role during the intervention.

Multi-component interventions

NATURE OF THE INTERVENTION

This category included interventions that combined two or more conceptually different approaches into one program. Four reviews, all rated as moderate quality, reviewed multi-component interventions (Pinquart and Sorensen, 2006; Parker *et al.*, 2008; Olazaran *et al.*, 2010; Elvish *et al.*, 2013).

OUTCOME MEASURES

A range of outcome measures were reported. Only one systematic review, Elvish *et al.* (2013), stated a primary outcome measure (psychosocial measure of carer well-being). Olazaran *et al.* (2010) included outcomes for carers, people with dementia, and also cost effectiveness. Parker *et al.* (2008) included outcomes for carers and health service utilization, and Pinquart and Sorensen (2006) included outcomes related to carers, symptoms of people with dementia, and institutionalization.

KEY FINDINGS

Elvish *et al.* (2013) identified six quantitative and one qualitative study. All six quantitative studies reported significant positive results for outcome measures predominantly focused on depression and social support for carers. Olazaran *et al.* (2010) reported evidence from the pooling of three RCTs testing multi-component interventions for carers, that these interventions are associated with a delay in the institutionalization of people with mild to moderately severe Alzheimer's disease. The essential components of these interventions were individual assessment, information, counseling, and support. After 6 or 12 months of intervention, the overall institutionalization rate was 10.6% in the intervention groups versus 14.9% in the control groups (OR 0.67 , 95% CI $0.49-0.92$). They also found evidence that multi-component interventions improved caregiver mood. Parker *et al.* (2008) identified 12 studies reporting multicomponent interventions; 10 of the 12 reported significant outcomes across a broad range of outcome measures but none of the studies were suitable for meta-analysis. They concluded that there was evidence to suggest well-designed

multi-component interventions may assist carers. Pinquart and Sorensen (2006) found no effect of multi-component interventions on most of the outcomes, but they were significantly related to delayed institutionalization (15 studies; OR 0.65, 95% CI; 0.44, 0.98); however, the positive effects were seen only with highly structured multi-component interventions and not with less structured ones.

Summary: Evidence from multi-component interventions highlight the need to be clear about the content and delivery of interventions. There is evidence to suggest that well-designed and clearly structured multi-component interventions can delay entry into residential or nursing care for people with dementia and improve carer mood.

Technology-based interventions

NATURE OF THE INTERVENTION

This category included interventions delivered via telephone, computer, or another form of technology. Seven reviews reported on studies of technology-based interventions; six were of moderate quality (Pusey and Richards, 2001; Peacock and Forbes, 2003; Thompson *et al.*, 2007; Olazaran *et al.*, 2010; Elvish *et al.*, 2013; Boots *et al.*, 2014) and one was high quality (Lins *et al.*, 2014). Reviews varied considerably in the degree of definition of the intervention; two reviews did not specify any definition (Pusey and Richards, 2001; Peacock and Forbes, 2003). Two reviews included both computer and telephone-based systems which provided information and support (Thompson *et al.*, 2007; Olazaran *et al.*, 2010); one review focused only on interventions delivered over the internet (Boots *et al.*, 2014).

OUTCOME MEASURES

Of the seven reviews, only two (Elvish *et al.*, 2013; Lins *et al.*, 2014) stated a primary outcome measure, which were carer well-being and depressive symptoms, respectively. Lins *et al.* (2014) also identified secondary outcome measures for their evaluation of efficacy; these included carer outcomes (burden, distress, anxiety, quality of life, self-efficacy, and satisfaction) and outcomes for people with dementia outcomes (institutionalization, mood, quality of life). For their evaluation of experience, they included all experiences regarding the intervention of interest. All reviews that pre-defined outcomes for inclusion specified outcome measures of psychosocial well-being for carers. In addition, Olazaran *et al.* (2010) included outcomes for people with dementia and cost effectiveness. Peacock included institutionalization and healthcare expenditure and Thompson included

outcomes for people with dementia, healthcare utilization, and economic outcomes.

KEY FINDINGS

Three of the seven reviews reported meta-analyses of technology-based interventions (Thompson *et al.*, 2007; Olazaran *et al.*, 2010; Lins *et al.*, 2014). The one high-quality review assessed the efficacy and experiences of telephone counseling for carers of PWD (Lins *et al.*, 2014) and identified nine RCTs. Meta-analyses indicated a reduction of depressive symptoms from telephone counseling without additional intervention (three trials, 163 participants: SMD 0.32, 95% CI 0.01 to 0.63, *p* value 0.04). There were no clear positive effects for other outcomes (burden, distress, anxiety, quality of life, self-efficacy, satisfaction, and social support).

Olazaran *et al.* (2010) found evidence that carer mood improved after 6–12 months of use of the electronic devices (four studies; ES 0.196; 95% CI –0.004, 0.395). Thompson *et al.* (2007) classified four studies as technology-based interventions (three of the studies were also identified by Olazaran *et al.* (2010)). They reported a meta-analysis of three trials (229 participants) and found a positive effect size of 0.62 but was not statistically significance (95% CI –1.98 to 3.22). One of the most recent reviews in this category (Boots *et al.*, 2014) (including 12 studies of internet-based supportive interventions) reported evidence for some carer outcomes (confidence, depression, and self-efficacy) but concluded the evidence was of low quality due to variations in intervention type, dosage, and duration and methodological quality of the included studies. A review of studies that used either computer-assisted screen telephones or ordinary telephones (Elvish *et al.*, 2013) found all five quantitative studies (reported a significant positive impact on depression, burden, and social support).

Summary: Interventions delivered via technology were diverse, with components including counseling and information and support; methods of delivery included the telephone and computers, with sessions targeted at individuals or groups. At present, there is evidence to suggest that telephone counseling can be effective at reducing depressive symptoms in carers and internet-based supportive interventions may improve some outcomes for carers. Findings should be interpreted with caution as the methodological quality of included studies was often poor.

Discussion

Maintaining the health of informal carers of people with dementia, so they can continue to

care for their loved ones and thus prevent or delay institutionalization, has high economic and social significance (Kinosian *et al.*, 2000; Prince *et al.*, 2013). In the literature, multi-component interventions are consistently reported as the most effective for maintaining carer health (Prince *et al.*, 2011); however, the most effective combination of individual components which should be delivered in practice is yet to be determined. This review has shown that despite an increasing volume of both primary research and systematic reviews in this field, this remains a very complex area for service providers to translate into real-world settings. Our findings reveal the most effective interventions to maintain the psychological health of carers should incorporate both an educational component, focused on enhancing carers' knowledge of dementia and the caring role, and a therapeutic component, for example, CBT/cognitive reframing. The effectiveness of such interventions can be further increased if delivered in a support group format rather than as individual therapy. Incorporating a technological component, via ongoing telephone/online support, could potentially be more cost-effective. There is good evidence that multi-component interventions for carers also benefit the PwD through delaying entry in to nursing or residential care.

Strengths and limitations

The key strength of this systematic review of systematic reviews is that it included only reviews graded as high or moderate quality; thus, providing a comprehensive summary of "best evidence," in an area in which there has been considerable empirical research, in order to inform clinical practice; notwithstanding a large number of reviews were considered of insufficient quality to include. There are however limitations to our systematic review of systematic reviews. The included reviews varied considerably in their scope and inclusion criteria. This together with the frequent absence of a primary outcome measure and a broad range of other outcomes used to measure carer psychological health, influence the wider generalizability of our findings. In addition, the individual studies included in the systematic reviews often lacked essential detail about the nature and composition of the interventions. This caused considerable difficulty in categorizing interventions and influenced our subsequent analysis. The period of time between original publication of the empirical research to inclusion and publication in a systematic review can be lengthy. This is problematic in a rapidly changing field such as technology-based interventions.

A further limitation of this review is the extent that it can shed light on the mechanisms by which psychosocial interventions work for carers of people with dementia. The majority of the included 13 reviews had little to say on such mechanisms. However, there were two notable exceptions (Vernooij-Dassen *et al.*, 2011; Elvish *et al.*, 2013). Vernooij-Dassen *et al.* (2011) clearly reviewed the literature on one element within psychosocial interventions, cognitive reframing, and set out a hypothesis on how it may work. They found evidence that cognitive reframing can be an effective underlying mechanism for reducing carers' psychological morbidity and stress. They hypothesize that cognitive reframing operates primarily through carers' attributions about personal strength and resilience and recommend that this hypothesis is empirically tested. Elvish *et al.* (2013) found that interventions underpinned by cognitive/cognitive-behavioral models can produce meaningful change but acknowledged that it is difficult to draw conclusions about the use of other theoretical standpoints due to their relative scarcity. Furthermore, in a report of the same systematic review, Elvish and colleagues suggest social support as a key mechanism to change. They proposed a model, based on three studies, whereby psychosocial interventions may help carers to build and validate new friendships and lead to improved satisfaction with support resulting in a reduction in depression and stress appraisals (Elvish *et al.*, 2012).

The included reviews also varied in the details that they explored the characteristics of participants. The needs of carers are likely to be influenced by socio-demographic factors, their relationship to the PwD and the stage of dementia. Without clearer reporting of the details of participants (both carers and people with dementia), it will not be possible to target interventions in a timely manner to those who may benefit most. This is especially important given that it was rare for studies to follow-up participants beyond 6 months. Longer follow-up periods are needed to address the changing needs and responses to interventions of carers in relation to their stage in the caregiving trajectory (Thompson *et al.*, 2007).

Implications for future research and practice

The number of people with dementia is predicted to almost double in the next 15 years and the majority will remain at home cared for by family and friends. There is thus a considerable need, and some urgency, to implement acceptable and cost effective interventions to support family carers and

maintain their health in real-world settings (World Health Organization and Alzheimer's Disease International, 2012). The number of high-quality trials evaluating a multi-component intervention for family carers of people with dementia continues to increase (Livingston *et al.*, 2014; Blom *et al.*, 2015) and it is interesting to compare our findings with the results of these recent trials in terms of the composition and delivery of the intervention being evaluated. In one RCT, where the intervention group showed significantly lower depressive symptoms and anxiety (Blom *et al.*, 2015), the internet delivered intervention, *Mastery over Dementia*, developed from the results of systematic reviews (Pinquart and Sorensen, 2006) and with active carer participation via activities, comprised the key components we found most effective: education (on dementia and carer coping skills); CBT (cognitive reframing), and guidance on increasing social support (Blom *et al.*, 2015). In contrast, a RCT of a multi-component dyadic intervention (education, exercise, and social activities) delivered by home visits but lacking the psychological component of cognitive reframing, revealed no significant benefits in any of the carer outcomes (Prick *et al.*, 2015). The authors suggest that a wider choice of instruments beyond measuring carers' psychological distress may improve our understanding of the effects of interventions. They recommend future research includes measures on positive outcomes, such as pleasure, quality of relationship, self-management, and resilience.

Livingston *et al.* (2014) present evidence of the effectiveness of an eight session manual-based coping intervention delivered by psychology graduates. The intervention group showed positive effects on carer mood and anxiety levels for two years. An accompanying qualitative investigation (Sommerlad *et al.*, 2014) highlighted different components of the intervention that carers identified as important. These included relaxation techniques, education about dementia, strategies to help manage behavior, and changing unhelpful thoughts. The authors identify the flexibility of the intervention and the diversity of the strategies as a benefit that enabled the intervention to suit different circumstances of carers. This flexibility may be necessary to adapt to carers' changing needs as they care for someone with a progressive condition.

It would appear that multi-component interventions have considerable potential to improve the health of carers of people with dementia and also lead to benefits in costs of dementia care. However, future studies should consider the adoption of an appropriate taxonomy to categorize and describe in detail the nature and composition

of such complex interventions and characteristics of participants in order that accurate comparisons can be drawn across studies. In addition, it is essential in the context of the rising costs of dementia care, to establish whether simpler interventions, with fewer components, are more cost effective than more complex ones; such studies would need to include longer term follow-up, to the point of institutionalization, and a nested health economic analysis. Although internet delivered approaches will not suit all carers (most research to date only included those under 65 years (Choi and Dinitto, 2013)), the cost effectiveness potential of e-based interventions is considerable and there is certainly a need for greater research in this area (Knapp *et al.*, 2013a) and of other low-cost approaches to delivery (for example, interventions delivered by graduates rather than qualified clinical psychologists (Knapp *et al.*, 2013b)). A better understanding of how to successfully translate effective interventions from research settings into real-world practice is needed. Future trials should incorporate a nested process evaluation to identify factors which facilitate integration into routine care. Finally, research is needed to explore which interventions work best for which subgroups of carers, at different stages of the trajectory of caring for a PwD.

Conclusions

This paper illuminates the evidence-base of psychosocial interventions for carers of people with dementia. While effectiveness is important, it is also pertinent to consider how realistic or practical interventions are and the experiences of those who take part.

Conflict of interest

This paper presents independent research funded by the National Institute for Health Research (NIHR). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health. Louise Robinson is funded by a National Institute for Health Research Research Professorship (NIHR-RP-011-043).

Description of the authors' roles

L. Robinson was principal investigator for the study. Authors C. Dickinson, J. Dow, G. Gibson, S. Robalino, and L. Robinson designed the study and developed the search protocol. C. Dickinson,

G. Gibson, and L. Hayes were the principal reviewers carrying out screening, selection, and data extraction, with assistance from L. Robinson. All authors contributed to the interpretation of results, writing of the paper, and have seen and approved the final paper.

Supplementary Material

To view supplementary material for this paper, please visit <http://dx.doi.org/10.1017/S1041610216001447>.

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