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

Authors

Claire Dickinson¹, Johanne Dow¹, Grant Gibson², Louise Hayes³, Shannon Robalino³, Louise Robinson¹
(corresponding author)

1. Institute of Health and Society, Newcastle University, Newcastle Biomedical Research Building, Campus for Ageing and Vitality, Newcastle upon Tyne, NE4 5PL, United Kingdom.
2. Colin Bell Building, University of Stirling, Stirling, FK9 4LA, United Kingdom.
3. Institute of Health and Society, Newcastle University, Baddiley-Clark Building, Newcastle upon Tyne, NE2 4AX, United Kingdom.

Dr Claire Dickinson, Research Associate; Dr Johanne Dow, Academic GP Trainee; Grant Gibson, Lecturer in Dementia Studies; Louise Hayes, Research Associate; Shannon Robalino, Information Specialist; Louise Robinson, Professor of Primary Care and Ageing.

Corresponding author:

Louise Robinson: Newcastle University Institute for Ageing and Institute for Health & Society, Newcastle University, Newcastle Biomedical Research Building, Campus for Ageing and Vitality Newcastle upon Tyne, NE4 5PL, United Kingdom.

Email: a.l.robinson@ncl.ac.uk; Telephone: +440191 208 7013; Fax: +44 (0) 191 208 1101

Abstract

Background: Psychosocial interventions for carers of people with dementia are increasingly recognised 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.

Design: 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 multicomponent interventions can help maintain the psychological health of carers of people with dementia and delay institutionalisation 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.

Keywords: mental health, carers, dementia, psychosocial interventions

Running title

Psychosocial interventions for dementia caregivers

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 Organisation, 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 but also their informal/ family carer. In England it is estimated that there are more than 500,000 family members caring for a person with dementia (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 (Brodaty *et al.*, 2003; Burns and Illiffe, 2009; Grasel, 2002). 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 recognised nationally and internationally (Prince *et al.*, 2011; Stoltz *et al.*, 2004).

Psychosocial interventions are derived from wide-ranging theories and concepts and as such have disparate targets (Moniz-Cook *et al.*, 2008). In the past there has been criticism that interventions have conceptualised the carer role from a stress-coping perspective and this has 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 increasing 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 behavioural therapy 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 multicomponent 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 summarise 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 versus 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 cognitive behavioural therapy (CBT), psychotherapy, family therapy, counselling, anxiety/depression management, stress management, education or psychoeducation, health education and social support amongst 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 customised 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: 2 were rated as high quality, 11 were rated as moderate quality and 18 were rated as low quality. 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. The 18 systematic reviews rated as low quality are listed in supplementary appendix 1.

All reviews identified through the search were published after 2000. 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 person with dementia 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 had the widest age range from 19 to 84 years).

Reporting of the relationship of the carer to the person with dementia was often limited to spouse and adult child. Four studies reported on the length of time carers had provided care. This ranged from 20 months to 70 months. Few reviews reported details about the person with dementia who was the recipient of care. Chien et al reported disease severity and found that 33.3% included studies did not report this information. Of those studies that did 16.7% scored included people with mild dementia (MMSE 21-24) and 50% related to people with moderate dementia (MMSE 10-20).

Figure 1. 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.

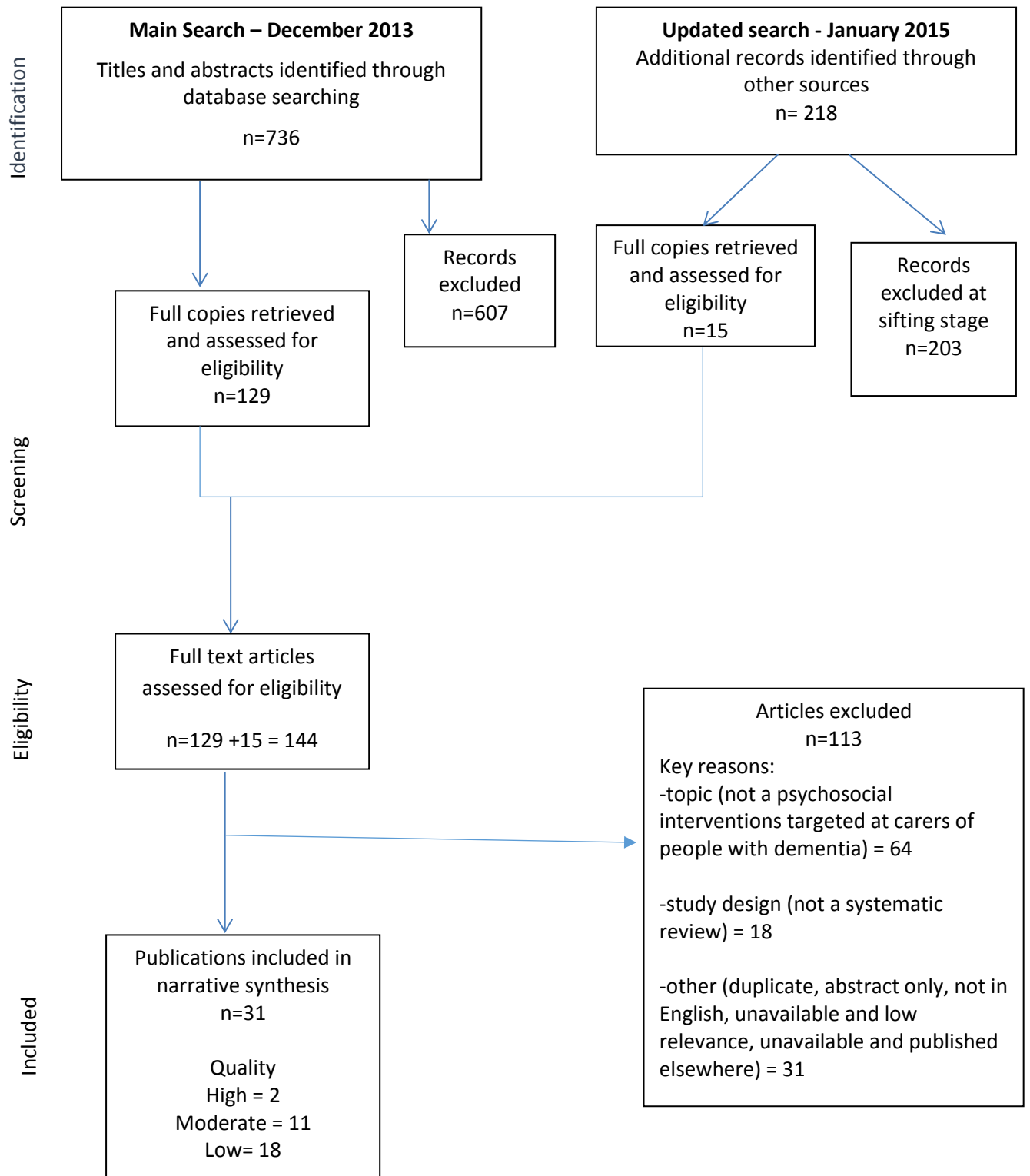


Table 1: Summary of included reviews rated as high or moderate quality

	Lead Author (Year)	How studies combined	Categories of interventions reported						Quality
			PSI#	TI	MCI	I & S	Ed	Tech	
1	Boots, 2014	Narrative summary						✓	Moderate
2	Brodsky, 2003	Meta-analysis	✓						Moderate
3	Chien, 2011	Meta-analysis				✓			Moderate
4	Elvish, 2013	Narrative summary		✓	✓		✓	✓	Moderate
5	Lins, 2014	Meta-analysis & narrative summary						✓	High
6	Marim, 2013	Meta-analysis					✓		Moderate
7	Olazaran, 2010	Meta-analysis			✓		✓	✓	Moderate
8	Parker, 2008	Meta-analysis & narrative summary			✓	✓	✓		Moderate
9	Peacock, 2003	Narrative summary		✓			✓	✓	Moderate
10	Pinquart, 2006	Meta-analysis		✓	✓	✓	✓		Moderate
11	Pusey, 2001	Narrative summary	✓					✓	Moderate
12	Thompson, 2007	Meta-analysis				✓	✓	✓	Moderate
13	Vernooij-Dassen, 2011	Meta-analysis		✓					High
			2	4	4	4	7	7	

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

Psychosocial interventions

Nature of the intervention

Only two of the included systematic reviews (Brodaty *et al.*, 2003; Pusey and Richards, 2001) used the broad umbrella term 'psychosocial interventions' to categorise the interventions included; the other eleven reviews differentiated between different types of psychosocial interventions according to the content of components (e.g. psychoeducational, therapeutic, support) or methods of delivery (technology-based interventions). 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, counselling, 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 (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 (2010) 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

Four reviews presented results from studies evaluating psychotherapeutic interventions for carers of people with dementia (Elvish *et al.*, 2013; Peacock and Forbes, 2003; Pinguart and Sorensen, 2006; Vernooij-Dassen *et al.*, 2011). 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/ counselling to classify included studies. Pinguart and Sorensen (2006) focused on techniques based on cognitive-behavioural therapy (CBT) and Vernooji-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 wellbeing. The other three reviews included a wide range of measures. Vernooji-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 utilisation 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 institutionalisation 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 institutionalisation.

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 (standardised 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' behaviours or institutionalisation of the person with dementia. The authors concluded that cognitive reframing may be an effective component of individualised, multi-component interventions for carers. Pinquart and Sorensen (2006) pooled data from studies on CBT and found evidence it was associated with improvement in burden (9 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 wellbeing 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 institutionalisation of the person with dementia, even at follow up 3.5 years later. Elvish *et al.* (2013) identified only one study which fitted their criteria for psychotherapy-counselling studies. This was a mixed methods study which reported clinicians' views of delivering a counselling intervention for older couples confronting Alzheimer's disease. Findings included a shift in participants' attitudes towards becoming more accepting and non-judgemental 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 counselling.

Information and support

Nature of the interventions

Four reviews, all rated as moderate quality, reported on information and support interventions (Chien *et al.*, 2011; Parker *et al.*, 2008; Piquart and Sorensen, 2006; Thompson *et al.*, 2007). Three reviews (Chien *et al.*, 2011; Parker *et al.*, 2008; Piquart and Sorensen, 2006) 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 organised 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. Piquart 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 utilisation 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). Pinqart and Sorensen (2006) reported that supportive interventions improved subjective well-being, although this effect was based on only one study (1 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

Seven reviews, all rated as moderate quality, reported on educational/ psychoeducational interventions (Elvish *et al.*, 2013; Marim *et al.*, 2013; Olazaran *et al.*, 2010; Parker *et al.*, 2008; Peacock and Forbes, 2003; Pinquart and Sorensen, 2006; Thompson *et al.*, 2007). 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 wellbeing. 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 person with dementia and rates of institutionalisation (Pinquart and Sorensen, 2006), health care expenditure and rates of institutionalisation (Peacock and Forbes, 2003) and outcomes for people with dementia, health service utilisation and economic outcomes (Thompson *et al.*, 2007).

Key findings

Four of the reviews reported meta-analyses (Marim *et al.*, 2013; Parker *et al.*, 2008; Pinguart and Sorensen, 2006; Thompson *et al.*, 2007). In the most recent meta-analysis of psychoeducational interventions, Marim *et al.* (2013) investigated the effectiveness of educational and support programmes 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 favouring the educational intervention group (4 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 8 studies of psychoeducational interventions. They found no significant impact of psychoeducational interventions on subjective-wellbeing, self-efficacy or carer health. However, they did find small but significant results for the impact of these interventions on carer depression (4 studies; WMD -1.93; 95% CI -3.79, -0.07) and burden (7 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 favour of the intervention (5 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 (5 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 (7 studies; ES -0.21; 95% CI -0.61, 0.20)) or self-efficacy (2 studies; ES 0.37; 95% CI -0.28, 1.02)).

Pinguart 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 wellbeing (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 institutionalisation. 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 wellbeing 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 towards caregiving and anxiety. They found that the majority of interventions in this category drew on cognitive-behavioural theory and principles and also theoretical models of stress and coping. Peacock and Forbes (2003) identified four studies utilising 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 behaviours 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.

Multicomponent interventions

Nature of the intervention

Four reviews, all rated as moderate quality, reviewed multicomponent interventions (Elvish *et al.*, 2013; Olazaran *et al.*, 2010; Parker *et al.*, 2008; Pinguart and Sorensen, 2006). Multicomponent

interventions were defined in different ways; there was, however, consensus in that they comprise at least two different categories of psychosocial interventions such as therapy, education and support.

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 utilisation, and Pinquart and Sorensen (2006) included outcomes related to carers, symptoms of people with dementia and institutionalisation.

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 multicomponent interventions for carers, that these interventions are associated with a delay in the institutionalisation of people with mild to moderately severe Alzheimer's disease. The essential components of these interventions were individual assessment, information, counselling and support. After 6 or 12 months of intervention, the overall institutionalisation 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 multicomponent interventions improved caregiver mood. Parker *et al.* (2008) identified 12 studies reporting multicomponent interventions; ten of the twelve 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 multicomponent interventions may assist carers. Pinquart and Sorensen (2006) found no effect of multicomponent interventions on most of the outcomes, but they were significantly related to delayed institutionalisation (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 multicomponent 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 multicomponent interventions can delay entry into residential or nursing care for people with dementia and improve carer mood.

Technology-based interventions

Nature of the intervention

Seven reviews reported on studies of technology-based interventions; six were of moderate quality (Boots *et al.*, 2014; Elvish *et al.*, 2013; Olazaran *et al.*, 2010; Peacock and Forbes, 2003; Pusey and Richards, 2001; Thompson *et al.*, 2007) and one was high quality (Lins *et al.*, 2014). Reviews varied considerably in the degree of definition of the intervention; 2 reviews did not specify any definition (Peacock and Forbes, 2003; Pusey and Richards, 2001). Two reviews included both computer and telephone based systems which provided information and support (Olazaran *et al.*, 2010; Thompson *et al.*, 2007); 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 wellbeing 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 (institutionalisation, 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 institutionalisation and healthcare expenditure and Thompson included outcomes for people with dementia, healthcare utilisation and economic outcomes.

Key findings

Three of the seven reviews reported meta-analyses of technology-based interventions (Lins *et al.*, 2014; Olazaran *et al.*, 2010; Thompson *et al.*, 2007). The one high quality review assessed the efficacy and experiences of telephone counselling for carers of PWD (Lins *et al.*, 2014) and identified nine RCTs. Meta-analyses indicated a reduction of depressive symptoms from telephone counselling without additional intervention (three trials, 163 participants: standardised mean difference (SMD) 0.32, 95% confidence interval (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 (4 studies; ES 0.196; 95% CI -0.004, 0.395). Thompson *et al.* (2007) classified four studies as technology-based interventions (3 of the studies were also identified by Olazaran *et al.* (2010)). They reported a meta-analysis of 3 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 5 quantitative studies (reported a significant positive impact on depression, burden and social support).

Summary: Interventions delivered via technology were diverse, with components including counselling 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 counselling 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 institutionalisation, 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 person with dementia 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 generalisability 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 as well as a theoretical understanding of the likely process change. This caused considerable difficulty in categorising 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.

Implications for future research and practice

The number of people with dementia is predicted to almost double in the next fifteen 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 (Blom *et al.*, 2015; Livingston *et al.*, 2014) 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 8 session manual-based coping intervention delivered by psychology graduates. The intervention group showed positive effects on carer mood and anxiety levels for 2 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 behaviour and changing unhelpful thoughts. The authors identify the flexibility of the intervention and the diversity of the strategies as a benefit that enables the intervention to suit different circumstances of carers.

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 categorise 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 institutionalisation, 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 groups of carers, as experiences may differ according to sociodemographic factors.

Conclusions

This paper illuminates the evidence-base of psychosocial interventions for carers of people with dementia. Whilst 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) under its 'NIHR Research Professorship' scheme (Reference Number NIHR-RP-011-043). The views expressed are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

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 manuscript.

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Supplementary Information 1: Sample search strategy for MEDLINE (OVID)

1. (carer or care?giv* or caregiv* or care giv*).ti,ab.
2. (caretak* or care tak* or care?tak*).ti,ab.
3. informal care.ti,ab.
4. children caring.ti,ab.
5. (children provid* adj3 care).ti,ab.
6. ((parent or parents or mother or mothers or father or fathers) adj2 (care or caring)).ti,ab.
7. ((son? or daughter? or friend?) adj2 (care or caring)).ti,ab.
8. ((husband? or wives or wife or spouse? or grandparent? or grandchild? or neighbour? or neighbor? or relatives) adj2 (care or caring or support or supporting)).ti,ab.
9. ((family or families) adj2 (caring or support)).ti,ab.
10. ((grandfather? or grandmother?) adj2 (care or caring or support or supporting)).ti,ab.
11. exp caregivers/
12. or/1-11
13. (Dementia or Alzheimer* or elderly or old age or oldest old or delirium or huntington* or creutzfeldt* or CJD* or binswanger* or korsakoff* or wernicke* or lewy*).ti,ab.
14. exp dementia/ or alzheimer disease/ or *COGNITION DISORDERS/
15. 13 or 14
16. 12 and 15
17. (Intervention* or non-pharmacologic* or non-pharmaceutic* or psycho?social or support or training or therapy or (multi-dimensional adj4 support) or (carer* adj2 support*) or counsel?ing or psycho?educational or education or (emotional adj2 support) or befriend* or one-to-one emotional or conversation group* or (multi-component adj3 intervention*) or (behavio?r adj3 manag*) or (telephone adj3 support) or (multi-component adj3 training) or (training adj3 carer*) or peer group* or support group* or information).af.
18. *health promotion/ or exp *community health services/ or preventive health services/ or "early intervention (education)"/ or exp health education/ or exp mental health services/ or personal health services/ or Self-Help Groups/
19. 17 or 18
20. 16 and 19
21. *health promotion/ or exp *community health services/ or preventive health services/ or "early intervention (education)"/ or exp health education/ or exp mental health services/ or personal health services/ or Self-Help Groups/
22. (((quality of life or qol or well being or qaly or quality-adjusted life year or ((caregiver* or carer*) adj2 health)) and well?being) or depression or (measure adj2 happiness) or outcome* or burden or mental health).af.
23. or/21-22
24. 20 and 23

25. (((comprehensive* or systematic*) adj3 (bibliographic* or review* or literature)) or (meta-analy* or metaanaly* or "research synthesis" or ((information or data) adj3 synthesis) or (data adj2 extract*))).ti,ab. or (cinahl or (cochrane adj3 trial*) or embase or medline or psyclit or (psycinfo not "psycinfo database") or pubmed or scopus or "sociological abstracts" or "web of science").ab. or "cochrane database of systematic reviews".jn. or ((review adj5 (rationale or evidence)).ti,ab. and review.pt.) or meta-analysis as topic/ or Meta-Analysis.pt.

26. 24 and 25

Additional File 1

Table 2: Table of inclusion criteria (outcome measures, study design and date range) used by the reviews

	Lead Author (Year)	Outcome measures*		Study designs	Dates range of included studies	Number of included studies
		Primary**	Secondary/ others			
1	Boots, 2014	NS	NS	Quantitative and qualitative studies	1988- 2013	12
2	Brodaty, 2003	Carer psychological morbidity & burden	Carers - coping skills, social support, knowledge PWD – mood, nursing home placement	Quantitative (Randomised Controlled trials, quasi-experimental studies)	1984-2000	30
3	Chien, 2011	NS	Carers – psychological well-being, burden, social consequence	Quantitative	1998- 2009	30
4	Elvish, 2013	Carer psychosocial wellbeing		Quantitative (studies that used random assignment) and qualitative	2005-2011	20
5	Lins, 2014	Depressive symptoms of carers	Carer – burden, distress, anxiety, quality of life, self-efficacy, satisfaction PWD-institutionalisation, mood, quality of life	Quantitative for efficacy (Randomised controlled trials or cross-over trials) and qualitative studies for experience	Up to 2013	12
6	Marim, 2013	NS	Carer- burden using the Zarit burden index	Quantitative (Randomised controlled trials with blinded assessments)	Up to 2011	7
7	Olazaran, 2010	NS	Carer- mood, psychological well-being, objective burden, quality of life PWD - cognition, activities of daily living, behaviour, mood, physical domain, quality of life, institutionalisation, restraint usage, mortality Economic - cost-effectiveness	Quantitative (Randomised controlled trials)	Up to 2008	179
8	Parker, 2008	NS	Carer - health service utilisation, satisfaction with health service utilisation, psychological morbidity, quality of life, knowledge/ competence PWD - health service utilisation	Quantitative (Systematic review, meta-analyses, randomised controlled trials, quasi-experimental studies, cohort studies, case control studies & observational studies without control groups)	2000-2005	40
9	Peacock, 2003	NS	Carers - wellbeing, depression, strain PWD - institutionalisation, healthcare expenditure	Quantitative (Control group or pre-post design)	1992-2002	11
10	Pinquart, 2006	NS	Carers - Burden, depression, subjective well-being, ability/ knowledge PWD - symptoms, institutionalisation	Quantitative (Controlled studies)	1982-2005	127
11	Pusey, 2001	NS	Carer - psychological health, physical health, quality of life (including perception of burden)	Quantitative (Randomised controlled trials or controlled trials)	Up to 1999	30
12	Thompson, 2007	NS	Carer – quality of life, physical and mental health, burden or satisfaction PWD - activities of daily living or behaviours, health service utilisation Economic – time spent on caring activities	Quantitative (Randomised controlled trials)	Up to 2005	44
13	Vernooij-Dassen, 2011	NS	Carer - psychological morbidity and distress, quality of life, appraisal of performance PWD - healthcare utilisation	Quantitative (Randomised controlled trials)	Up to 2009	11

*NS= Not specified, ** primary outcomes only reported if so termed by original review authors

