Meta-review of international evidence on interventions to support carers

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Glossary

CES-D	Center for Epidemiologic Studies Depression Scale
COPD	Chronic obstructive pulmonary disease
Dartmouth COOP charts	Dartmouth Primary Care Co-operative
DARE	Database of Abstracts of Reviews of Effects
EuroQoL	EuroQoL Quality of Life Measure
GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
RCT	Randomised controlled trials
SF-36	Short Form (36) Health Survey

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Chapter 1 Introduction

As the UK population grows in size, it is becoming increasingly older (ONS, 2009). Between 1983 and 2008, the number of people aged 65 years and over increased from 15 per cent in 1983 to 16 per cent in 2008, an increase of 1.5 million people in this older age group. Those aged 85 years and over, the ‘oldest old’, have witnessed the fastest population growth. Since 1983, the number of people aged 85 years and over has doubled - to 1.3 million in 2008. It is predicted that population ageing will continue for a considerable number of years to come. For example, by 2033, the number of people aged 85 and over is projected to increase to 3.2 million and represent five per cent of the total UK population. Nearly one-quarter (22 per cent) of the population will be aged 65 and over.

Whilst the population is living longer, this does not mean that people are in good health and living lives free of illness or disability (ONS, 2008). Life expectancy is growing at a faster rate than health expectancy. This imbalance means that demand for long-term care will increase substantially (Pickard, 2008). It is well known that community care relies on the contributions of relatives and friends who provide support, on an unpaid basis, to sick, disabled or older people to enable them to continue living in their own homes. For instance, in England, around 85 per cent of disabled older people living at home are in receipt of informal care; of these, over 80 per cent have care from a spouse, an adult child, or both (Pickard *et al*., 2007). Projections show that the numbers of disabled older people receiving care from their adult children are projected to increase by around 90 per cent (Wittenberg *et al*., 2007).

According to the 2001 Census, there are approximately 5.2 million people in England and Wales with caring responsibilities (Carers UK, 2009). This is one in ten of the population. The peak age for caring is 50 to 59 years. Women are more likely to have care-giving responsibilities than men. Three in five people will become a carer at some point in their lives (George, 2001). Women have a 50:50 chance of providing care by the time they are 59, men by the time they reach the age of 74.

Since the first UK review of evidence on carers (Parker, 1985), the national and international body of research literature has grown substantially. It now covers data on, *inter alia*, the prevalence of care-giving; the impact and outcomes of caring for those who have care-giving responsibilities; issues related to combining paid work and care; and the effectiveness of support and services for carers. Whilst some studies cover carers in general, others examine issues from the perspective of specific sub-groups of carers, for example: older carers; children and young people who provide care; carers of people with particular medical conditions. Likewise, studies adopt different methodologies ranging from randomised control trials to small-scale qualitative pieces of work. Despite this diversity, and the heterogeneity of carers, a key theme to emerge consistently from the research literature over the past 25 years is that caregiving can have negative effects on carers' physical and emotional health, financial situation, social networks and ability to take part in the labour market.

In recent years, successive UK governments have attempted to address issues raised by researchers and national carers' organisations such as Carers UK and the Princess Royal Trust for Carers. England is exceptional in that it has introduced three pieces of legislation aimed specifically at carers: the Carers (Recognition and Services) Act 1995; the Carers and Disabled Children Act 2000; and the Carers (Equal Opportunities) Act 2004. The three Acts of Parliament each strengthen carers' rights. Two of the main aims of the 2004 Act are to ensure that statutory carers' assessments consider a carer's ability to take part in education, training, employment and leisure activities, and that local authorities have a duty to inform carers of their right to be assessed.

The revised cross-government national strategy for carers, published in 2008, contains the Government's ten-year vision for carers (HM Government, 2008). The strategy aims to ensure that carers have increased choice and control, and are empowered to have a life over and above their care-giving responsibilities. A specific outcome identified for 2018 is that carers will have access to the integrated and personalised services they need to support them in their caring role.

Given the increasingly valuable and essential role that carers play in society, it is timely to undertake a comprehensive review of the research literature on interventions for carers. The present overview of the evidence base relating to the outcomes and cost-effectiveness of support was intended to inform thinking by the Department of Health and the Standing Commission on Carers about how best to improve outcomes for carers, as well as identifying future research areas.

We must emphasise here that this review is of interventions developed specifically to support carers. We were not asked to and did not review studies that examine how generic services, such as home care, act to support carers even when they are 'for' the person being supported by the carer. As we know from other research, these services can be crucial in maintaining carers' physical and psychological well-being.

Chapter 2 Research Methods

2.1 Introduction

A review of reviews, or meta-review, was conducted, following advance decisions made about searching, screening, appraising and synthesising relevant literature. The literature searches aimed to identify high quality systematic reviews and/or meta analyses that provided insights about the effectiveness of interventions for carers. A protocol was drawn up to guide the review process; this aimed to ensure that the research methods were transparent and explicit, and to minimise bias in the selection of reviews for inclusion in the present meta-review. This chapter documents the different stages of the review process: search methods; evaluation of included reviews; data extraction and synthesis.

2.2 Aims of the meta-review

The overall aim of the meta-review was to provide the Department of Health with an overview of the evidence base relating to the outcomes and cost-effectiveness of support for unpaid carers of sick, disabled or older people. Specific objectives were:

- to undertake a scoping review of systematic reviews on support and interventions for carers
- to map out the extent, range and nature of the identified reviews on support and interventions for carers
- to summarise the main findings of the identified reviews
- to identify gaps and weaknesses in the evidence base.

2.3 Search strategy

A range of health and social care resources was searched to identify published reviews on support and interventions for carers. These included:

- searches of appropriate electronic databases
- scrutinizing bibliographies of all relevant reviews for further relevant studies
- checking relevant internet sites
- searching for publications of experts in this area

The review team included an information scientist from the Centre for Reviews and Dissemination (CRD), who was instrumental in developing the electronic search strategies. Box 2.1 lists the databases searched for references for potentially relevant systematic reviews, with a range of keywords and search strategies.

Box 2.1 Electronic databases searched

The Cochrane Database of Systematic Reviews (CDSR) (via the Cochrane Library) (http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME)

Database of Abstracts of Reviews of Effects (DARE) (via The Cochrane Library) (http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME)

Health Technology Assessment Database (via The Cochrane Library) (http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME)

NHS Economic Evaluations Database (via The Cochrane Library) (http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME)

MEDLINE (OvidSP) (http://ovidsp.ovid.com/)

EMBASE (OvidSP) (http://ovidsp.ovid.com/)

PSYCINFO (OvidSP) (http://ovidsp.ovid.com/))

Health Management and Information Consortium (HMIC) (OvidSP) (http://ovidsp.ovid.com/)

CINAHL (EBSCO) (http://www.ebscohost.com/)

ASSIA (CSA Illumina) (http://www.csa.com/)

Social Services Abstracts (CSA Illumina) (http://www.csa.com/)

Social Science Citation Index (Web of Science) (http://www.isinet.com/)

Social Care Online (http://www.scie-socialcareonline.org.uk/)

A previously published strategy by Golder *et al.* (2008) to locate studies on respite care for carers of frail older people was used as a basis for developing the search strategies for this meta-review. The strategy by Golder *et al.* (2008) contained relevant free-text terms and subject headings relating to carers, combined with terms for specific interventions. As the current scoping review was concerned with any interventions or support for carers, terms for specific interventions were omitted. This resulted in a more sensitive search strategy to retrieve any literature about carers. Where possible, a study design filter was added to the strategy to limit the search to reviews only for each database. A date limit of 2000-2009 was applied and all searches were restricted to English language papers only. The search strategies used for each database can be found in Appendix A.

The records from each electronic database were downloaded into an Endnote library and de-duplicated. Supplementary, targeted web searches were carried out to identify any reports or grey literature not retrieved by the database searches. Potentially relevant literature accessed via this and other sources, for example by contacting experts and manually searching bibliographies, was also recorded in the Endnote library.

2.4 Selection of systematic reviews

Every literature review had to pass three stages, detailed below, before it was acceptable for inclusion in the final meta-review. Two researchers (GP and HA) independently appraised all the relevant literature at each of the three stages to ensure consistency in decision-making. Any disagreements were discussed on a case-by-case basis and resolved consensually.

Step 1: The researchers screened the titles and abstracts of all the identified references to determine relevance to the meta-review's focus of interest. Full papers and reports were retrieved in all instances where the abstract or title indicated that it was broadly relevant. If abstracts were not available, and/or it was not possible to ascertain a review's potential relevance or value beforehand, then the document was obtained and a decision was made on the basis of the full report.

Step 2: All potentially relevant reports were then independently appraised for eligibility for inclusion in the meta-review using an inclusion and exclusion checklist. Six criteria, outlined more fully in Box 2.2, were applied, focusing on: population of interest; types of intervention; geographical coverage; language; period of interest; type of literature review. Key reasons for eliminating articles were that: the review did not report any outcomes for carers; carers were not the intended primary beneficiaries of the interventions or support services reviewed; the article did not describe itself as a systematic review or meta-analysis based on systematic identification of papers.

Box 2.2 Inclusion and exclusion criteria

Inclusion criteria	*Exclusion criteria*
Population of interest • Carers of all ages (including children and young adults) supporting adults	• Parent carers of disabled children (n.b. review does cover transition from children's services to adult services) • Carers of people with mental health problems (n.b. after search commissioned, agreed with DH to include reviews of carers of people with mental health problems if picked up in standard searching; also conducted a wider search on Cochrane Reviews database)
Types of interventions • Primarily aimed at carers (rather than patients/care recipients) • Single, or multi-component	• Primarily aimed at patients/care recipients, but from which carers might benefit • Medical/pharmacological
Geographical coverage • Systematic reviews drawing on primary data from studies in any country, if the nature of the intervention could be transferable to the UK health and social care system	• Systematic reviews drawing on primary data from studies in any country, where the nature of the intervention could not be transferable to the UK health and social care system, for example because of substantially different funding issues or culture
Language • Studies in the English language	• Studies not published in English
Period of interest • Systematic reviews published from 2000 onwards	• Systematic reviews published prior to 2000
Type of literature review • Published systematic literature reviews (addressing effectiveness, where carers are primary sample and primary outcomes for carers are reported) • Published meta-analysis (addressing effectiveness, where carers are primary sample and primary outcomes for carers are reported) • Cochrane Collaboration methodology	• Unsystematic literature reviews (unless covering areas where systematic review evidence is not available, and then reported separately as another form of evidence) • Report of single primary research studies • Grey literature • Research in progress

Step 3: the two researchers independently assessed the quality of all relevant literature reviews using a quality criteria tool adapted from one employed by Egan and colleagues (2008) in their systematic meta-review of psychosocial risk factors in home and community settings. This tool had itself been adapted for epidemiological reviews from two critical appraisal guides: the University of York's Centre for Reviews and Dissemination's DARE criteria for quality assessment of reviews and a systematic review tool created by Oxman and Guyatt (1991). The set of criteria applied to relevant reviews embodied seven questions:

- Is there a well defined question?
- Is there a defined search strategy?
- Are inclusion/exclusion criteria stated?
- Are study designs and number of studies clearly stated?
- Have the primary studies been quality assessed?
- Have the studies been appropriately synthesised?
- Has more than one person been involved at each stage of the review process?

The criteria were scored as follows: yes=1; in part=0.5; no or not stated=0. High scoring reviews (i.e. those reviews that scored 4 and over) went forward for full data extraction for the meta-review. Only brief summary information was extracted from reviews of lower quality (i.e. those scoring less than 4).

2.5 Data extraction and synthesis

An Excel spreadsheet was used to manage data extraction. The spreadsheet recorded a uniform set of information about each review included in the meta-review.

Detailed summaries were completed for high quality reviews. These included quality assessment scores and information about: the intervention(s) under review; target group(s); number, type and date range of primary studies included in the review; sample sizes. Detailed information was then extracted in relation to seven potential outcomes for carers: physical health; mental health (e.g. depression, anxiety); burden and stress; coping; satisfaction; well-being or quality of life; ability and knowledge.

As noted above, for the lower quality reviews basic information only about intervention(s), target carer group(s) and outcomes was extracted. This allowed us to present summary information about the scope of the evidence base. However, no detailed structured data about outcomes for carers were extracted from these lower quality reviews.

2.5.1 Synthesis

The reviews included in our meta-review took two main approaches to reporting their findings. First, there were those that reported the findings of both qualitative and quantitative material using what we have called here a ‘qualitative’ approach. In others words, they described what their primary studies found, but did not sum up or synthesise findings formally. Secondly, there were those that took a quantitative approach to quantitative findings, either by carrying out formal statistical meta-analysis, or by ascribing different weights to findings reported in primary studies of different quality or robustness. In either case, this quantitative approach gives more weight to RCTs than to non-randomised studies, and more weight to studies with control groups than to those without, and so on down the ‘hierarchy’ of research designs.

The distinction between these approaches is not perfect, and some of our included reviews had elements of both. However, given the different ways in which these reviews reported their findings, and ascribed weight to them, we decided to divide the reviews into groups that broadly fell into these two categories and to analyse them separately. Our results chapter is thus in two main sections. In our concluding chapter, we bring the evidence from these two types of approach together in order to come to overarching conclusions about the current state of evidence about the impact of interventions for carers.

Chapter 3 Scoping the Literature

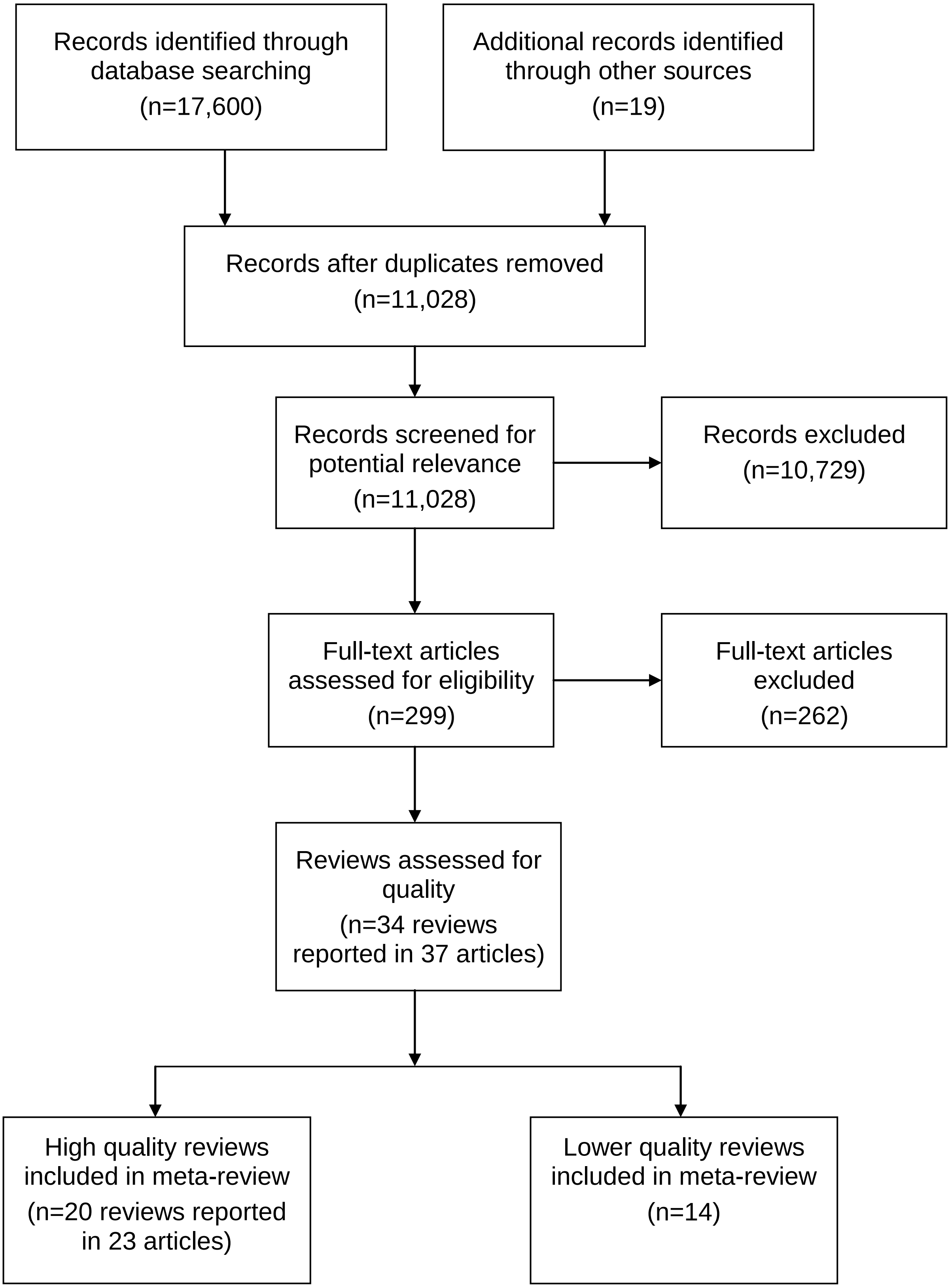
3.1 Introduction

In this chapter, we report the numbers of reviews of research on carer interventions that we found through our searching, the numbers that we selected at the first stage, and the numbers that crossed our quality threshold and which we therefore included in the meta-review. We also describe the scope of the existing research field by analysing the focus and coverage of the reviews that we selected at the first stage. For ease of reading, we refer to all reviews by their first author and date only; bibliographical details are in the references section at the end of the report.

3.2 Systematic reviews retrieved

Figure 3.1 shows the number of reviews identified or included at each stage of the process. A total of 11,009 records was retrieved through the main database searches after de-duplication. A further 19 references were accessed through other sources. On screening, 299 of these 11,028 records were judged to be potentially relevant and further appraised. Of these, 262 articles were eliminated when the inclusion and exclusion criteria were applied. The remaining 37 articles, reporting on 34 reviews, were included in the first stage of the meta-review. Of these, 20 reviews, reported in 23 articles, met the quality appraisal criteria of a score of four and above and were therefore assessed as higher quality. The remaining 14 publications did not meet the quality threshold to be included in the full meta-review, but were included in the summary of the scope of the area that we report in this chapter.

Figure 3.1 Flow chart showing search and selection process



Adapted from Moher *et al.* (2009)

3.3 Scoping the field: overview of both high and lower quality reviews

This section of the report scopes the field, drawing on data from both high and lower quality reviews included at the first stage of the meta-review.

3.3.1 What type of carers?

Most of the reviews included primary studies that focused on interventions aimed at adult carers of people with dementia (14) and/or carers of older people with some form of cognitive or physical frailty (6). A small number of included reviews incorporated interventions for carers of stroke survivors (4). A handful of reviews each focused on carers of just one condition group, namely: carers of people with kidney disease (1); carers of heart patients (1); palliative and cancer carers (3); carers of bipolar patients (1); carers of people with chronic obstructive pulmonary disease (COPD) (although this last review found no eligible effectiveness studies of interventions for carers). The remaining reviews focused on carers in general rather than any specific group or category.

3.3.2 What type of intervention?

In terms of the focus of intervention examined in primary studies, the largest grouping of reviews included studies looking at the effectiveness of psychosocial interventions (7), psycho-education (4) and psychological interventions (2). These could be targeted at either individuals or be group based. They were sometimes, but not necessarily, defined or described in more detail. Where they were, however, this more detailed information gave the impression of potential for overlaps in terms of categorisation. For example, one review of psychosocial interventions for stroke carers (Eldred, 2008) covered primary studies of education with family counselling, education with individual counselling and both individual and group telephone support. Another review of family psychosocial interventions (Martire, 2004) included primary studies examining combinations such as education and emotional support, emotional support and skills training, and education with emotional support and skills training. A further review of what were described as psychological interventions for carers (Selwood, 2007) incorporated primary studies evaluating educational interventions, group/individual coping strategies, and group/individual behavioural management techniques.

Further, other reviews (8) included mixed types of interventions which, in some cases, included those defined in other reviews as psychosocial or psycho-educational.

Three reviews included in the meta-review covered primary studies examining respite care solely; others focused on interventions related to information, education, knowledge and/or communication (5). One review looked at ‘health service interventions’, and another simply at ‘support’ for carers.

Finally, several reviews (8) included primary studies covering a diverse range of interventions, with little homogeneity between them. For example, one encompassed interventions aimed at supporting carers to access services, at improving carers’ health, at emotional and social support, at education, training and employment, and at respite care and short breaks for carers (Victor, 2009).

3.3.3 What types of outcomes?

Most reviews included in the meta-review reported results from primary studies dealing with multiple outcomes for carers. There were some exceptions; for example, two focused only on carers’ psychological or mental health (Selwood, 2007; Lee, 2007), three only on burden (Acton, 2001; Yin, 2002; Torti, 2004) and one on anxiety only (Cooper, 2007). The most commonly measured outcome overall was carer burden, strain or stress (at least[1] 24 reviews), closely followed by some aspect of psychological or mental health (at least 23 reviews). Other carer outcomes that were reported frequently included subjective well-being or quality of life (at least 12 reviews), knowledge or caring ‘competence’ (at least 17 reviews), physical health (at least 10 reviews) and satisfaction (at least 9 reviews). Only five reviews reported any aspects of costs, whether of the intervention itself or of costs borne by carers and families, including their expenditure on health care.

In general, reported outcome domains were negative rather than positive. For example, only one study looked at carers’ happiness and relaxation.

3.3.4 How many primary studies were included in reviews?

There was wide variation in the numbers of studies and/or publications included in the reviews identified at stage 1. In part, this was explained by their focus (there is clearly more intervention research available about carers of people with dementia than for any other group) and by their selection criteria (some reviews included only randomised controlled trials (RCTs), others took a more inclusive approach to selection). However, it also seems likely that the quality and coverage of search strategies influenced how many studies were identified at the outset and, therefore, how many studies went forward to be reviewed. Not all reviews were clear about the

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[1] Because of the different ways in which reviews defined these outcomes it is impossible to be more precise about how many reviews in total included the listed outcomes.

numbers of primary studies they included and reviewed. Of those that did report this clearly, the number of included primary studies ranged from none (Caress, 2009, no intervention studies about carers of people with COPD were found) to 154, reported in 174 publications (Shaw, 2007, respite care for frail older people, which included both quantitative and qualitative evidence).

We need to highlight here, too, that some reviews were more careful than were others about first ensuring that they obtained all publications from individual studies. Those that did, clearly accounted for both the number of studies and number of publications and indicated where and why these were not the same. Some reviews were also more careful than others were about ensuring that multiple publications from individual studies were entered only once in analysis. Those that did not do this ran the danger of biased reporting when they synthesised or summarised findings on outcomes.

3.3.5 Overlap of primary studies

From the outset of our work, it was clear that there was substantial overlap of primary studies in the reviews we included. Because there were more reviews on dementia, and because there is a larger intervention literature about the carers of people with dementia, the issue of overlap was most obvious with this topic. However, it was evident in other areas too. Further, some reviews of interventions for diverse groups of carers also included dementia-related primary studies. The effect of this overlap is difficult to judge without substantial additional analysis, but it could run the risk of exaggerating effects.

3.3.6 International coverage

Not all reviews gave clear accounts of where the primary studies they had reviewed had been carried out. Where this was clear, publications from the USA predominated, followed at some distance by publications from the UK.

Chapter 4 Results

In what follows we present our analysis of material, first, from reviews that synthesised findings about the outcomes of interventions for carers using what we defined as a ‘qualitative’ approach. We then present our analysis of the material from reviews that synthesised findings using a quantitative approach. In the final section of this chapter, we attempt to bring the two types of material together. As explained in Chapter 3, for ease of reading we refer throughout to the reviews by the name of the first author only and date. Full bibliographical details are included in the references section.

4.1 Reviews using a qualitative approach to data synthesis

4.1.1 Overview of included reviews

Seven higher quality reviews were included in the meta-review that synthesised findings about outcomes of interventions for carers qualitatively. Five reviews focused on interventions for carers of people with dementia (Cooke, 2001; Pusey, 2001; Peacock, 2003; NCCMH, 2007; Cooper, 2007). The sixth review focused on support for ‘family carers who care for an elderly person at home’ (Stoltz, 2004), including five studies that reported evidence about interventions for people with dementia, carers of stroke survivors and older family members. The seventh review (Victor, 2009) was very wide ranging in terms of the carer population targeted. The 107 eligible intervention studies covered all unpaid carers looking after relatives and friends of all ages and all condition groups. This review was exceptional, in the sense that it focused on primary studies from the UK only compared to the other reviews that all took an international perspective.

Two reviews focused on psychosocial interventions (Cooke, 2001; Pusey, 2001). The remaining five each encompassed a diverse range of interventions (Peacock, 2003; Stoltz, 2004; NCCMH, 2007; Cooper, 2007; Victor, 2009).

There was considerable overlap and duplication of primary studies identified in the reviews. This was particularly evident in the two reviews of psychosocial interventions where up to 16 of the same evaluations were included in both reviews (Cooke, 2001; Pusey, 2001). Although Victor (2009) covered over 100 primary studies, there was more limited overlap. However, the appraisal tool used in the Victor (2009) review suggested that the quality of 97 of the 107 outcome measurement studies was poor. Other review authors likewise comment on the poor quality of the primary studies. Cooke (2001) went so far as to say that ‘[m]any of the studies reviewed suffered from serious methodological problems’ (p.131).

Authors of reviews adopted different approaches to their analysis. Some reported the results of identified studies in terms of mode of delivery, for example technology-based interventions, group based interventions, individually based interventions and service configuration (Pusey, 2001). Others reported findings by outcomes for carers (Victor, 2009) and yet others organised the evidence according to type of intervention (Peacock, 2004; Cooper, 2007).

In this section of the chapter, we synthesise the messages from the different reviews in relation to impact on carers' physical health, mental health, burden and stress, satisfaction, well-being or quality of life, and ability or knowledge. Where possible, we further divide the synthesis according to the condition of the person the carer was looking after. Table 4.1 summarises the number of primary studies included in each review and the number and types of interventions evaluated.

Table 4.1 Reviews using a qualitative approach to analysis: number of primary studies and interventions evaluated

First author and year	Number of primary studies analysed in review	Type of intervention in primary studies
Cooke 2001	40	All 'psychosocial'
Cooper 2007	24	5 group cognitive behaviour therapy 3 behavioural management techniques 1 group counselling 1 IT support for caregivers 2 groups involving relaxation/yoga 2 exercise therapy 3 additional professional support 3 respite 1 services for care recipient 3 care home for care recipient
NCCMH (2007)	20	Not listed in detail, but interventions reported on include support groups, education and a telephone helpline
Pusey 2001	30	All 'psychosocial'
Stoltz 2004	5 (5 studies out of 26 reviewed included studies focused on intervention evaluation)	2 psycho-educational support group 1 psychosocial 1 peer visitor support scheme 1 in-hospital respite care
Peacock 2003	11 (11 out of 36 relevant studies were rated as 'strong'; these were the focus of analysis for the review)	4 case management 4 education 2 psychotherapy 1 computer networking

First author and year	Number of primary studies analysed in review	Type of intervention in primary studies
Victor (2009; see Table 2, p. 22)	107	33 access to services • 11 assessment • 5 information services • 1 direct payments • 16 support workers 2 health 25 emotional support • 8 support groups • 14 stress management • 1 befriending • 2 complementary therapies 21 education and training • 9 education • 12 training 1 employment 25 breaks

4.1.2 Physical health

Carers of people with dementia

Only three reviews reported physical health outcomes of interventions for carers of people with dementia (Cooke, 2001; Pusey, 2001; Peacock, 2003). In general, physical health was not defined in any detail in the reviews, and neither was information provided about the outcome measures used.

Only one of the 30 studies of psychosocial interventions included in Pusey (2001) found any positive impact on carers' physical health (in sleep quality). In the other reviews that included physical health as an outcome, single primary studies reported no positive impact on carers' health of a psychosocial intervention (Cooke, 2001) or an education programme (Peacock, 2003).

Carers of people with diverse conditions

A single study of in-hospital respite care for caregiver elderly dyads in the Stoltz (2004) review found that carers experienced improved sleep, but effects were short term; two weeks after the respite ended, no significant difference could be found.

The Victor (2009) review identified ten papers reporting on a range of interventions with the potential to improve carers' physical health. There was weak or limited evidence of better physical health following statutory carer assessment; GP-based interventions prompting carers to identify and attend to their own health needs; chair massage and aromatherapy; and carer breaks.

4.1.3 Mental health

Evidence about carers' mental health was a common outcome reported in the included reviews (Cooke, 2001; Pusey, 2001; Peacock, 2003; Stoltz, 2004; NCCMH, 2007; Victor, 2009).

The primary studies included in the review defined or conceptualised mental health in ways that could overlap and/or were not necessarily consistent. This was reflected in the terminology used, which included depression, anxiety, psychological distress, psychological morbidity, psychological well-being, emotional well-being, and psychiatric symptoms. A wide diversity of measures was employed in primary studies, including the Hamilton Depression and Anxiety Scales, the anxiety subscale of the Brief Symptom Inventory, the General Health Questionnaire, the Spielberger State-Trait Anxiety Inventory, the Beck Anxiety Inventory, the Hospital and Anxiety Depression scale (HADS) and others.

Carers of people with dementia

The included reviews reported mixed results in relation to depression.

A review of 11 RCTs, all of which were judged to be 'strong' studies, identified three which reported findings about the impact of interventions on carers' levels of depression (Peacock, 2003). Only one of these – that evaluated the impact of an education intervention – reported positive findings in relation to depression in carers. The other two trials showed no effect on overall psychological well-being, including depression and strain, from education interventions or from case management.

Similarly, Pusey (2001) also reviewed psychosocial interventions and identified over 20 studies that examined outcomes relating to depression. Half of the eight identified RCTs or controlled studies reported a positive effect of the intervention; half did not.

A single study in a review (NCCMH, 2007) that underpinned NCCMH (2007) joint guidance on the treatment and care of people with dementia and their carers, suggested that better informed carers have lower levels of depression, but not lower anxiety or better physical health. This led the primary researchers to suggest that whilst educational interventions and the provision of information about dementia at an early stage after diagnosis might have potential to lead to beneficial outcomes for carers, this might be at the expense of carers' anxiety.

One review (Cooper, 2007) of 24 diverse interventions focused solely on anxiety as the outcome measure (although this had been the primary outcome measure in only one of the studies reviewed). The review found limited evidence of efficacy for any type of intervention. One RCT of three that included group cognitive behaviour therapy (CBT) reported a significant reduction in anxiety, but none of those that included behavioural management techniques. A single RCT of IT support found no effect on anxiety, while there were inconsistent findings in three studies of ‘additional support’ for carers. One, a controlled trial, found reduced anxiety in carers in receipt of eight months of the Admiral nursing service, which works primarily with carers, compared with community mental health services but the others reported no positive impact on anxiety. Exercise therapies and respite were also reported to be ineffective in reducing anxiety in caregivers. The authors of the review concluded, overall, that CBT and other therapies developed primarily to treat depression did not effectively treat anxiety.

The two reviews of psychosocial interventions also identified a small number of studies that reported anxiety as an outcome. Results were contradictory, and positive evidence was limited. Only one study out of five that looked at anxiety as an outcome in Cooke (2001) found that participants in the intervention group showed improvements in some aspects of anxiety when compared to the control group. Pusey (2001) included a single study – a controlled trial – that explored impact on anxiety. This showed reduced anxiety scores in all participants across time but with a greater reduction among carers receiving an Admiral Nurse service.

These two reviews of psychosocial interventions also identified a number of studies that looked at mental health concepts such as psychological morbidity, self-esteem, morale and distress. However, none showed any significant effect of interventions on these particular outcome measures when compared to control groups, over time or other intervention groups.

The overall conclusion of the Cooke (2001) review of psychosocial interventions, was that of the 29 studies evaluating over 40 interventions that reported findings about some aspect of carers’ psychological well-being or mental health, fewer than half (41 per cent) demonstrated improvements for those receiving the intervention.

Carers of people with diverse conditions

Stoltz (2004) identified two relevant intervention studies that reported outcomes relating to depression, anxiety and psychological stress. Only one – a study of in-hospital respite for elderly people with dementia – showed a positive impact on psychological stress (hostility, anxiety, depression, obsessive-compulsion) during respite. However, this effect was short-lived as no significant difference could be detected two weeks post-respite.

As outlined earlier, the Victor (2009) review covered a very wide range of interventions, conditions and research designs. Here we report the evidence of impact on psychological health depending on the nature of the intervention.

First, Victor (2009) identified 16 studies looking at a range of carer ‘support workers’ in health and social care, or the voluntary sector. These were people who specialised in working with carers and included GP-based carer support workers; South Asian advocacy workers; mental health specialist carer support workers; support workers for carers of people with dementia; support nurse work with carers of people with lung cancer; and stroke specialist support workers. There was some evidence to suggest that this type of intervention contributed to carers’ improved psychological well-being. However, the evidence was relatively weak and in studies where the research design was stronger, the findings of improvements in carer well-being were less convincing. Two studies examining the outcomes of GP-based health interventions for carers suggested that this form of support could also deliver better outcomes in terms of carers’ emotional well-being.

Secondly, there were 11 studies examining the impact of statutory carer assessment. Although the studies were judged to be weak, the findings suggested that the most notable potential benefits were outcomes relating to emotional well-being. However, there was also evidence to indicate that for some carers being assessed can be perceived as a test of ability to care, suggesting that not all carers will experience emotional benefits.

Thirdly, Victor (2009) concluded that carer support groups might have the potential to lead to improvements in carers’ emotional well-being, through mutual support, confidence building and developing a positive self-identity as a carer. However, there was mixed evidence about the impact of stress management, coping and counselling programmes on well-being. For example, there was (weak) positive evidence of change from studies of interventions aimed at carers of people with dementia, Parkinson’s Disease or stroke. In contrast, studies of this type of intervention for carers of people attending palliative care and carers of people with schizophrenia did not find evidence of improvements to carers’ emotional well-being.

Fourthly, many of the 12 studies of training in Victor (2009) looked at carers’ emotional well-being; with just one exception, they all reported improved well-being for carers.

A single RCT of the impact of access to a befriending scheme for carers of people with dementia showed no evidence of benefits in terms of depression, anxiety, loneliness, positive affect or global health. However, analysis comparing depression amongst those carers who actually used the befriending scheme with the control group did find a marginally significant difference in favour of the intervention group at 15 months. The review also found weak evidence of chair massage and aromatherapy contributing to improvements in carers’ emotional well-being.

Finally, Victor’s (2009) review identified 25 studies of interventions designed to give carers a break from care giving. However, these studies demonstrated little robust quantitative evidence of improvements to carers' emotional well-being over time. In addition, the studies provided mixed qualitative evidence about carers' perceptions of improved emotional well-being. Whilst perceived benefits included feelings of normality, freedom, peace of mind and relief, there was also consistent evidence that breaks could cause carers to experience negative emotions including anxiety about the experience of the care recipient during the break and guilt about using these sorts of services.

4.1.4 Burden, stress and strain

Many of the systematic reviews of interventions aimed at supporting the carers of people with dementia identified primary studies that reported outcomes of carer burden, stress, and strain. These concepts were not defined in any way, so it was not possible to identify overlaps. Where reported, commonly used measures included the Zarit Burden Inventory, the Caregiver Strain Index and the Relative Stress Scale. None of the reviews covering the carers of people with other conditions directly addressed burden, stress or strain.

Over 20 studies reporting on 30 interventions for carers of people with dementia identified in the Cooke (2001) review of psychosocial interventions looked at burden as an outcome. Only three of 12 controlled studies and three of 14 studies using other designs showed any positive effect on carers' burden. The Pusey (2001) review of 30 psychosocial interventions reported similarly mixed findings from the RCTs and controlled trials identified for inclusion. Cooke (2001) points out that the two primary studies reviewed that incorporated some form of follow up assessment for carers found delayed effects on caregiver burden. In other words, improvements on measures of burden became apparent at later assessment points suggesting a delay in the impact of interventions. This was also apparent for other outcomes, for instance psychological well-being, quality of life, coping and knowledge.

As well as levels of burden, some interventions also aim to reduce stress and/or strain for carers. Based on four studies identified, Peacock (2003) reported that case management interventions overall did not have an effect on levels of strain for carers in spite of support from case managers and access to community services. Likewise, the results of the review's analysis of four educational interventions indicated that this type of intervention was insufficient to decrease strain.

4.1.5 Coping and coping skills

Four included reviews reported findings related to coping and coping skills. No definitions were provided, and only one study referred to measures used in the relevant primary study, which included a care-giving competence scale and a coping responses index.

Carers of people with dementia

The two reviews of psychosocial interventions (Cooke, 2001; Pusey, 2001) both identified studies looking at coping/coping skills as an outcome for carers of people with dementia. Three of the five included studies, of various designs, in Cooke (2001) reported a positive impact on some aspect of coping among carers who had received an intervention. Similarly, Pusey (2001) reviewed two RCTs and a controlled trial that identified positive effects on aspects of carers' coping. By contrast, two other RCTs reported no effect.

Carers of people with diverse conditions

One of the outcomes that Victor 2009 examined was 'ability to care', which included skills development and coping. The review identified 14 studies that evaluated stress management, coping and counselling programmes. There was some weak evidence to suggest that the interventions led to behavioural change, but two included RCTs found no difference in coping amongst participants in intervention and control groups.

4.1.6 Satisfaction

Satisfaction was not a commonly reported outcome in the reviews focusing on interventions for people with dementia, with insufficient evidence to review here.

Among the carers of people with diverse conditions, Victor (2009) looked at satisfaction as an outcome of interventions for carers. There was weak evidence to suggest that carers were satisfied with the process and outcomes of assessment but when services were provided, carers were not necessarily satisfied with them. Similarly, the studies reviewed provided limited evidence that carers were satisfied with information services. Quantitative evidence from studies of stroke specialist support workers showed higher levels of satisfaction amongst carers in the intervention group compared to the control groups. Victor (2009) argues that this finding is helpful because it suggests that carers can experience benefits from interventions even if differences are not apparent on other outcome measures.

The eight studies evaluating carer support groups included in Victor (2009) reported that a high proportion of carers (but not all) were satisfied with the support group attended. Likewise, the majority of carers taking part in stress management, coping and counselling programmes were satisfied with interventions targeted at different groups: carers of people with schizophrenia, dementia, stroke and Parkinson's Disease.

Evidence about satisfaction with educational programmes for carers was inconsistent in Victor (2009). Studies of stroke education programmes found no or small differences in the satisfaction levels of carers taking part in the intervention and control groups. On the other hand, two studies of written information relating to head injury and aphasia respectively reported high levels of acceptance and satisfaction with the interventions. There were generally high levels of satisfaction with training for carers. The 12 included studies looked at a range of training provision: care skills training in stroke rehabilitation; training for carers of people with eating disorders; carer empowerment training; carers of people with schizophrenia who received behavioural management training and health education.

As far as respite care and short breaks were concerned, findings from the 25 studies in Victor (2009) generally reported carer satisfaction in relation to the organisation of services and/or provision for care recipients. However, some dissatisfaction was expressed (or suggestions for improvements made) concerning flexibility and quality of care.

4.1.7 Well-being and quality of life

The majority of reviews included in the meta-review reported findings relating to carer well-being and quality of life, concepts which generally were not defined. Little information was provided about the measures used in primary studies, apart from reference to quality of life items on the Dartmouth COOP charts and selected items from the SF-36.

Carers of people with dementia

The two reviews of psychosocial interventions (Cooke, 2001; Pusey, 2001) included in the meta-review both identified studies that looked at quality of life as an outcome of interventions for carers. Findings in both reviews were mixed. In Cooke (2001), no controlled studies and only one study using another design reported any positive impact on some aspect of well-being or quality of life. In Pusey (2001) one RCT out of five identified controlled studies showed improvement for carers receiving the intervention, three showed no difference, and one showed a reduction in some aspect of quality of life or well-being.

Peacock and Forbes (2003) identified just one technology-based study in their review that was an RCT that evaluated the effects of a special computer network on caregivers of people with Alzheimer’s Disease. However, the networking intervention did not decrease social isolation as no significant differences were found between the intervention and control groups on that particular outcome measure.

Carers of people with diverse conditions

Three of the five intervention studies included in the Stoltz (2004) review examined quality of life outcomes. Results were mixed. Whilst an RCT of a multi-component intervention found no significant differences for carers' quality of life, a small clinical trial of an intervention for family carers of stroke survivors showed that nearly all participants reported the 'peer visitor' intervention had made their situation easier. A third evaluation of in-hospital respite care found that carers experienced 'increased freedom'; however, as with other outcomes, the effects were not long lasting and no significant difference could be detected two weeks after respite.

Victor (2009) included 25 studies of respite care and short breaks in her review. These studies reported evidence that breaks enabled carers to have some rest and relief from care-giving, and to have some time for themselves which in turn enabled them either to enjoy social activities and leisure pursuits, or alternatively undertake everyday household jobs or complete more substantial tasks such as decorating or spring cleaning. However, there was little robust quantitative evidence that carers' emotional well-being improved through the use of respite care. Victor suggests this could reflect the fact that some of the studies included in her review focused on carers of people with dementia. The progressive nature of dementia may mean that carers' emotional well-being worsens, rather than improves, over time. Exceptionally, one study reported some negative findings: the time spent was not enjoyable, it involved other commitments, and carers spent time worrying about their situation. Although this finding was based on a small-scale longitudinal study without a control group, it suggests some issues that might explain the apparent lack of positive effect in studies of respite care.

4.1.8 Ability and knowledge

Five reviews reported findings about the impact of interventions on carers' ability and knowledge. Generally, authors did not define the topic areas covered by the concept of 'knowledge', apart from one that focused on knowledge of the care recipient's illness. The only review that reported the measures used in the primary studies stated that studies used either the Alzheimer's Disease Knowledge Test or developed their own measures.

Carers of people with dementia

Some of the effectiveness studies identified in the reviews of psychosocial interventions (Cooke, 2001; Pusey, 2001) reported carer outcomes relating to ability and knowledge. As would be expected, these tended to be evaluations of interventions that included education and/or information. Eleven of 16 studies in Cooke (2001) reported improvements in knowledge, as did four RCTs included in Pusey (2001) of interventions such as an educational and behaviour intervention programme. Specifically, they were: a self-help telephone programme focusing on peer support compared with an information lecture series – knowledge in both groups improved; a support group; an educational and behaviour intervention programme; and an educational programme for spouses. However, only three of the 11 studies in the Cooke (2001) review that reported improved knowledge also reported corresponding improvements in psychological well-being or caregiver burden. In other words, improving carers' knowledge of illness did not necessarily lead to improvements in their well-being or a reduction in burden.

Carers of people with diverse conditions

The Victor (2009) review identified a small number of studies that showed some (limited) evidence of increased knowledge gained through statutory carer assessment. Studies of stroke specialist workers and of a lung cancer carer support service also found that carers in the intervention group might have improved their knowledge base. There was weak evidence that information-based services improved carers' knowledge and uptake of services.

Evidence from most of the eight evaluations of carer support groups included in Victor (2009) showed that carers gained a wide range of types of information and advice through a variety of sources, including both professionals and other carers in the group. There was some evidence that this can be particularly important for Asian carers who can struggle to obtain relevant information in an accessible language.

Improvements in knowledge were also identified in studies of stress management, coping and counselling programmes for carers of people with schizophrenia, dementia, or Parkinson's Disease, and of palliative care users (Victor, 2009). Between them, these studies reported better knowledge of the relevant condition, ways of caring, stress, and stress management, and support services.

The nine studies of carer education programmes in the Victor (2009) review provided mixed evidence of effectiveness relating to knowledge outcomes, in part reflecting the carer group targeted. For instance, some studies of education programmes aimed at carers of people with dementia and carers of people with schizophrenia showed significant and often quite large improvements to knowledge. However, only one of two RCTs looking at the impact of stroke education programmes showed improved knowledge outcomes.

Finally from the Victor (2009) review, the 12 evaluations of training for carers provided some evidence that these sorts of interventions could validate existing expertise, and provide new knowledge (especially in relation to the condition of the care recipient) and understanding. In terms of the practical aspects of care-giving, studies of carer training showed this could lead to skills improvement, as well as the development and application of new skills, although some evidence suggested that carers' use of new skills may not be maintained over time. In addition, there was some evidence that carer training could improve perceptions of the difficulties of the care recipient's condition, the negative aspects of care-giving and the ability to provide care.

4.1.9 Overall conclusions drawn by reviews

Overall, authors of the higher quality reviews included in the meta-review reported negative findings. In this final section, we summarise the overall conclusions that the authors of the seven reviews came to, grouping them by the condition of the person carers were looking after. We also add any comments that we feel need to be made about the reviews and the security of their findings.

Carers of people with dementia

Cooke (2001) concluded that out of the 40 studies included in their review of psychosocial interventions for people with dementia, approximately two-thirds did not show improvements in psychological well-being or burden outcomes. On the other hand, there was evidence that some interventions could lead to improved levels of knowledge of the care recipient's condition, although improved knowledge did not appear to have a positive impact on psychological well-being or burden. Studies showing improved outcomes for carers tended to focus on interventions that included social components (e.g. social support), or a combination of social and cognitive components (e.g. problem solving), which appeared to be relatively effective in improving carers' psychological well-being.

The Pusey (2001) review of 30 psychosocial interventions concluded that individualised interventions that involved problem solving and behaviour management demonstrated the best evidence of effectiveness. They went on to claim that this approach was also closest to the effective model of psychosocial interventions for people with severe and enduring mental illnesses and their carers (Baugley and Baugley, 1999). The authors of Pusey (2001) suggest that it would be worth exploring the development of interventions based more specifically on this model to improve support for carers of people with dementia.

Peacock (2003) concluded that the systematic review of 11 'strong' studies found few significant effects for interventions for carers, apart from an educational intervention that found decreased levels of depression in carers at three months follow up and the use of a computer networking intervention that improved carers' decision-making confidence. However, the 'double counting' of some studies in this review mean that the strength of the finding about depression may be exaggerated.

The Cooper (2007) review was exceptional in that it focused on one outcome only: anxiety in carers of people with dementia. Based on review of 24 intervention studies, the conclusion was that there was little evidence of efficacy for any CBT or other intervention developed primarily to target *depression* to reduce anxiety in this particular carer group. The sole intervention that showed reductions in carers' levels of anxiety was the only one specially designed to target this outcome, which the authors suggest may mean that specific strategies might be required to reduce anxiety for carers of people with dementia. There was preliminary evidence that yoga and relaxation techniques might be effective.

The NCCMH (2007) review of qualitative evidence suggested that carers might benefit from educational/information-giving interventions, support groups and help lines. Educational interventions for carers of people with dementia at an early stage after diagnosis could be helpful in terms of lower depression, but risk having a detrimental effect on carers' levels of anxiety.

The Stoltz (2004) review of five intervention studies concluded that there was moderate evidence to show that caregiver education programmes are a good and effective way to support family carers and the older people they are supporting. On the other hand, they found insufficient evidence about the efficacy of in-hospital respite care.

Finally, the Victor (2009) review of 107 interventions suggested that statutory carer assessment can be helpful to some carers and that other interventions (e.g. support workers) may achieve beneficial outcomes in terms of emotional support. There was weak evidence to suggest that carer support groups may lead to a wide range of significant outcomes. Studies of stress management, coping and counselling programmes identified improvements in knowledge, but more mixed evidence for improvements in emotional well-being. Studies of education and training programmes also found evidence of improvements in knowledge; there was some evidence that training could also have a beneficial impact on emotional well-being. There was evidence that carer breaks offer carers a rest (emotionally and physically). However, the relationship between breaks and carers' emotional well-being is not straightforward; whilst they might offer relief and a sense of normality and freedom, at the same time they can lead to negative feelings, such as guilt and anxiety.

4.1.10 Overall conclusions from the meta-review of findings reported qualitatively

There was no evidence of benefit from interventions in relation to the physical health of people caring for those with dementia and only weak evidence of impact in relation to carers of people with diverse conditions.

In relation to carers’ mental or psychological health, there was no consistent message from the reviews about the impact of interventions on carers of people with dementia or carers of people with diverse conditions. Neither was there any consistent evidence about the impact of interventions on the experience of burden, stress or strain among those caring for people with dementia.

There were no consistent messages from the reviews included here about the impact of psychosocial interventions on the well-being or quality of life of people caring for those with dementia. Neither was there any consistent evidence of impact on any interventions for people caring for those with diverse conditions.

Alone among the outcomes we have reviewed here, there is slightly stronger evidence that psychosocial interventions may improve the coping abilities or skills of carers of people with dementia, and some (weak) evidence also in relation to those caring for people with diverse conditions.

As one might hope, psychosocial interventions that included some element of education or giving information did increase the knowledge of carers looking after people with dementia. However, this increase in knowledge did not necessarily lead to reductions in burden or improvements in well-being. There was also some evidence that carer support groups and carer training could increase the knowledge of carers of people with diverse conditions, and that carer education could increase knowledge among those looking after people with dementia or schizophrenia. By contrast, there were less consistent messages from the evidence on stroke education interventions.

Finally, among people caring for those with diverse conditions, there was evidence of satisfaction with a range of different interventions. However, as with much service evaluation research, it is often difficult to know whether this satisfaction simply reflects being grateful for receiving ‘something’ rather than ‘nothing’.

4.2 Reviews that synthesised findings on outcomes for carers quantitatively

4.2.1 Overview of included reviews

We included in our work 13 higher quality reviews that addressed the issue of outcomes from interventions to support carers and synthesised quantitative findings, using either meta-analysis or some form of narrative synthesis. Six of these focused on dementia and between them covered information and ‘carer support’ (Thompson, 2007), psychological interventions for carers (Selwood, 2007), a range of interventions including respite and psycho-education (Acton, 2001), psychosocial interventions (Brodaty, 2003), a range of interventions including psycho-education and multi-component interventions (Parker, 2008), and respite care (Lee, 2004). Three reviews focused on stroke and between them covered education or ‘carer support’ (Lee, 2007), carer interventions (Brereton, 2007) and information (Smith, 2009). Two reviews both covered the impact of respite care on those looking after frail older people (Mason, 2007; Shaw, 2009). Finally, two reviews covered chronic illness: Tong (2008) reviewed the evidence on support for the carers of people with chronic kidney disease, while Martire (2008) reviewed the impact of family psychosocial intervention on carers of people with a very wide range of chronic conditions, including dementia.

There was considerable overlap and duplication of primary studies identified in the reviews. This was particularly evident in relation to the reviews of psychological or psychosocial interventions for carers of people with dementia. So, for example, a study by Brennan *et al*. (1995) was included in four of the reviews on dementia, and a study by Gendron *et al*. (1996) in five. One of these (Brennan *et al*., 1995) was also included in the Martire (2008) review of support for carers of people with chronic conditions. There was some overlap in the two reviews of respite care for frail older people but not as much as might have been expected, given their common focus and their closeness to each other in time. This may be explained in part by differences in inclusion strategies. Mason (2007) included only RCTs of effectiveness, except where insufficient data were found, in which case well-designed, non-randomised controlled studies were included. By contrast, Shaw (2009) included RCTs and quasi-experimental studies, longitudinal before and after studies, cross-sectional studies, and qualitative studies (the last were used to explore carers’ views about respite and these findings are not included in our meta-review).

Authors of reviews also adopted different approaches to their analysis. Some reported the results of identified studies in terms of mode of delivery, for example comparing individual or group-based interventions or by the nature of the intervention – information, education, therapy, day respite care, and so on. In some cases, mode of delivery and nature of the intervention were combined. For example, Selwood (2007) categorised psychological interventions into: educational interventions, supportive therapy, group approaches to improving coping skills, individual approaches to improving coping skills, group approaches to behavioural management training, and individual approaches to behavioural management training, which were further divided by whether the training was delivered in fewer than or more than six sessions. By contrast, some reviews aggregated results from a wide range of different types of interventions with varied modes of delivery either in part (e.g. Martire, 2008) or throughout (e.g. Brodaty, 2003). Finally, some reviews that drew on more than one type of research evidence analysed the material by the methods used in the primary studies. Thus, Shaw (2009) synthesised findings from RCTs, before and after, and cross-sectional studies separately.

There was also considerable variation in how reviews categorised different outcomes. Some, for example, had a clear focus on depression and synthesised findings only from studies that reported depression as an outcome, using well-established measures. Lee (2007) included only studies that used the SF-36 to measure carers' well-being. Others took a wider approach and synthesised findings on a wide range of outcomes related to psychological health – for example depression, anxiety, and adjustment to illness (Brodaty, 2003). Where possible (i.e. where the reviews have reported it) we list the measures used in the primary studies and the reviews' synthesis.

In this section of our report, we synthesise the messages from these very different reviews in relation to impact on carers' physical health, mental health, burden and stress, satisfaction, well-being or quality of life, and ability or knowledge.

4.2.2 Physical health

Only two of the reviews that presented synthesis of quantitative results dealt with the impact of the interventions on carers' physical health (Mason, 2007; Parker, 2008).

Seven of the studies of respite care reviewed in Mason (2007) reported carers' physical health as an outcome. Of these, only one found that respite offered any statistically significant benefit. One other study in this review concluded from sub-group analysis that there was a positive effect on the measure of chemical stress levels for 'vulnerable' carers (defined as those where there was a substantial mismatch between the demands of caring and help received). However, the numbers of carers involved here was small and the authors of the original study advised caution in the interpretation of the results.

Parker (2008) reviewed studies of any intervention intended to support those caring for people with dementia. Only three of the 13 studies of psycho-educational interventions and none of the studies of other interventions they reviewed were included in their meta-analysis of impact on physical health. This showed no significant overall impact, either positive or negative.

4.2.3 Mental health

Mental health outcomes were a focus of most of the reviews that presented synthesis of quantitative results (see Table 4.2). The exceptions were Acton 2001 (interventions to support carers of people with dementia) and Tong (2008) (interventions to support carers of people with kidney disease).

Table 4.2 Mental health outcomes for carers in reviews reporting quantitative synthesis

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
						Summary of narrative synthesis			
Brodaty 2003	Psychosocial interventions	Dementia	Weighted mean effect size (d) (random)	23 (16 RCTs)	Various	0.31	0.13 to 0.50	Not given *(sig)*	Last follow-up, for most studies this was post-test.
Lee 2004	Respite care	Dementia							
	Depression		Mean difference	1	Hamilton Depression Scale (HDS)	-0.18	-3.82 to 3.46	.92	1m follow-up
	Anxiety		As above	1	Hamilton Anxiety Scale	0.05	-3.76 to 3.86	.98	As above
	Psychological distress		As above	1	Brief Symptom Inventory	0.04	-0.29 to .37	.91	As above
Parker 2008	Range of interventions incl. psycho-education, multi-component	Dementia			Various				
	Psycho-education studies only		Weighted mean difference (random)	4	Various	-1.93	-3.79 to -0.07	.04	Studies with follow-up 'up to' 6 months
	Any intervention study using CES-D as outcome measure		Weighted mean difference (random)	6	CES-D	-2.26	-3.82 to -0.69	.005	As above
	As above, at any follow-up		Weighted mean difference (random)	8	As above	-2.31	-3.76 to -0.86	.002	At any follow-up

First author and date	**Type of intervention/sub-group analysis**	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	Any intervention study using any depression measure		Standardized mean difference (random)	6	CES-D, BDS, GDS	-0.22	-0.37 to -0.06	.007	Studies with follow-up 'up to' 6 months
	As above, at any follow-up		Standardized mean difference (random)	11	As above	-0.27	-0.38 to -0.15	.00001	At any follow-up
Selwood 2007	Psychosocial interventions for carers	Dementia			Not reported				
	Educational interventions		Evidence of benefit on outcomes. Grade of recommendation (GR)	5 (1 RCT)[1]		No evidence of benefit on 'distress, depression and burden'. GR = B			Not clear
	Group coping strategies		As above	9 (6 RCTs)		Effective in relation to depression immediately and up to 3m after intervention GR = B			Immediately and 3m
	Individual coping strategies		As above	7 (4 RCTs)		Effective in relation to 'distress and depression' immediately and up to 3m after intervention GR = B			As above
	Group behavioural management		As above	10 (7 RCTs)		Not effective for 'depression, burden and distress' immediately or up to 8m after intervention. GR = B			Immediately and up to 8m
	Individual behavioural management (<6 sessions)		As above	5 (5 RCTs)		Not effective for 'depression, distress or burden' immediately or up to 6m after intervention. GR = B			Immediately and up to 6m. Immediately

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
						Summary of narrative synthesis			
						Inconclusive for up to 12m after intervention. GR = D			and up to 12m
	Individual behavioural management (6 or more sessions)		As above	9 (8 RCTs)		Effective for depression immediately and up to 32m after intervention. GR = A			Immediately and up to 32m
	Supportive therapy		As above	9 (4 RCTs)		Not effective for 'depression, anxiety or burden' immediately. GR = B			Immediately only.
Thompson 2007	Information, carer support	Any							
	Technology-based computer interventions		Weighted mean difference (fixed)	3	Not reported	.62	-1.98 to 3.22	.64	
	Group-based psycho-education		Standardised mean difference (random)	5	Not reported	-.71	-0.95 to -0.46	.00001	
	Individual-based psycho-education		Standardised mean difference (mean)	7	Not reported	-.21	-0.61 to 0.210	.32	
Brereton 2007	Carers intervention	Stroke	Narrative	2 in tables. Results from 1 only.	CES-D only	Of two studies reviewed, one showed that training 'improved carers' well-being and quality of life by reducing their depression, anxiety and burden' (p.870)			Not addressed
Lee 2007	Education, carer support	Stroke	Mean weighted effect size (d) for each study included, overall and for sub-groups.		SF-36 only				

First author and date	**Type of intervention/sub-group analysis**	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	Overall			4 RCTs		0.277	0.118 to 0.435	.001	Between 13 weeks and 7m depending on study
	Education programmes			2 RCTs		0.354	0.087 to 0.621	<.01	13 weeks and 6m
	Support programmes			2 RCTs		0.234	0.037 to 0.432	.02	6m and 7m
Smith 2009	Information	Stroke	Narrative		HADS				
	Passive information intervention			1 RCT		No statistically significant difference in depression scores			6m follow-up
	Active information intervention			1 RCT		Intervention group scores better at statistically significant level			12m follow-up
Mason 2007	Respite	Frail elderly	Standardized mean difference (random)	Not clear overall. For meta-analysis 1 RCT, 2 quasi-experimental	HDS, GDS, CES-D	0.32	-0.62 to -0.02	.04	Not addressed
Shaw 2009	Respite	Frail elderly		Not clear overall. 4 before and after studies for depression.					
	Depression: overall RCT/quasi-experimental up to 6m follow-up		Mean effect size (random)	5	Various	-0.23	-0.49 to 0.03	.089	Up to 6m after intervention

First author and date	**Type of intervention/sub-group analysis**	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	As above up to 12m follow-up		As above	3	As above	0.08	-0.41 to 0.24	.623	
	Day care		Mean effect size (fixed)	4	As above	0.13	-0.29 to 0.03	.100	Not clear
	Home care		Mean effect size (random)	2	As above	-0.47	-1.31 to 0.37	.845	Not clear
	Before and after		As above	4	As above	-0.16	-0.57 to 0.25	.434	
	Longitudinal observational studies		Narrative	3	As above	No positive effect on carer depression.			
	Observational cross-sectional studies		Narrative	15	As above	No consistent or clear evidence of impact on mental health, though most reported positive or no effect.			
	Anxiety overall: RCT/quasi-experimental up to 6m follow-up		Mean effect size (fixed)	3	As above	.02	-0.16 to 0.19	.829	
	As above up to 12m follow-up		Mean effect size (random)	2	As above	0.27	-0.28 to 0.82	.330	
	Day care		Mean effect size (random)	3	As above	0.12	-0.33 to 0.57	.612	
Martire 2004	Family psychosocial intervention	Chronic illness (included dementia and wide range of other conditions)	Mean weighted effect size (random)		Not reported				

First author and date	**Type of intervention/sub-group analysis**	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	Depression overall			41		.10	.03 to .18	.02	First follow-up, whenever that was
	Depression in non-dementia studies	*Not dementia*		18		.17	.02 to .32	.03	
	Depression where mixed family members were target			29		.10	.01 to .20	.04	
	Depression where carer was target			24		.15	.03 to .27	.01	
	Depression in relationship focused interventions			22		.16	.04 to .27	.01	
	Anxiety overall			9	Not reported	.14	-.01 to .29	.07	
	Anxiety in relationship focused interventions			9		.21	.00 to .42	.05	As above

1. It is not clear how many included studies related to each reported outcome. The numbers reported here are the totals included in each group of interventions

BDS	Brief Depression Scale
CES-D	Center for Epidemiologic Studies Depression Scale
GDS	Geriatric Depression Scale
HADS	Hospital Anxiety and Depression Scale
SF-36	Short Form (36) Health Survey

Five reviews covered the carers of people with dementia; three of these included a range of interventions, predominantly defined by the authors as ‘psychsocial’ or psychological, intended to support carers of people with dementia (Brodaty, 2003; Selwood, 2007; Parker, 2008), one respite care (Lee, 2004) and the fourth information and/or ‘carer support’. Three reviews focused on those caring for people with stroke and covered ‘carer interventions’ (Brereton, 2007), education and/or ‘carer support’ (Lee, 2007) and information (Smith, 2009). Two reviews covered respite care for carers of frail older people (Mason, 2007; Shaw, 2009). Finally, one review looked at interventions for those caring for a wide range of chronic conditions, including dementia (Martire, 2004) and reviewed evidence on family psychosocial interventions.

The reviews fell into distinct groups in relation to how they analysed the material. First, there were those that attempted to examine interventions by their underlying aims or theoretical underpinnings. Thus, for example, Selwood (2007) analysed separately material for educational interventions, group or individual interventions that targeted coping or behavioural management, and general ‘supportive therapy’. By contrast, Brodaty (2003) analysed a wide range of psychosocial interventions as a single group. Secondly, some reviews focused their analysis on single outcome measures, while others amalgamated studies that used different measures, some of which were intended to measure different types of mental health outcomes. Using the first approach, for example, Lee (2007), Smith (2009) and Brereton (2007) analysed only studies that used, respectively, the SF-36, the HADS, and the Center for Epidemiologic Studies Depression Scale CES-D as measures of mental health. By contrast, Brodaty (2003), used a wide range of measures of ‘psychological morbidity’ most but not all of which related to depression, while Thompson (2007) and Selwood (2007) did not report the measures used in the studies they reviewed at all.

This mix of highly focused and rather diffuse studies makes coming to overall conclusions difficult. A further difficulty is the overlap of included studies that we referred to earlier.

Carers of people with dementia

The results in Table 4.2 suggest that, overall, psychosocial interventions to support carers are likely to have a positive impact on carer depression. However, the type of intervention that is most helpful in this respect is not entirely clear, partly because of the different ways in which the reviews categorised particular interventions. Parker (2008) suggests that psycho-education, so defined, is effective, as does Thompson (2007), while Selwood (2007) suggests that group and individual interventions to help carers develop coping strategies and individual interventions of six or more sessions that help them manage the behaviour of the person with dementia have an impact on depression. By contrast, Selwood (2007) suggests that there is no evidence of benefit in relation to carer depression for educational interventions, group interventions that help carers to manage the behaviour of the person with dementia, individual interventions of less than six sessions that help carers manage the behaviour of the person with dementia, or supportive therapy. Thomson (2007) found no evidence of positive impact for individually based psycho-education or for technology-based computer interventions and Lee (2004) no evidence of impact for respite care.

Carers of people who have had a stroke

The number of studies available to those reviewing the evidence on interventions to help carers of people who have had a stroke was smaller than that in relation to dementia, in part because all three reviews confined themselves to primary studies that used a single outcome measure when examining carers' mental health outcomes. Thus Brereton (2007) identified two studies that used CES-D as a measure. One of these showed that training carers improved their 'well-being and quality of life by reducing their depression, anxiety and burden' (p.870). Smith (2009) synthesised two RCTs reporting use of the HADS, one of which (reporting an 'active' information intervention) reported better outcomes for carers receiving the intervention and the other of which (a 'passive' information intervention) reported no difference in outcome. Lee (2007) identified four RCTs that used the SF-36 as an outcome measure. Analysed together, these showed a positive effect on carers' scores at follow up if they had received education or carer support. Statistically significant better outcomes for those receiving the intervention were also evident in sub-group analyses that divided the RCTs into those that provided education and those that provided carer support more generally.

Carers of frail older people

Two large reviews of respite care for frail older people came to different conclusions about the impact of respite on carers' mental health. Mason (2007) included one RCT and two quasi-experimental studies in a meta-analysis of impact on depression. This showed a significantly positive effect for carers experiencing respite care. By contrast, Shaw (2009) included five RCTs or quasi-experimental studies that used a variety of measures of mental health in a meta-analysis and this showed no overall positive effect. Sub-group analysis, similarly, showed no statistically significant effect for day care or home care respite. This review also carried out meta-analysis on before and after studies and narrative synthesis of longitudinal and cross-sectional observational studies. In no case was any consistent or clear evidence found of a positive effect of respite on carers' mental health status.

The difference in the findings of these two reviews may relate in part to the different levels of focus on specific mental health outcomes; the Mason (2007) meta-analysis was confined to validated depression measures, while the Shaw (2009) meta-analysis included a wider range of measures, including the General Health

Questionnaire, a ‘psychological distress scale’ and the Brief Symptom Inventory. Further, while both studies identified the Quayhagen et al (2000) RCT of day respite care, Mason (2007) did not include it in the meta-analysis of impact on depression while Shaw 2009 did (using results from the Brief Symptom Inventory). However, the Mason (2007) review does point out that the positive result of its meta-analysis is largely driven by findings from the Zarit *et al*. (1998) quasi-experimental study of day respite, which had a number of methodological and analytical flaws.

Carers of people with diverse conditions

One review (Martire, 2004) covered family psychosocial interventions in families caring for people with a wide range of ‘chronic illness’, among which dementia was included. It is impossible to tell from the report which of the 70 identified RCTs were included in the meta-analysis of impact on carer depression or anxiety, nor is there any report of the measures used in the primary studies to measure these outcomes. The meta-analysis presented suggests that the interventions reviewed have a positive impact on depression across the groups studied, and in ‘non-dementia’ studies (which were in the minority in the review). Sub-group analysis also found statistically significant impact on depression in interventions that targeted the carer specifically, as well as in those that targeted the family as a whole, and those where the intervention focused on family relationships. This review also looked at anxiety as an outcome. Here, results were less clear with a non-significant effect across all interventions that reported this outcome, and a significantly positive effect in sub-group analysis of interventions that focused on family relationships. All other sub-group analyses showed no significant effect, which means that there was no impact on carers’ depression in the dementia studies, nor in interventions that focused only on spouse carers, and no effect on anxiety in interventions that did not focus on family relationships. This finding about impact on depression in dementia studies is, of course, in direct contrast to that from the reviews that focused specifically on this condition.

4.2.4 Burden, stress and strain

Table 4.3 summarises the findings of reviews that synthesised quantitative data on carer burden or stress.

Table 4.3 Burden and stress outcomes for carers in reviews reporting quantitative synthesis

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
Acton 2001	Various, including respite and psycho-education	Dementia							
	All interventions		Pooled effect sizes with outliers removed until homogeneity achieved	21	Zarit Burden Interview, Montgomery Burden Scale, Lawton burden measure, Poulshok measure, Vitaliano measure	-0.08	-.19 to .02	Not reported NS	As close as possible to end of intervention
	Support group		As above	1	As above	0.00	-.54 to .54	Not reported NS	As above
	Education		As above	5	As above	-0.52	-.86 to -.18	Not reported. Significant	As above
	Psycho-education		As above	10	As above	-0.06	-.21 to .10	Not reported NS	As above
	Counselling		As above	4	As above	-0.07	-.34 to .19	Not reported NS	As above
	Respite care		As above	4	As above	-0.02	-.20 to .16	Not reported NS	As above
	Multi-component intervention		As above	3	As above	+0.46	.14 to .78	Not reported Sig	As above

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
Brodaty 2003	Psychosocial interventions	Dementia	Weighted mean effect size (d) random	20 – difficult to tell how many were RCTs	Included Burden Interview, Rankin Scale, Caregivers' Hassles Scale, Screen for Caregiver Burden, 'other objective burden scales'.[1]	.09	-.09 to .26	Not reported NS	Not clear
Lee 2004	Respite care	Dementia	Mean difference	1	Zarit Burden Interview	-5.51	-12.38 to 1.36	.12	Not reported
Parker 2008	Range of interventions incl. psycho-education, multi-component	Dementia							
	Psycho-education studies only		Standardised mean difference (model not reported)	7	Not clear which were used in studies included in meta-analysis[2]	0.02	-.37 to .42	Not reported NS	Not clear
	Support interventions		Standardised mean difference (random)	2	Neuropsychiatric Inventory of Distress	-0.41	-.80 to -.02	.04	As above
	Any intervention study using Zarit Burden Interview as outcome measure		Weighted mean difference (random)	3	Not clear	-1.89	-6.37 to 2.60	.41	As above
	Any intervention study using RMBPC as outcome measure		Weighted mean difference (random)	3	Not clear	-1.60	-3.35 to .05	.06	As above

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
Selwood 2007	Psychosocial intervention for carers	Dementia							
	Educational interventions		Evidence of benefit on outcomes. Grade of recommendation (GR)	5 (1 RCT)[2]	Not reported	Education by itself is not effective either immediately or some months later for carer burden. GR = B			Not clear
	Group coping strategies		As above	9 (6 RCTs)[2]	As above	Evidence of effectiveness is inconsistent GR = D			Not clear
	Individual coping strategies		As above	7 (4 RCTs)[2]	As above	Not enough studies to be conclusive GR = D			Not clear
	Group behavioural management		As above	10 (7 RCTs)[2]	As above	Not effective either immediately or after 8 months GR = B			Up to 8m
	Individual behavioural management (<6 sessions)		As above	5 (5 RCTs)[2]	As above	Not effective either immediately or up to 6 months GR = B Inconclusive evidence over the longer term GR = D			Up to 6m Up to 12m
	Individual behavioural management (6 or more sessions)		As above	9 (8 RCTs)[2]	As above	Not effective at reducing carer burden GR = C			Not clear

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	Supportive therapy		As above	9 (4 RCTs)[3]	As above	Not effective for immediate improvement of carer burden GR =B			Immediately after intervention
Thompson 2007	Information, carer support	Dementia							
	Group-based psycho-education		Weighted mean difference (fixed)	3	Not reported	-2.15	-5.97 to 1.66	0.27	Not reported
	Group-based support interventions		As above	5	Not reported	-0.40	-5.69 to 4.90	0.88	Not reported
Brereton 2007	Carers intervention	Stroke	Narrative	7	Carers Burden Scale, Burden Interview	1 study showed that training improved carers' well-being and quality of life by reducing their burden			13 weeks, 6m
Smith 2009	Information	Stroke		2 RCTs					
	Stress		Peto odds ratio	4 RCTs	HADS, GHQ using appropriate cut-off scores to dichotomise data	OR 1.13	0.65 to 1.97	0.65	Not clear
	Burden		Narrative	3 RCTs	Not reported	I study of passive information showed no effect. I study of active information showed a significant reduction of burden, other showed no effect.			Not clear
Mason 2007	Respite	Frail elderly	Narrative and some meta-analysis using weighted mean	4 RCTs for pooled meta-analysis[4]	Not entirely clear. Could include: Zarit Burden Measure, Novak and Guest	-0.03	-0.19 to 0.13, NS		

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
			difference (random)		Carer Burden Inventory, Robinson Caregiver Strain Index, Montgomery and Borgatta Caregiver Impact Questionnaire, 'Role overload'.				
			Narrative	13 studies in total	See above	8/13 found no differences between intervention and control, 3/13 did, 1 did not report results separately for two groups, and 1 used 'duration of caring' as a proxy for burden. Authors raise doubts about 3 studies reporting positive impact.			Not clear
Shaw 2009	Respite	Frail elderly							
	RCTs/quasi-experimental studies		Weighted mean difference (random)	2 RCTs, 1 quasi-experimental	Not reported	-0.11	-0.38 to 0.17	.458	6m follow-up
	Before and after		As above	3	Not reported	-0.46	-0.82 to – 0.10	.013	2/3m follow-up
	Longitudinal observational		Narrative synthesis	5	Not reported	No consistent evidence of effects of respite on burden			n/a
	Cross-sectional observational		As above	23	Not reported	No consistent or clear evidence of impact of respite on carer burden			n/a

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
Martire 2004	Family psychosocial intervention	Chronic illness (included dementia and wide range of other conditions)							
	Burden overall		Weighted mean difference (random)	40	Not reported	0.10	.06 to .15	<.01	At first follow-up, whenever that was
	Burden in dementia studies	*Dementia only*	As above	25	As above	0.10	.04 to .16	<.01	As above
	Burden in non-dementia studies	*Not dementia*	As above	15	As above	0.20	.09 to .31	<.01	As above
	Burden in interventions where spouse was target		As above	7	As above	0.26	.11 to .42	<.01	As above
	Burden where mixed family members were target		As above	33	As above	0.09	.04 to .14	<.01	As above
	Burden where carer was target		As above	24	As above	0.17	.08 to .26	<.01	As above
	Burden where patient and carer were target		As above	16	As above	0.11	.03 to .20	.01	As above

First author and date	**Type of intervention/*sub-group analysis***	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
						Summary of narrative synthesis			
	Burden in relationship-focused intervention		As above	18	As above	0.22	.13 to .32	<.01	As above
	Burden where intervention was not relationship-focused		As above	22	As above	.07	.02 to .12	.01	As above

1. Also included other measures for this outcome when a burden measure was not used in primary study. Impossible to tell what was included where, but seems to cover both coping and social support.
2. The outcomes listed in the paper seem to include beliefs, resentment, strain, mastery, distress, ways of coping, and burden measures *per se*.
3. It is not clear how many included studies related to each reported outcome. The numbers reported here are the totals included in each group of interventions.
4. Reporting of the meta-analysis is confusing with reference to four RCTs and four quasi-randomised studies being included, but table 12 saying that pooling of results was not attempted because of studies reporting a mix of change scores and endpoint scores. However, text does include a pooled effect size for the RCTs and this is reported here.

GHQ	General Health Questionnaire
HADS	Hospital Anxiety and Depression Scale
RMBPC	Revised Memory Behaviour Problem Checklist.

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Carers of people with dementia

Six dementia reviews (Acton, 2001, Brodaty, 2003, Lee, 2004, Parker, 2008, Selwood, 2007, Thompson, 2007) reported results in relation to burden or stress, although the ways in which these concepts were defined or categorised varied considerably (see notes to Table 4.2). The only review that found any evidence of effectiveness was Parker (2008), which suggested that support interventions had a statistically significant positive impact on carer 'distress'.

Carers of people who have had a stroke

Two reviews synthesised evidence about the impact of interventions for carers of people who had had a stroke (Brereton, 2007; Smith, 2009). Neither reported any conclusive evidence of positive impact on burden or stress of interventions to support carers or information.

Carers of frail older people

Mason (2007) and Shaw (2009) both reviewed evidence on the impact of respite care on those looking after frail older people. Neither found any consistent or conclusive evidence of positive impact on carers. The meta-analysis of longitudinal before and after studies in Shaw (2009) did suggest some statistically significant positive impact, but this was not repeated in results synthesised from RCTs or from any other type of research design. Mason (2007) reported that three of the 13 studies they reviewed reported positive impact, while eight did not and the remaining two could not be used in the analysis. They also raised doubts about methodological quality of the three studies reporting positive impact.

Carers of people with diverse conditions

Martire (2004), which reviewed evidence on psychosocial interventions for those caring for people with chronic conditions, including dementia, alone among the reviews included in this section, reported consistently positive effects on carer burden or stress. However, the lack of detail about the studies included in the meta-analysis and the measures used to judge effect, and the use of data from the first follow-up, whenever that was, limit our ability to judge the security of these findings. A particular contrast with other reviews included here is the Martire (2004) sub-group analysis of studies about dementia only. As we saw above, none of the reviews that focused specifically on dementia suggested any consistent message about impact of interventions on burden or stress.

4.2.5 Coping

Only three reviews synthesised quantitative information on carers' coping, two in relation to dementia (Parker, 2008; Thompson, 2007) and one in relation to stroke (Brereton, 2007) – see Table 4.4.

Table 4.4 Coping outcomes for carers in reviews reporting quantitative synthesis

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
Parker 2008	Range of interventions incl. psycho-education, multi-component	Dementia							
	Psycho-education		Standardised mean difference (random)	4 in meta-analysis	Various reported but not clear which were used in studies in meta-analysis	0.30	-.04 to .65	Not reported NS	Not reported
Thompson 2007	Information, carer support	Dementia	Standardised mean difference (random)	2 in meta-analysis	Not reported – defined as 'self-efficacy'	0.37	-.20 to 1.02	.26	Not reported
Brereton 2007	Carers intervention	Stroke	Narrative	3 apparently	Only one mentioned is Utrecht Coping List (1 study)	Reports positive impact on coping skills in two studies (face-to-face psychosocial support; telephone-based support), and no impact in the third (telephone-based support).			

Neither dementia review found evidence of positive impact on carers' coping, either from a range of psychsocial interventions (Parker, 2008) or from information or carer support (Thompson, 2007). In relation to those caring for people who had had a stroke, there were no consistent messages (Brereton, 2007). One of the trials reviewed - of face-to-face psychsocial support - and another about telephone-based support, reported positive effects, while a third, that also tested the effect of telephone-based support, showed no impact.

4.2.6 Satisfaction

Three reviews synthesised quantitative information on carers' satisfaction with a range of issues. Smith (2009) looked at satisfaction with two types of information in those caring for people who had had a stroke, Mason (2007) at satisfaction with respite care for those caring for frail older people, and Martire (2008) at carers' satisfaction with their relationship with the person with a chronic illness that they were looking after. As Table 4.5 shows, no review identified any evidence of positive impact of the interventions in question on these different types of satisfaction.

Table 4.5 Satisfaction for carers in reviews reporting quantitative synthesis

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
Smith 2009	Information	Stroke							
	Information on recovery and rehabilitation		Odds ratio	2 for meta-analysis	Pound Scale or version of it	1.78	0.88 to 3.60	.11	
	Information on allowances and services		As above	3 for meta-analysis	As above	1.30	.71 to 2.37	.39	
Mason 2007	Respite	Frail elderly	Narrative	3 out of 13 that reported significance of between group differences	Various	All three reported significantly higher levels of satisfaction with respite, compared with usual care or the provision of information and a single counselling session			Not reported
Martire 2004	Family psychosocial intervention	Chronic illness (included dementia and wide range of other conditions)	Mean weighted effect size (d) – random effects	6	Not reported	0.08	-.27 to .10	.38	First available follow-up

4.2.7 Well-being or quality of life

Only five reviews reported carer well-being or quality of life outcomes; one related to interventions to support carers of people with dementia (Parker, 2008); two to stroke (interventions to support carers, Brereton, 2007; information, Smith, 2009); and two to respite care for people looking after frail older people (Mason, 2007; Shaw, 2009).

Table 4.6 shows a degree of inconsistency in the conclusions reached in the different reviews. Parker (2008) suggests a positive effect of psycho-education on dementia carers' 'subjective well-being' (though see the comment at the bottom of Table 4.6). By contrast, Shaw (2009) found an overall negative effect of respite care on the quality of life of those looking after frail older people in meta-analysis of results from three studies. Mason (2007), reviewing the evidence on respite care for carers of frail older people, found only one trial with a significant effect on carers' quality of life, and, again, this was negative. Brereton (2007) and Smith (2009) found no evidence of consistent positive effect of support or information, respectively, on carers of people who have had a stroke.

Although the Mason (2007) and Shaw (2009) reviews had a common focus, they took rather different approaches to what constituted a measure of well-being or quality of life (and thereby what was included in the synthesis) and included different studies when looking at this outcome. Thus, while Shaw (2009) had identified and included in their review all the studies that Mason (2007) used in their synthesis of results on quality of life or well-being, they did not include any of them in *their* meta-analysis of this outcome. By contrast, none of the studies included in the Shaw (2009) meta-analysis was included in the Mason (2007) review. This was not simply a result of the later date of the Shaw (2009) review, as two of these studies had been published well before the Mason (2007) literature searches were completed. However, while puzzling, this differential inclusion of studies does allow a greater degree of security about common findings drawn from different studies.

Table 4.6 Well-being and quality of life outcomes for carers in reviews reporting quantitative synthesis

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
Parker 2008	Range of interventions incl. psycho-education, multi-component	Dementia							
	Psycho-education		Standardised Mean Difference (random)	5	Relatives Stress Scale; State Trait Anxiety Scale; Perceived Stress Scale; 'one-off' distress measure[1]	0.16	-.32 to 0	.04	Not reported
Brereton 2007	Carers intervention	Stroke	Narrative	5	SF36 (2 studies); EuroQol (2 studies).	Only one study reported any positive effect on carers' quality of life.			
Smith 2009	Information	Stroke							
	Passive information intervention		Narrative	1	Not reported	No evidence of effect on carer perceived quality of life			
	Active information intervention		Narrative	3	EuroQol visual analogue scale; SF36; not reported	One trial found positive effect. Other two found no positive effect or effect in relation to one domain only (social functioning).			Not clear
Mason 2007	Respite	Frail elderly	Narrative	4	Various, including measures covering physical and psychological health, burden and carer attitudes	Only one study reported any significant effect on carers' quality of life and this was negative.			
Shaw 2009	Respite	Frail elderly		3 single group before and after studies					

First author and date	**Type of intervention/sub-group analysis**	**Condition**	**Analytical approach**	**N of studies**	**Measures used**	**Meta-analysis results**	**95% CI**	**p value**	**Calculated at:**
	At first or only follow-up		Mean effect size (random)	Quality of Life in Alzheimer's Disease; Quality of Life Index; Self-Anchoring Striving Scale.	3	-0.18	-0.35 to -0.01	.043	6-12 m follow-up
	At final or only follow-up		Mean effect size (fixed)	As above	3	-0.22	-0.27 to -0.17	<.001	6-12m follow up

1. Parker (2008) defines these as measures of 'subjective well-being'. We include them here, although they might be better seen as measures of stress.

EuroQoL	EuroQoL Quality of Life Measure
SF 36	Short Form (36) Health Survey

4.2.8 Ability or knowledge

As shown in Table 4.7, five of the reviews that synthesised quantitative data reported studies that had included impact on carers' abilities (as carers) or knowledge as outcomes. One was the review of psychosocial interventions for carers of people with dementia (Brodaty, 2007); two were about carers of people who had had strokes (Brereton, 2007, support interventions; Smith, 2009, information); one was about respite care for those looking after frail elderly people (Mason, 2007); and the fifth was the Tong (2008) review of carer support for those looking after people with chronic kidney disease.

Given that the focus of the Smith (2009) review was solely on information interventions, it is perhaps not surprising that a positive impact on carer knowledge about stroke was detected in the meta-analysis. Brodaty (2003) similarly reported a significant impact on carers' knowledge from RCTs of psychsocial interventions. Tong (2008) reported that the two included studies of carer support interventions found evidence of increased carer knowledge about chronic kidney disease afterwards and the single study (of education and counselling for stroke carers) in Brereton (2007) also found improved carer knowledge at follow-up. The only review not to find positive impact on carers knowledge was Mason (2007) which, given its focus on respite care, is perhaps not surprising.

Table 4.7 Ability or knowledge in relation to caring for carers in reviews reporting quantitative synthesis

First author and date	Type of intervention/sub-group analysis	Condition	Analytical approach	N of studies	Measures used	Meta-analysis results	95% CI	p value	Calculated at:
Brodaty 2003	Psychosocial interventions	Dementia	Weighted mean effect size (random)	Said to be 8 but difficult to see how many were RCTs	Alzheimer's Disease Knowledge Test, Dementia Quiz, Dementia Knowledge Test and 'other individual knowledge measures'.	0.51	.05 to .98	Not reported. Significant	'Most current' follow-up – post-test for most.
Brereton 2007	Carers intervention	Stroke	Narrative	1 RCT	'SCIT' – carer knowledge of stroke	1 study of education and counselling improved carer knowledge at both follow-up points			6m and 12m
Smith 2009	Information	Stroke	Standardised mean difference (random)	4/6 RCTs included in meta-analysis	Majority 'one-off' and not validated	0.74	.06 to 1.43	.03	Not clear
Mason 2007	Respite	Frail elderly	Narrative	1 RCT	'Carer attitude' measure included assessment of caring 'competence'	No difference found between groups			?12m
Tong 2008	Carer support	Chronic kidney disease	Narrative	2 before and after	Not reported	Both studies found evidence of increased carer knowledge about the condition at post-test assessment			1 week (1 study); 5 months (1 study)

4.2.9 Overall conclusions drawn by included reviews

The conclusions from the reviews included in our analysis are not strong. In this sub-section, we summarise the overall conclusions that the authors of the 13 reviews that use a predominantly quantitative approach to synthesis came to, grouping them by the condition of the person carers were supporting. We also add any comments that we feel need to be made about the reviews and the security of their findings.

Carers of people with dementia

Selwood (2007) concluded that there was ‘consistent, excellent evidence’ (p.86) that six or more sessions of individually-based behaviour management training (IBMT) was effective both immediately and in the longer-term in alleviating carers’ depression. It also concluded that there was good evidence that individual and group carer support interventions alleviated ‘depression and distress’ immediately and for some months. The review’s authors point out that the research literature on support for carers often fails to describe adequately what is actually being delivered, whether it is consistently implemented and the overlap of types of interventions between categories. They also say that findings are limited by the lack of good quality studies. Despite this, however, they remain convinced of their findings about the effectiveness of individually based behaviour management training.

There are some problems with the Selwood (2007) review, not least of which is the apparent ‘double counting’ of a single RCT reported in different publications at different stages of the trial. This means that there are actually only two high quality studies in support of the effectiveness of IBMT in reducing depression, and in one of these, follow-up measurement was carried out only in the intervention group. There is no clear account of the measures used to address depression, burden or stress/distress, and the latter two are sometimes used interchangeably. The other issue is the lack of any placebo condition in the studies said to support the effectiveness of IBMT. Some IBMT interventions included very substantial contact between carers and professionals, which raises the very real possibility of an effect on depression that has nothing to do with the content of the intervention.

The Acton (2001) review concludes from meta-analysis that a range of interventions designed to reduce carer burden had no effect on it or, in some cases, had a negative effect. However, this is not entirely the case as the meta-analysis in this review did show a positive effect on carer burden from interventions defined as education.

Brodaty (2003) concludes that carer interventions, broadly defined, show some modest but significant positive impact on carer knowledge, psychological morbidity, and some other outcome measures such as coping. However, the review does acknowledge the small numbers involved in some of the studies contributing to these conclusions.

Our view is that the Brodaty (2003) review's conclusion overstates the case. There is no reporting of the quality of the studies used in the meta-analysis, although the authors claim that there was no significant correlation between study quality and reported effect sizes. However, this relationship was tested only for some outcomes and results are not reported directly in the publication. The other weakness of this review, compared to some others included here, is that it aggregates results from a very wide range of carer support interventions. While this means we can say that something might be better than nothing for carers of dementia sufferers, it provides no help in understanding whether some types of 'something' are more worthwhile than others.

The overall conclusion of Thompson (2007) is that only group interventions, underpinned by psycho-educational theoretical foundations, appear to have a positive impact on depression. However, they raise the question of whether the benefits are clinically, rather than simply statistically, significant, and point to issues of study quality and samples. For example, some studies selected participants on the basis of existing psychological ill-health so might, therefore, have had more scope for demonstrating impact. By contrast with psycho-educational interventions, this review found no evidence that information or support group interventions were uniformly effective.

Parker (2008) concludes that the meta-analysis of evidence from RCTs shows that psycho-education has a small and immediate effect in reducing carer depression and in improving subjective well-being. However, this conclusion was reached when all but one of the studies in their analysis crossed the line of effect i.e. were statistically inconclusive. As a result, the authors state, more studies of this type of intervention, using standardised measures and adequate sample sizes are needed. In relation to generic support interventions, the overall conclusion that this type of intervention might reduce burden is, again, couched around with recommendations for the need for more and better research. Similarly, multi-component interventions may have some impact on carer depression and burden, but this remains to be tested adequately in good quality research. Finally, this review aggregated the results of all the interventions included and came to the same conclusion as Brodaty (2003), that something is probably better than nothing, but with the suggestion that psycho-education might be the best 'something'.

Our conclusion is that the results of the meta-analysis in Parker (2008) are emphasised at the cost of synthesis of the studies that were not entered into the meta-analysis. This may have given an undue weight to the meta-analysis results. For example, only eight of the 13 studies of psycho-education were in the meta-analysis. Further, there was no reported synthesis – either narrative or meta-analysis – of the results of studies of ‘other’ interventions.

The Lee (2004) review of respite care comes to the stark conclusion that current evidence does not allow any reliable conclusions to be drawn about the efficacy of respite care for carers of people with dementia, reflecting the lack of high quality research in this area.

Carers of people who have had a stroke

Brereton (2007) concludes that all the carer interventions reviewed had some positive impact for carers, but only training carers in nursing and personal care techniques and providing ‘problem-solving partnerships’ and support had any significantly positive effects on carers’ quality of life and well-being. Telephone-based support and a group or home-visit support programme were the only interventions to have a positive impact on carers’ coping skills. Further, the review points to the overall low quality of the studies reviewed, small sample sizes and the lack of power calculations for most. Differences in baseline characteristics between intervention and control participants were often not controlled for in analysis of individual studies, there was variety and inconsistency in the outcomes and the interventions studied, and around half of the studies reviewed had no theoretical underpinnings. Overall, then, the review exposed poor quality studies and a weak evidence base.

By contrast with Brereton (2007), the Lee (2007) review does conclude that the education and carer support interventions included did improve the mental health of carers. However, this review was very narrow in its focus, including only studies that used the SF-36 as an outcome measure.

The Smith (2009) review also had a more restricted focus than some reviews we included. Here, only interventions intended to provide carers with information were reviewed. As one might have hoped, the analysis did show that information increased carers’ knowledge of stroke, leading the authors to conclude that providing information routinely to stroke patients and their carers would be worthwhile. However, they found no evidence to suggest that better knowledge led to any other types of improved carer outcomes. While the review was not able to identify the best way of providing information, the results did suggest that strategies that involved carers’ active participation, and that had planned follow-up to provide clarification and reinforcement were better than ‘passive’ information strategies. As with so many other of the reviews, the authors point to variable quality of RCTs available to provide evidence.

Carers of frail older people

As we have seen above, the two reviews of respite care for frail older people appeared to come to rather different conclusions despite including many of the same studies.

The overall assessment of Mason (2007) is that respite care has a small positive effect on carer burden and carers' mental or physical health. There is also some tentative evidence that some types of carers may benefit more than others do. However, carer satisfaction with all types of respite is generally high and carers appear more satisfied with respite care than with usual care. However, the authors also conclude that much of the existing literature is unable to inform policy and practice, because of its poor quality.

The Shaw (2009) review also found a small but statistically non-significant impact on carers' depression in the short term (up to six months) but not over the longer term. There was no consistent evidence of any impact on anxiety or carer burden. Analysis of the results of three studies suggested that respite might have a *negative* impact on carers' quality of life.

Carers of people with chronic illness

The Tong (2008) review of support for carers of people with chronic kidney disease found a very weak evidence base and no findings that would confirm the benefit of carer interventions.

Martire (2004), in a very wide-ranging review (both in terms of the conditions and interventions covered) concluded that the strongest evidence of efficacy was in relation to burden, with an overall effect and a significant effect with every sub-group of 'moderators'. Interventions also appeared to result in reduced depression in carers and to reduced anxiety if they focused on relationship issues between the carer and the person with the chronic condition.

The findings from this review are driven in very large part by the high number of dementia studies included. There is thus substantial overlap between this review and those that focused specifically on dementia. This makes the contrast in findings between the reviews difficult to explain. However, the Martire (2004) review made no reference to the quality of the studies included in the meta-analysis and, although it is difficult to tell from the publication, there were two very large trials (of unknown quality) that seem to have dominated some of the findings. Alone among the reviews included here, however, Martire (2004) did address the issue of unknown selection effects when randomisation is done via the 'patient' but trials fail to involve all carers. Unless there is a high response rate from carers, bias is very likely; to deal with this issue the Martire (2004) review included only those studies where the proportion of carers enrolled was at least 90 per cent of the number of patients enrolled. This still does not mean, however, that carers have been randomised to the intervention or not.

4.2.10 Overall conclusions from the meta-review of quantitative findings on outcomes

In this final sub-section, we outline the conclusions of our meta-review, based on our synthesis of 13 higher quality reviews that adopted a quantitative approach to synthesis and our views of their methodological strengths and weaknesses.

This part of our meta-review finds no evidence for the impact of respite care on physical health for those caring for frail older people, or of support interventions, widely defined, for carers of dementia sufferers. Only two reviews dealt with this outcome and relatively few of the primary studies they reviewed evaluated the impact of intervention on carers' physical health. This is an obvious gap in the research evidence, given that we know that carers' physical health can be affected by caring.

Mental health was an outcome included in most of the reviews included in this section, but despite the amount of material reviewed, the conclusions that can be drawn are limited. There is some evidence to suggest that psychosocial support for carers of people with dementia may have a positive impact on depression in carers, but it is not clear which particular interventions might be best. Further, the overlap of studies in the dementia reviews means that the strength of this evidence is exaggerated. The more focused reviews of interventions for carers of people who had had a stroke suggested that educating or training carers or intervening with 'active' information strategies did improve mental health outcomes. This seems a relatively secure finding from these reviews, given their careful selection of RCTs and of single outcome measures. Further, while there was overlap in the trials included in these reviews, the fact that each selected a different measure of mental health outcome means that the evidence is not exaggerated in the way that it was in relation to dementia.

Results from the two reviews of respite care for those caring for frail older people came to contradictory conclusions, one showing a positive effect of respite on carers' mental health, the other showing negative effects. Given that the two reviews did not use the same studies to come to their conclusions, it seems that the evidence about this outcome remains inconclusive.

One review (Martire, 2004) covered a diverse range of conditions, although most of the primary studies included were about dementia carers. This review, alone among those we have included here, reported many positive findings in its meta-analysis of impact of interventions on carers' mental health. Some of these findings seemed in direct contrast to those in other reviews. There were methodological issues with this review that make it difficult to know how much weight to put on its findings.

None of the reviews, with the exception of Martire (2004) and of Parker (2008), found any evidence of positive impact of any type of intervention on carers' burden. Again, the findings of the Martire (2004) sub-group analysis of studies about dementia were in direct contrast to those of the reviews that specifically focused on dementia.

There was no evidence of a positive impact of interventions on coping among carers looking after people with dementia. One review of those caring for people who had had a stroke suggested that support for carers might have some positive effect on their coping, but this finding was based on two studies only.

No review found any evidence of interventions having a positive impact on carers' satisfaction levels.

The evidence on the impact of interventions on carers' well-being or quality of life is varied but this, in part, seems related to the nature of the intervention. Thus, there is a suggestion from both reviews covering respite care for people looking after frail older people, that it has a *negative* impact on measures of carers' well-being or quality of life. This finding is strengthened by the fact that the two reviews did not include the same studies when carrying out their synthesis of findings. A single review of studies about dementia found a positive effect of psycho-education on carers' 'subjective well-being', although the measures used in the synthesis were largely measure of stress or anxiety. By contrast, two reviews of interventions to support people caring for those who had had a stroke found no evidence of consistent positive effects on carers' well-being or quality of life.

As one would hope, reviews of education, training or information interventions did suggest that carers' knowledge or abilities (as carers) improved when they received the intervention. By contrast, the only review that included this outcome not to find a positive impact was one that examined the effects of respite care on those looking after frail older people.

4.3 Cost-effectiveness of interventions to support carers

Although five reviews in total looked for outcomes related to costs of interventions or costs to carers (including the time they spent on caring) only two (Mason, 2007; Shaw, 2009) addressed the issue of cost-effectiveness in their analysis. The Mason 2007 review included only five primary studies, two of which were based on RCTs, that included economic evaluation of respite care that considered outcomes for carers. All of these compared day respite care with 'usual' care. Of the five studies, only one was based in the UK, making generalisation of findings from the others difficult. In addition, this review found three studies of respite care that included information about its costs, only one of which was about the UK. Other studies found included respite as part of multi-dimensional support programmes and economic evaluations of respite care that did not report outcomes for carers.

The overall conclusion from the Mason (2007) review was that the five economic evaluations suggested that ‘day care tended to be associated with higher costs and either similar or a slight increase in benefits, relative to usual care’ (p.xii). However, poor reporting in the primary studies was felt to limit their potential for exploring how applicable their findings were to the UK.

Shawl (2009) identified and included exactly the same five economic evaluations as Mason (2007) and came to broadly the same conclusions.

Chapter 5 Conclusions

In this concluding chapter, we discuss the implications of the material reported in Chapters 3 and 4, both for practice and for research. First, however, we outline the strengths and limitations of our meta-review, of the reviews we drew on to carry out our work, and of the underlying primary research that informed those reviews.

5.1 Strengths and limitations

5.1.1 The meta-review

This meta-review has been carried out over a relatively short time (six months) and, as was always intended, has scoped the evidence base and attempted to synthesise the overall messages and their strength from higher quality reviews of evidence. This work was never intended to be a full meta-review of evidence. However, our approach has been systematic, with a clear search strategy, fully documented inclusion and exclusion criteria, decisions on inclusion and exclusion made by two people, and with clear and documented data extraction. It has also involved quality appraisal of the identified reviews and we have synthesised material only from the higher quality reviews.

5.1.2 The included reviews

Despite our decision only to include the higher quality reviews in our synthesis of findings, weaknesses in the conduct of some of them became clear as we progressed.

As we outline in Chapter 3, some reviews were not careful about identifying all the papers related to individual studies and thus might have come to different conclusions about them from those reviews that did identify all outputs. So, for example, an early paper about an intervention study might report early, positive findings when a later paper, based on a completed sample or further analysis, might be more circumspect.

A related issue was that some reviews were not careful about ensuring that all publications included were independent of one another. As a result, some reviews treated, say, results from two papers as from two different studies, when in fact they were from the same study but reporting findings at different stages of sample formation. Multiple publication of the same results, but with differential authorship, was also a danger here.

The quality of reporting of methods, results (in terms of papers found), and synthesis of outcomes was variable, making it difficult for us sometimes to know what weight to put on the findings reported. A particular problem in some reviews was synthesis of quantitative data on outcomes from several studies, without it being clear whether the outcome measures or the study designs warranted meta-analysis of the type carried out.

5.1.3 The primary studies

Almost without exception, the authors of the higher quality reviews referred to the poor overall quality of the studies they reviewed. Those reviews that took the approach of including only the highest quality RCTs, for example Lee (2004), ended up with very few studies to review and no opportunities to synthesise findings on outcomes from more than one study. Other reviews took the approach of including a wide range of types and quality of study, but then found themselves hampered in what they could say about overall messages from their work, because of the average quality of the studies they included.

A particular weakness in the evidence base is the lack of studies that can throw any light onto the cost-effectiveness of interventions to support carers. Where there is evidence of effectiveness there is rarely evidence of costs, whether to health and social care services or to carers and families themselves.

Another issue with the primary evidence is the apparent absence of what we might call ‘proof of principle’ for the interventions being evaluated. Several reviews pointed to the lack of any conceptual or theoretical underpinnings for the interventions, which indicates that there had been no attempt to carry out what, in more clinically oriented research, are called phase 1 and 2 trials. In these stages, interventions are developed based on clear theoretical understanding about how one might *expect* them to work and which outcomes one would *expect* them to affect. They are then piloted to see if they do have any apparent effect on these outcomes. If they do (that is they have been shown to be efficacious) then, and only then, would the evaluation proceed to compare the new intervention with existing interventions or services (that is, to test their effectiveness). Without this preliminary research, it is perhaps not surprising to find that so many evaluations of interventions appear to find no positive impact.

5.2 Implications for practice and research

As we outlined in chapter 1, this review was not intended to examine evidence about the ways in which generic services directed to the person being supported might also act to support carers. Rather, our focus was on interventions specifically targeted at carers and which had, in many cases, been developed with this particular aim. This is an important point because, as we know from other types of research, the services that the person being supported receives are often crucial to the carers’ own health and well-being.

The strongest evidence of effectiveness of any sort from our meta-review is in relation to education, training and information for carers. As one would hope, interventions of this type, particularly when active and targeted rather than passive and generic, increase carers’ knowledge and abilities as carers. There is some suggestion that this might thereby also improve carers’ mental health or their coping. However, this latter conclusion remains to be tested rigorously in research specifically designed to do so and which explores both effectiveness and costs.

Beyond this, there is little secure evidence about any of the interventions included in the reviews. We must emphasise that this is **not** the same as saying that these interventions have no positive impact. Rather what we see here is poor quality research, often based on small numbers, testing interventions that have no theoretical ‘backbone’, with outcome measures that may have little relevance to the recipients of the interventions. The evidence on respite care is the key example of this. While qualitative evidence shows that respite care is often a lifeline for carers, the research that has evaluated it has often been too small to allow statistically significant effects to be identified, has been poorly designed, and has used outcome measures that are sometimes frankly baffling. To take a single example from a study included in one of the reviews, why would we expect respite care to increase carers’ knowledge, or to improve their sleep patterns *after* it has finished?

In sum, the meta-review raises important questions about the scientific quality of the primary research studies, which in turn casts doubt on the weight of the evidence presented in the systematic reviews. The size and complexity of the issue of providing carers with the best possible support to enable them to continue helping those they love deserves better primary research than our meta-review has uncovered.

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Appendix A Literature Search Strategies

The Cochrane Database of Systematic Reviews (CDSR)
Database of Abstracts of Reviews of Effects (DARE)
Health Technology Assessment Database (HTA)
NHS Economic Evaluations Database (NHS EED)
via the Cochrane Library
(http://www3.interscience.wiley.com/cgi-bin/mrwhome/106568753/HOME)
2009 issue 3
Search date: 13 August 2009.

The search strategy below retrieved 2,261 records in total, 173 from CDSR, 48 from DARE, 16 from HTA and 172 from NHS EED.

#1 MeSH descriptor **Caregivers,** this term only (838)
#2 MeSH descriptor **Respite Care,** this term only (26)
#3 caregiv*:ti,ab (1594)
#4 care NEXT giv*:ti,ab (123)
#5 carer*:ti,ab (494)
#6 "informal care":ti,ab (48)
#7 befriending:ti,ab (26)
#8 caretak*:ti,ab (100)
#9 care NEXT taker*:ti,ab (2)
#10 care NEXT taking:ti,ab (17)
#11 children NEXT caring:ti,ab (176)
#12 families NEXT caring:ti,ab (45)
#13 families NEAR/2 support:ti,ab (223)
#14 respite:ti,ab (42)
#15 (parent OR parents OR mother OR mothers OR father OR fathers) NEAR/2 care:ti,ab (104)
#16 (parent OR parents OR mother OR mothers OR father OR fathers) NEAR/2 caring:ti,ab (104)
#17 (parent OR parents OR mother OR mothers OR father OR fathers) NEAR/2 support:ti,ab (127)
#18 (parent OR parents OR mother OR mothers OR father OR fathers) NEAR/2 supporting:ti,ab (127)
#19 (sons OR daughters OR friends) NEAR/2 care:ti,ab (3)
#20 (sons OR daughters OR friends) NEAR/2 caring:ti,ab (3)
#21 (sons OR daughters OR friends) NEAR/2 support:ti,ab (19)
#22 (sons OR daughters OR friends) NEAR/2 supporting:ti,ab (19)
#23 (husband* OR wives OR wife OR spouse* OR grandparent* OR grandchild* OR neighbour* OR neighbor* OR relatives) NEAR/2 care:ti,ab (56)

#24 (husband* OR wives OR wife OR spouse* OR grandparent* OR grandchild* OR neighbour* OR neighbor* OR relatives) NEAR/2 caring:ti,ab (56)
#25 (husband* OR wives OR wife OR spouse* OR grandparent* OR grandchild* OR neighbour* OR neighbor* OR relatives) NEAR/2 support:ti,ab (38)
#26 (husband* OR wives OR wife OR spouse* OR grandparent* OR grandchild* OR neighbour* OR neighbor* OR relatives) NEAR/2 supporting:ti,ab (38)
#27 (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17 OR #18 OR #19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26), from 2000 to 2009 (2261)

MEDLINE

(OvidSP) (http://ovidsp.ovid.com/))
1950 to August Week 1 2009
Search date: 13 August 2009

The search strategy for MEDLINE below incorporated the Hedges optimised sensitivity and specificity balanced search filter for retrieval of systematic reviews in MEDLINE.(2) 3,258 records were retrieved.

1 Caregivers/ (13,630)
2 Respite Care/ (750)
3 caregiv$.ti,ab. (19,580)
4 care giv$.ti,ab. (2,914)
5 carer$.ti,ab. (4,762)
6 informal care.ti,ab. (530)
7 befriending.ti,ab. (49)
8 caretak$.ti,ab. (2,371)
9 care taker$.ti,ab. (86)
10 care taking.ti,ab. (149)
11 children caring.ti,ab. (18)
12 families caring.ti,ab. (159)
13 (families adj2 support).ti,ab. (671)
14 respite.ti,ab. (873)
15 or/1-14 (34688)
16 meta-analysis.mp,pt. (36,230)
17 review.pt. (1478504)
18 search$.tw. (138,593)
19 16 or 17 or 18 (1590624)
20 15 and 19 (5352)
21 limit 20 to yr="2000 - Current" (3,625)
22 limit 21 to english language (3,279)
23 (animals not (humans and animals)).sh. (3335965)
24 22 not 23 (3,258)

MEDLINE(R) In-Process & Other Non-Indexed Citations

(OvidSP) (http://ovidsp.ovid.com/)
August 12, 2009
Search date: 13 August 2009

The search strategy below retrieved 1,249 records.

1 caregiv$.ti,ab. (1,006)
2 care giv$.ti,ab. (101)
3 carer$.ti,ab. (229)
4 informal care.ti,ab. (31)
5 befriending.ti,ab. (4)
6 caretak$.ti,ab. (76)
7 care taker$.ti,ab. (3)
8 care taking.ti,ab. (5)
9 children caring.ti,ab. (2)
10 families caring.ti,ab. (2)
11 (families adj2 support).ti,ab. (21)
12 respite.ti,ab. (30)
13 or/1-12 (1,416)
14 (animals not (humans and animals)).sh. (8)
15 13 not 14 (1,416)
16 limit 15 to (english language and yr="2000 -Current") (1,249)

EMBASE

(OvidSP) (http://ovidsp.ovid.com/)
1996 to 2009 Week 32
Search date: 13 August 2009

The search strategy for EMBASE below incorporated the Hedges best optimization of sensitivity and specificity filter for retrieval of systematic reviews in EMBASE (3) 3,335 records were retrieved.

1 Caregivers/ (14,247)
2 Caregiver support/ (404)
3 Respite Care/ (52)
4 caregiv$.ti,ab. (13,912)
5 care giv$.ti,ab. (1,903)
6 carer$.ti,ab. (3,729)
7 informal care.ti,ab. (427)
8 befriending.ti,ab. (36)
9 caretak$.ti,ab. (1,746)

10 care taker$.ti,ab. (47)
11 care taking.ti,ab. (107)
12 children caring.ti,ab. (11)
13 families caring.ti,ab. (76)
14 (families adj2 support).ti,ab. (410)
15 respite.ti,ab. (555)
16 or/1-15 (25,547)
17 meta-analys$.mp. (45,771)
18 search$.tw. (113,996)
19 review.pt. (949,302)
20 17 or 18 or 19 (1055401)
21 16 and 20 (5,042)
22 limit 21 to yr="2000 - Current" (3,877)
23 limit 22 to english language (3,348)
24 exp Animal/ (18,283)
25 exp animal-experiment/ (1309394)
26 nonhuman/ (3265067)
27 (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs
or cat or cats or bovine or sheep).ti,ab,sh. (2090786)
28 24 or 25 or 26 or 27 (3686268)
29 exp human/ (6639651)
30 exp human-experiment/ (260459)
31 29 or 30 (6640519)
32 28 and 31 (674397)
33 28 not 32 (3011871)
34 23 not 33 (3,335)

PSYCINFO

(OvidSP) (http://ovidsp.ovid.com/)
1987 to 2009 August Week 2
Search date: 13 August 2009

The search strategy for PSYCINFO below incorporated an adapted version of the Centre for Reviews and Dissemination search strategy for retrieving reviews from PSYCINFO. 1,800 records were retrieved.

1 Caregivers/ (12,084)
2 Respite Care/ (335)
3 caregiv$.ti,ab. (20,155)
4 care giv$.ti,ab. (1,171)
5 carer$.ti,ab. (3,626)

6 informal care.ti,ab. (358)
7 befriending.ti,ab. (102)
8 caretak$.ti,ab. (2,343)
9 care taker$.ti,ab. (23)
10 care taking.ti,ab. (84)
11 children caring.ti,ab. (34)
12 families caring.ti,ab. (141)
13 (families adj2 support).ti,ab. (687)
14 respite.ti,ab. (797)
15 or/1-14 (28,958)
16 metaanaly*.ti,sh. (46)
17 meta-analy*.ti,sh. (5,905)
18 cochrane*.ti. (53)
19 (review* or overview*).ti,ab. (227,742)
20 meta analysis/ (2,654)
21 meta analysis.md. (6,705)
22 (review adj2 literature).ti. (1,316)
23 "literature review".md. (54,597)
24 "systematic review".md. (2,201)
25 (synthes* adj3 (literature* or research or studies or data)).ti. (301)
26 pooled analys*.ti,ab. (172)
27 ((data adj2 pool*) and studies).ti,ab. (283)
28 ((hand or manual* or database* or computer* or electronic*) adj2 search*).ti,ab. (2,370)
29 ((electronic* or bibliographic*) adj2 (database* or data base*)).ti,ab. (808)
30 or/16-29 (245,186)
31 ("review software other" or "review media" or editorial or letter or "review book").dt. (71,769)
32 (electronic collection or dissertation abstract or encyclopedia).pt. (189,923)
33 (rat or rats or mouse or mice or hamster or hamsters or animal or animals or dog or dogs or cat or cats or bovine or sheep).ti,ab,sh. (114,179)
34 31 or 32 or 33 (351,118)
35 30 not 34 (175,835)
36 15 and 35 (3,035)
37 limit 36 to (english language and yr="2000 -Current") (1,800)

Health Management and Information Consortium (HMIC)

(OvidSP) (http://ovidsp.ovid.com/)
July 2009
Search date: 13 August 2009

The search strategy for HMIC incorporated a strategy for finding reviews which was translated from the Centre for Reviews and Dissemination search strategy for retrieving reviews from ASSIA. This was used to search the database for the period 2000-2007. For 2008-2009 all document types were retrieved to capture any recent reports or grey literature. 928 records in total were retrieved.

1 Carers/ (3,214)
2 Informal Care/ (380)
3 exp Respite Care/ (419)
4 caregiv$.ti,ab. (822)
5 care giv$.ti,ab. (250)
6 carer$.ti,ab. (6,677)
7 informal care.ti,ab. (392)
8 befriending.ti,ab. (87)
9 caretak$.ti,ab. (96)
10 care taker$.ti,ab. (2)
11 care taking.ti,ab. (44)
12 children caring.ti,ab. (26)
13 families caring.ti,ab. (82)
14 (families adj2 support).ti,ab. (463)
15 respite.ti,ab. (690)
16 or/1-15 (9,632)
17 exp LITERATURE REVIEWS/ (4,537)
18 meta analysis/ (386)
19 (metaanaly$ or meta-analy$).ti,ab. (962)
20 (meta study or meta synthes$ or meta evaluat$).ti,ab. (13)
21 (synthes$ adj3 (literature$ or research$ or studies or data or trials or findings or evidence)).ti. (55)
22 quantitative synthes$.ti,ab. (22)
23 pooled analys$.ti,ab. (36)
24 ((data adj3 pool$) and studies).ti,ab. (65)
25 (pooling adj2 studies).ti,ab. (4)
26 (medline or medlars or embase or cinahl or cochrane or scisearch or psychinfo or psycinfo or psychlit or psyclit).ti,ab. (1,368)
27 ((hand or manual$ or database$ or computer$ or electronic$) adj3 search$).ti,ab. (997)
28 ((electronic$ or bibliographic$) adj3 database$).ti,ab. (717)
29 review$.ti,ab. (36,940)

30 overview$.ti,ab. (4,990)
31 evaluation synthes$.ti,ab. (4)
32 evaluation review$.ti,ab. (42)
33 what works.ti,ab. (2,213)
34 or/17-33 (44,572)
35 16 and 34 (1,630)
36 limit 35 to yr="2000 - 2007" (684)
37 limit 16 to yr="2008 -Current" (244)

CINAHL

(EBSCO) (http://www.ebscohost.com/)
1982-present
Search date: 14 August 2009

The search strategy below incorporates a section to restrict the search to reviews only. This part of the strategy was based on the Centre for Reviews and Dissemination search strategy for retrieving reviews from CINAHL. 2150 records were retrieved.

S39 S37 and S15 Limiters - English Language; Published Date from: 200001- (2,150)
S38 S37 and S15 (2,876)
S37 S35 not S36 (166,046)
S36 PT book review (5,950)
S35 S16 or S17 or S18 or S19 or S20 or S21 or S22 or S23 or S24 or S25 or S26 or S27 or S28 or S29 or S30 or S33 or S34 (170,040)
S34 AB review* or AB overview* (99,837)
S33 S31 and S32 (30,245)
S32 AB systematic* or AB methodologic* or AB quantitative* or AB research* or AB literature* or AB studies or AB trial* or AB effective* (296,893)
S31 PT review (69,370)
S30 TX electronic* N2 database* or TX electronic* N2 data base* or TX bibliographic* N2 database* or TX bibliographic* N2 data base* (1,994)
S29 (MH "Reference Databases+") or (MH "Reference Databases, Health+") (13,771)
S28 TX hand N2 search* or TX manual N2 search* or TX database* N2 search* or TX computer* N2 search* (8,500)
S27 TX pooled analy* or TX data N2 pool* (1,355)
S26 TX medline or medlars or embase or scisearch or psycinfo or psychinfo or psychlit or psyclit (16,684)
S25 TX synthes* N3 literature* or TX synthes* N3 research or TX synthes* N3 studies or TX synthes* N3 data (2,779)

S24 (MH "Literature Searching+") or (MH "Computerized Literature Searching+") (5,201)
S23 (MH "Literature Review+") (7,392)
S22 TI review* or TI overview* (53,557)
S21 PT systematic review (15,347)
S20 PT nursing interventions (779)
S19 AB cochrane or TI Cochrane (6,743)
S18 TI meta-analy* or AB meta-analy* (6,648)
S17 TI metaanaly* or AB metaanaly* (207)
S16 (MH "Meta Analysis") (8,222)
S15 S1 or S2 or S3 or S4 or S5 or S6 or S7 or S8 or S9 or S10 or S11 or S12 or S13 or S14 (1,768)
S14 TI respite or AB respite (712)
S13 TI families N2 support or AB families N2 support (756)
S12 TI families caring or AB families caring (141)
S11 TI children caring or AB children caring (11)
S10 TI care taking or AB care taking (86)
S9 TI care taker* or AB care taker* (26)
S8 TI caretak* or AB caretak* (681)
S7 TI befriending or AB befriending (29)
S6 TI informal care or AB informal care (309)
S5 TI carer* or AB carer* (4,682)
S4 TI care giv* or AB care giv* (1,577)
S3 TI caregiv* or AB caregiv* (14,923)
S2 (MH "Respite Care") (794)
S1 (MH "Caregivers") (10,123)

ASSIA

(CSA Illumina) (http://www.csa.com/)
1987-current
Search date: 14 August 2009

The search strategy below incorporates a section to restrict the search to reviews only. This part of the strategy was based on the Centre for Reviews and Dissemination search strategy for retrieving reviews from ASSIA. 521 records were retrieved.

(DE=(informal care) OR DE=(carers) OR DE=(respite care) OR TI=(caregiv* OR care giv*) OR AB=(caregiv* OR care giv*) OR TI=(carer*) OR AB=(carer*) OR TI=(informal care) OR AB=(informal care) OR TI=(befriending) OR AB=(befriending) OR TI=(caretak*) OR AB=(caretak*) OR TI=(care taking) OR AB=(care taking) OR TI=(caretaker*) OR AB=(caretaker*)

OR TI=(children caring) OR AB=(children caring) OR TI=(families caring) OR AB=(families caring) OR TI=((families) WITHIN 2 (support)) OR AB=((families) WITHIN 2 (support)) OR TI=(respite) OR AB=(respite)) and(TI=(metaanaly* OR meta-analy*) OR AB=(metaanaly* OR meta-analy*) OR KW=(meta study OR meta synthes* OR meta evaluat*) OR DE=(literature reviews) OR KW=(synthes* WITHIN 3 literature*) OR KW=(synthes* WITHIN 3 research*) OR KW=(synthes* WITHIN 3 studies) OR KW=(synthes* WITHIN 3 data) OR KW=(synthes* WITHIN 3 trials) OR KW=(synthes* WITHIN 3 findings) OR KW=(synthes* WITHIN 3 evidence) OR KW=(quantitative synthes*) OR KW=(pooled analys*) OR KW=((data WITHIN 3 pool*) AND studies) OR KW=(pooling studies) OR KW=(medline OR medlars OR embase OR cinahl OR cochrane OR scisearch OR psychinfo OR psycinfo OR psychlit OR psyclit) OR KW=((hand OR manual* OR database* OR computer* OR electronic*) WITHIN 3 search*) OR KW=((electronic* OR bibliographic*) WITHIN 3 database*) OR KW=(review*) OR KW=(overview*) OR KW=(evaluation synthes*) OR KW=(evaluation review*) OR KW=(what works))

Social Services Abstracts

(CSA Illumina) (http://www.csa.com/)
1979-current
Search date: 14 August 2009

The search strategy for Social Services Abstracts was the same as the strategy used for ASSIA as reported above. 300 records were retrieved.

Social Science Citation Index

(Web of Science) (http://www.isinet.com/)
2000-2009
Search date: 14 August 2009

The search strategy below incorporates a section to restrict the search to reviews only. This part of the strategy was based on the Centre for Reviews and Dissemination search strategy for retrieving reviews from the Social Science Citation Index. 1,681 records were retrieved.

29 1,681 #28 AND Language=(English)
Databases=SSCI Timespan=2000-2009
28 1,743 #27 AND #13
27 14,823 #26 OR #25 OR #24 OR #23 OR #22 OR #21 OR #20 OR #19 OR #18 OR

		#17 OR #16 OR #15 OR #14
# 26	359	TS=(respite)
# 25	227	TS=("families A support") OR TS=("support A families")
# 24	64	TS=("families caring")
# 23	6	TS=("children caring")
# 22	18	TS=(care-taker*)
# 21	18	TS=("care taker*")
# 20	677	TS=(caretak*)
# 19	46	TS=(befriending)
# 18	491	TS=("informal care")
# 17	2,402	TS=(carer*)
# 16	328	TS=("care giv*")
# 15	328	TS=(care-giv*)
# 14	11,595	TS=(caregiv*)
# 13	>100,000	#12 OR #11 OR #10 OR #9 OR #8 OR #7 OR #6 OR #5 OR #4 OR #3 OR #2 OR #1
# 12	13,097	TS=(evaluation synthes*) OR TS=(evaluation review*) OR TS=(what works)
# 11	10,294	TS=(overview*)
# 10	73,568	TS=(review*)
# 9	1,555	TS=(electronic* SAME database*) OR TS=(bibliographic* SAME database*)
# 8	4,384	TS=(hand SAME search*) OR TS=(manual* SAME search*) OR TS=(database* SAME search*) OR TS=(computer* SAME search*) OR TS=(electronic* SAME search*)
# 7	4,994	TS=medline OR TS=medlars OR TS=embase OR TS=cinahl OR TS=cochrane OR TS=scisearch OR TS=psychinfo OR TS=psycinfo OR TS=psychlit OR TS=psyclit
# 6	1,234	TS=(data SAME pool*) AND TS=studies
# 5	2,591	TS=quantitative synthes* OR TS=pooled analys* OR TS=pooling studies
# 4	3,194	TS=synthes* SAME (TS=literature* OR TS=RESEARCH* OR TS=STUDIES OR TS=DATA OR TS=TRIALS OR TS=FINDINGS OR TS=EVIDENCE)
# 3	20,708	TS=(literature review*)
# 2	8,001	TS=(meta study OR meta synthes* OR meta evaluat*)
# 1	13,934	TS=(metaanaly* OR meta-analy*)

Social Care Online

(http://www.scie-socialcareonline.org.uk/)
May 2005-present
Search date: 14 August 2009

The search strategy for Social Care Online incorporated a strategy for finding reviews which was translated from the Centre for Reviews and Dissemination (CRD) search strategy for retrieving reviews from ASSIA. This was used to search the database for the period 2000-2007. For 2008-2009 all document types were retrieved to capture any recent reports or grey literature. 1,969 records in total were retrieved.

Search strategy for reviews, 2000-2007
(topic="Carers" or topic="Young carers" or topic="respite care" or topic="informal care" or topic="befriending schemes" or freetext="caregiv*" or freetext="care giv*" or freetext="carer*" or freetext="informal care" or freetext="befriending" or freetext="caretak*" or freetext="care taker*" or freetext="care taking" or freetext="children caring" or freetext="families caring" or freetext="respite") and (topic="literature reviews" or topic="systematic reviews" or freetext="metaanaly*" or freetext="meta-analy*" or freetext="meta study" or freetext="meta synthes*" or freetext="meta evaluat*" or freetext="synthes*" or freetext="pooled analys*" or freetext="pooling studies" or freetext="medline" or freetext="medlars" or freetext="embase" or freetext="cinahl" or freetext="cochrane" or freetext="scisearch" or freetext="psychinfo" or freetext="psycinfo" or freetext=" psychlit" or freetext="psyclit" or freetext="search*" or freetext="review*" or freetext="overview*" or freetext="what works") and (publicationdate>1999 and publicationdate <2008)

Search strategy for all document types, 2008-2009
(topic="Carers" or topic="Young carers" or topic="respite care" or topic="informal care" or topic="befriending schemes" or freetext="caregiv*" or freetext="care giv*" or freetext="carer*" or freetext="informal care" or freetext="befriending" or freetext="caretak*" or freetext="care taker*" or freetext="care taking" or freetext="children caring" or freetext="families caring" or freetext="respite") and (publicationdate>2007)