

# Updated meta-review of evidence on support for carers

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## Scientific summary

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# Scientific summary

## Background

Policy and research interest in carers – those who provide support, on an unpaid basis, to ill, disabled or older people to enable them to live in their own homes – has grown in importance over the past 30 years. Since the first UK review of evidence on carers by Parker (Parker G. *With Due Care and Attention: A Review of Research on Informal Care*. London: Family Policy Studies Centre; 1985), the national and international body of research literature has grown substantially. Since 1995, the UK government has introduced legislation and policy measures aimed specifically at carers, as well as setting up a cross-departmental Standing Commission on Carers. In 2009, the Department of Health commissioned a meta-review for the Standing Commission on Carers from the Social Policy Research Unit at the University of York to inform their thinking about how best to improve outcome for carers, as well as identifying future research areas. The aim of the review, published in 2010 (Parker G, Arksey H, Harden M. *Meta-review of International Evidence on Interventions to Support Carers*. York: Social Policy Research Unit, University of York; 2010), was to provide the Department of Health with an overview of the evidence base relating to the outcomes and cost-effectiveness of support for carers of ill, disabled or older adults.

The overall conclusion of the meta-review was that the strongest evidence of effectiveness was in relation to education, training and information for carers. These types of interventions – particularly when active and targeted rather than passive and generic – appeared to increase carers' knowledge and abilities as carers. There was some suggestion that this might also improve carers' mental health or their coping. However, the review concluded that this latter possibility remained to be tested rigorously in research specifically designed to do so and that explored both effectiveness and costs.

Beyond this, there was little convincing evidence about any of the interventions included in the reviews. This does not mean that these interventions had no positive impact; rather, the review revealed poor-quality primary research, often based on small numbers, testing interventions that had no theoretical underpinning, with outcome measures that might have little relevance to the recipients of the interventions.

The National Institute for Health Research (NIHR) is keen to update the evidence in this area. Given the increase in published evidence since the meta-review in 2010, and the introduction of the latest Care Act in 2014 (Great Britain. *Care Act 2014. Chapter 23*. London: The Stationery Office; 2014), an updated meta-review was considered helpful to inform both the NHS and future research commissioning in relation to the needs of different types of carers and information about interventions to support carers.

## Objectives

For this update, we assessed what is known about effective interventions to support carers of all ages caring for adults who are ill, disabled or older. We adopted a pragmatic approach given the limited time and resources available, adapting (as necessary) the methods adopted in the original meta-review.

## Methods

We conducted a rapid meta-review of systematic reviews focusing on non-medical support interventions for carers of ill, disabled or older adults (including those with dementia, learning disabilities and mental health problems). Reviews of parent carers of disabled children were excluded. Outcomes of interest were any relating directly to carers, and interventions had to bear relevance to the UK health and social care system.

## Search strategy

Database search strategies from the 2010 review were checked and updated. Updates were necessary for some of the strategies to account for changes to the search interface or provider, or where new indexing terms had been introduced or changed since the searches were last run in August 2009.

The searches were rerun in January 2016 on all of the databases searched in the original meta-review: Applied Social Sciences Index and Abstracts, Cochrane Database of Systematic Reviews, Cumulative Index to Nursing and Allied Health Literature, Database of Abstracts of Reviews of Effects (DARE), EMBASE, Health Management Information Consortium, Health Technology Assessment database, MEDLINE, MEDLINE In Process & Other Non-Indexed Citations, NHS Economic Evaluations Database, PsycINFO, Social Care Online, Social Sciences Citation Index and Social Services Abstracts. In addition, PROSPERO was searched to identify any recently completed systematic reviews.

As with the original meta-review in 2010, a study design search filter was used to limit the search to reviews only, if an appropriate filter was available. When possible, searches were restricted to records added to the database during the period 2009–16. All searches were restricted to English-language papers only.

## Review methods

### Study selection and quality assessment

Search results were downloaded in EndNote X7.4 (Thomson Reuters, CA, USA) and split equally between two reviewers for the screening of titles and abstracts to eliminate obviously irrelevant items. A 20% sample was split equally between two additional reviewers to double screen. In addition, one reviewer used text-mining software in EPPI-Reviewer 4 (Evidence for Policy and Practice Information and Co-ordinating Centre, University of London, UK) to assess all of the records excluded at titles and abstracts stage to ensure that no relevant records had been missed during the single reviewer initial screening stage.

Full-text copies were subsequently ordered or downloaded for potentially relevant records. We applied our inclusion and exclusion criteria and used a Microsoft Excel® 2013 spreadsheet (Microsoft Corporation, Redmond, WA, USA) to record full-paper screening decisions simultaneously for study selection and quality assessment. This was carried out by two reviewers independently, with disagreements resolved by discussion or the involvement of a third reviewer if necessary.

As well as selecting reviews based on the inclusion and exclusion criteria, we assessed the quality of reviews to inform which were subject to full review.

We followed the approach and scoring for quality assessment used in the original meta-review adapted from criteria developed by Egan *et al.* (Egan M, Tannahill C, Petticrew M, Thomas S. Psychosocial risk factors in home and community settings and their associations with population health and health inequalities: a systematic meta-review. *BMC Public Health* 2008;**8**:239). From the initial searches it was clear that there had been substantial development in the volume, content and complexity of the literature since the original meta-review was carried out in 2008. Over 100 reviews were selected for potential inclusion in the update. As the average quality of reviews had improved, we decided to focus attention on those reviews that would provide the most robust information. To achieve this, a number of post-protocol decisions were discussed and agreed.

We refined the scoring system used in the original meta-review and introduced a second tier of criteria based on the process for inclusion of systematic reviews on DARE (produced by the Centre for Reviews and Dissemination) to further differentiate the better-quality reviews by splitting them into 'high' and 'medium' quality. We also excluded abstract-only publications.

Most of the reviews identified at this stage were about ill or disabled people with specific conditions or impairment, for example dementia, stroke or cancer. Therefore, prior to data extraction of the included

high-quality reviews, we grouped the reviews according to impairment or condition to establish any discernible patterns and weightings in the evidence base.

### Data extraction

We followed the approach to data extraction used in the 2010 review. After piloting the data collection forms, we summarised the high-quality review characteristics by target carer group, sociodemographic information, intervention (and comparator, when reported), outcomes, cost-effectiveness, number/study design and location of included studies, and findings. We then recorded key information according to the seven outcomes measured in the original meta-review, as follows: physical health, mental health, burden and stress, coping, satisfaction, well-being or quality of life, ability and knowledge. We extracted basic data for the medium-quality reviews, summarising the target carer groups, sociodemographic information, interventions (and comparators, when reported), outcomes, cost-effectiveness, and number/study design and location of included studies. For low-quality reviews, we recorded bibliographic detail only.

### Synthesis

Given the substantial growth in volume and complexity of the literature since the original meta-review, we adopted a pragmatic approach to the synthesis. To do this, we focused our synthesis primarily on the included high-quality reviews, aiming to identify any intervention effect (positive or negative, derived from narrative or quantitative synthesis), size of effect or heterogeneity, together with details of the population, intervention/comparator and outcome. We discussed review quality, highlighting the better-quality primary studies and particular findings of interest. We then summarised the medium- and low-quality reviews to identify any differences from the high-quality reviews in terms of review coverage.

### Public and patient engagement

We sought the views of four carers already known to us through previous work, who provided feedback on draft findings. We then incorporated their views into our discussion.

## Results

We initially identified 103 systematic reviews; after applying our post-protocol quality threshold (based on DARE), we included 61 reviews (27 of high quality, 25 of medium quality and nine of low quality). One medium-quality review (included in the total) was identified through the text-mining exercise. We excluded 38 reviews published in abstract form only, and four reviews with excluded interventions (delirium and case management).

Patterns in the literature were similar to those in the original meta-review. Although the quality of reviews had improved, primary study evidence remained limited in both quality and quantity. Among the high-quality reviews, 14 focused on carers of people with dementia, four focused on carers of those with cancer, four focused on carers of people with stroke, three focused on carers of those with various conditions at the end of life and two focused on carers of people with mental health problems. Many primary studies originated in the USA and Europe (including several in the UK). When sociodemographic data were reported, carers in general were white, female and spouses or adult children, with the age at which they started their caregiving roles ranging from their early forties up to at least 70 years.

A wide range of interventions was included. The details of what was delivered to control groups were sparse or were not reported. Multicomponent interventions featured prominently, making it difficult to identify causal relationships. Interventions generally focused on psychosocial or psychoeducational content, education and skills training. Multiple outcomes were explored, primarily in mental health, burden and stress, and well-being or quality of life. Negative effects found for respite care mirrored results from the meta-review in 2010, a finding that contradicted the views of the carers who gave their views on our draft report. No material differences in review topics were found across high-, medium- and low-quality reviews.

As with the original work, we found very little information about the cost-effectiveness of any of the interventions reviewed.

From the outset, it was clear that there was some overlap of primary studies in the reviews we included. The effect of this overlap is difficult to judge without substantial additional analysis, but it could run the risk of exaggerating effects from the undue influence of individual studies, and present difficulties arising from contradictory assessments of the same study.

## Conclusions and implications for practice

There is no 'one size fits all' intervention to support carers. However, what seems clear is that contact with others outside the carers' normal networks (whether professionals or other carers) may be beneficial, regardless of how it is delivered. As shown in *Table a*, which draws on the most robust evidence in the meta-review, there is potential for effective support in specific groups of carers. This includes shared learning, cognitive reframing, meditation and computer-delivered psychosocial intervention for carers of people with dementia, and psychosocial interventions, art therapy and counselling for carers of people with cancer. Counselling may also help carers of people with stroke. The effectiveness of respite care remains a paradox, given the apparent conflict between the empirical evidence and the views of carers.

**TABLE a** Best evidence for interventions that may have an effect on carers

Type of carer	Outcome improved	Type of intervention
Dementia	Anxiety	Cognitive reframing
	Anxiety	Psychosocial interventions (computer mediated)
	Burden	Educational interventions aimed at teaching skills
	Burden	Interdisciplinary education and support
	Burden (although outcome not explicitly defined)	Support groups
	Burden and stress	Cognitive reframing
	Burden and stress	Psychosocial interventions (computer mediated)
	Depression	Cognitive reframing
	Depression	Meditation-based interventions
	Depression	Psychosocial interventions (computer mediated)
Cancer	Depression	Support groups
	Depression	Telephone counselling
	Mental health	Art therapy
	Physical distress	Couples-based psychosocial interventions
	Psychological distress	Couples-based psychosocial interventions
Stroke	Quality of life	Psychosocial intervention based on problem solving and communication skills
	Quality of life: relationship functioning	Counselling therapy
Stroke	Family functioning	Counselling

### Views of carers

We asked an advisory group of carers to give us their views on the draft findings of our work and we incorporated their views into our discussion. We were particularly interested in whether or not they felt that the interventions for which the reviews seemed to have found evidence were ones that carers might find helpful.

These carers highlighted for us that carers of people with different conditions experience different caring experiences and trajectories. Thus, what might be useful and effective for one sort of carer might not be useful or effective for another. Similarly, what might be useful and effective at one stage in the trajectory might not be useful or effective at another stage. This underlined the difficulty, as they saw it, of knowing what a true 'control' carer or condition might be in a controlled research design.

They also felt that variations in caring situations and across carers made it difficult to see that a single intervention could be the 'answer' in supporting carers. Rather, as one put it 'because of the complexities of the situations there is unlikely to be a one size fits all that will be right at any one time'. As a result, she felt that *any* opportunity to engage with carers and the cared-for person might 'just press the right supportive button at that moment' and, hence, a 'pick-and-mix' approach, whereby various support options were on offer, would be the ideal.

All of the interventions that the high-quality reviews had suggested might have a positive effect on carers were seen as acceptable, but the advisers pointed out that what was actually available to carers was limited and incomplete, and that although education and training for the carer might have a part to play, this was no substitute for 'direct intervention on the carer's own behalf'. They also raised the issue of the value to carers of standard services, including respite, provided to the person they cared for.

### Implications for research

More good-quality, theory-based, primary research is warranted. Evidence is needed on the differential impact of interventions for types of carers, together with the effectiveness of constituent parts in multicomponent programmes. Further research triangulating qualitative and quantitative evidence on respite care is urgently required. The overlap of primary studies was not formally investigated in our review, and this warrants future evaluation.

### Study registration

This study is registered as PROSPERO CRD42016033367.

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