Updated meta-review of evidence on support for carers

Sian Thomas,¹* Jane Dalton,¹ Melissa Harden,¹ Alison Eastwood¹ and Gillian Parker²

¹Centre for Reviews and Dissemination, University of York, York, UK
²Social Policy Research Unit, University of York, York, UK

*Corresponding author

Declared competing interests of authors: Gillian Parker has in the past received, and is currently in receipt of, a number of other research grants from the National Institute for Health Research, all won in open competition.

Published March 2017
DOI: 10.3310/hsdr05120

Scientific summary

Updated meta-review of evidence on support for carers
Health Services and Delivery Research 2017; Vol. 5: No. 12
DOI: 10.3310/hsdr05120

NIHR Journals Library www.journalslibrary.nihr.ac.uk
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>
<thead>
<tr>
<th>Type of carer</th>
<th>Outcome improved</th>
<th>Type of intervention</th>
</tr>
</thead>
<tbody>
<tr>
<td>Dementia</td>
<td>Anxiety</td>
<td>Cognitive reframing</td>
</tr>
<tr>
<td></td>
<td>Anxiety</td>
<td>Psychosocial interventions (computer mediated)</td>
</tr>
<tr>
<td></td>
<td>Burden</td>
<td>Educational interventions aimed at teaching skills</td>
</tr>
<tr>
<td></td>
<td>Burden (although outcome not explicitly defined)</td>
<td>Support groups</td>
</tr>
<tr>
<td></td>
<td>Burden and stress</td>
<td>Cognitive reframing</td>
</tr>
<tr>
<td></td>
<td>Burden and stress</td>
<td>Psychosocial interventions (computer mediated)</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Cognitive reframing</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Meditation-based interventions</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Psychosocial interventions (computer mediated)</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Support groups</td>
</tr>
<tr>
<td></td>
<td>Depression</td>
<td>Telephone counselling</td>
</tr>
<tr>
<td>Cancer</td>
<td>Mental health</td>
<td>Art therapy</td>
</tr>
<tr>
<td></td>
<td>Physical distress</td>
<td>Couples-based psychosocial interventions</td>
</tr>
<tr>
<td></td>
<td>Psychological distress</td>
<td>Couples-based psychosocial interventions</td>
</tr>
<tr>
<td></td>
<td>Quality of life</td>
<td>Psychosocial intervention based on problem solving and communication skills</td>
</tr>
<tr>
<td></td>
<td>Quality of life: relationship functioning</td>
<td>Counselling therapy</td>
</tr>
<tr>
<td>Stroke</td>
<td>Family functioning</td>
<td>Counselling</td>
</tr>
</tbody>
</table>
**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.

**Funding**

Funding for this study was provided by the Health Services and Delivery Research programme of the NIHR.
Health Services and Delivery Research

This journal is a member of and subscribes to the principles of the Committee on Publication Ethics (COPE) (www.publicationethics.org/).

Editorial contact: journals.library@nihr.ac.uk

The full HS&DR archive is freely available to view online at www.journalslibrary.nihr.ac.uk/hsdr. Print-on-demand copies can be purchased from the report pages of the NIHR Journals Library website: www.journalslibrary.nihr.ac.uk

Criteria for inclusion in the Health Services and Delivery Research journal
Reports are published in Health Services and Delivery Research (HS&DR) if (1) they have resulted from work for the HS&DR programme or programmes which preceded the HS&DR programme, and (2) they are of a sufficiently high scientific quality as assessed by the reviewers and editors.

HS&DR programme
The Health Services and Delivery Research (HS&DR) programme, part of the National Institute for Health Research (NIHR), was established to fund a broad range of research. It combines the strengths and contributions of two previous NIHR research programmes: the Health Services Research (HSR) programme and the Service Delivery and Organisation (SDO) programme, which were merged in January 2012.

The HS&DR programme aims to produce rigorous and relevant evidence on the quality, access and organisation of health services including costs and outcomes, as well as research on implementation. The programme will enhance the strategic focus on research that matters to the NHS and is keen to support ambitious evaluative research to improve health services.

For more information about the HS&DR programme please visit the website: http://www.nets.nihr.ac.uk/programmes/hsdr

This report
The research reported in this issue of the journal was funded by the HS&DR programme or one of its preceding programmes as project number 13/182/07. The contractual start date was in December 2015. The final report began editorial review in July 2016 and was accepted for publication in November 2016. The authors have been wholly responsible for all data collection, analysis and interpretation, and for writing up their work. The HS&DR editors and production house have tried to ensure the accuracy of the authors’ report and would like to thank the reviewers for their constructive comments on the final report document. However, they do not accept liability for damages or losses arising from material published in this report.

This report presents independent research funded by the National Institute for Health Research (NIHR). The views and opinions expressed by authors in this publication are those of the authors and do not necessarily reflect those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health. If there are verbatim quotations included in this publication the views and opinions expressed by the interviewees are those of the interviewees and do not necessarily reflect those of the authors, those of the NHS, the NIHR, NETSCC, the HS&DR programme or the Department of Health.

© Queen’s Printer and Controller of HMSO 2017. This work was produced by Thomas et al. under the terms of a commissioning contract issued by the Secretary of State for Health. This issue may be freely reproduced for the purposes of private research and study and extracts (or indeed, the full report) may be included in professional journals provided that suitable acknowledgement is made and the reproduction is not associated with any form of advertising. Applications for commercial reproduction should be addressed to: NIHR Journals Library, National Institute for Health Research, Evaluation, Trials and Studies Coordinating Centre, Alpha House, University of Southampton Science Park, Southampton SO16 7NS, UK.

Published by the NIHR Journals Library (www.journalslibrary.nihr.ac.uk), produced by Prepress Projects Ltd, Perth, Scotland (www.prepress-projects.co.uk).
Health Services and Delivery Research Editor-in-Chief

Professor Jo Rycroft-Malone  Professor of Health Services and Implementation Research, Bangor University, UK

NIHR Journals Library Editor-in-Chief

Professor Tom Walley  Director, NIHR Evaluation, Trials and Studies and Director of the EME Programme, UK

NIHR Journals Library Editors

Professor Ken Stein  Chair of HTA Editorial Board and Professor of Public Health, University of Exeter Medical School, UK

Professor Andree Le May  Chair of NIHR Journals Library Editorial Group (EME, HS&DR, PGfAR, PHR journals)

Dr Martin Ashton-Key  Consultant in Public Health Medicine/Consultant Advisor, NETSCC, UK

Professor Matthias Beck  Chair in Public Sector Management and Subject Leader (Management Group), Queen’s University Management School, Queen’s University Belfast, UK

Dr Tessa Crilly  Director, Crystal Blue Consulting Ltd, UK

Dr Eugenia Cronin  Senior Scientific Advisor, Wessex Institute, UK

Ms Tara Lamont  Scientific Advisor, NETSCC, UK

Dr Catriona McDaid  Senior Research Fellow, York Trials Unit, Department of Health Sciences, University of York, UK

Professor William McGuire  Professor of Child Health, Hull York Medical School, University of York, UK

Professor Geoffrey Meads  Professor of Health Sciences Research, Health and Wellbeing Research Group, University of Winchester, UK

Professor John Norrie  Chair in Medical Statistics, University of Edinburgh, UK

Professor John Powell  Consultant Clinical Adviser, National Institute for Health and Care Excellence (NICE), UK

Professor James Raftery  Professor of Health Technology Assessment, Wessex Institute, Faculty of Medicine, University of Southampton, UK

Dr Rob Riemsma  Reviews Manager, Kleijnen Systematic Reviews Ltd, UK

Professor Helen Roberts  Professor of Child Health Research, UCL Institute of Child Health, UK

Professor Jonathan Ross  Professor of Sexual Health and HIV, University Hospital Birmingham, UK

Professor Helen Snooks  Professor of Health Services Research, Institute of Life Science, College of Medicine, Swansea University, UK

Professor Jim Thornton  Professor of Obstetrics and Gynaecology, Faculty of Medicine and Health Sciences, University of Nottingham, UK

Professor Martin Underwood  Director, Warwick Clinical Trials Unit, Warwick Medical School, University of Warwick, UK

Please visit the website for a list of members of the NIHR Journals Library Board:
www.journalslibrary.nihr.ac.uk/about/editors

Editorial contact: journals.library@nihr.ac.uk