

Peer support interventions for family carers of adults with chronic mental or physical illness who are living at home (Protocol)

Burnell K, Charlesworth G, Feast AR, Hoe J, Poland FM, Orrell M



**THE COCHRANE
COLLABORATION®**

This is a reprint of a Cochrane protocol, prepared and maintained by The Cochrane Collaboration and published in *The Cochrane Library* 2012, Issue 11

<http://www.thecochranelibrary.com>

WILEY

TABLE OF CONTENTS

HEADER	1
ABSTRACT	1
BACKGROUND	1
OBJECTIVES	3
METHODS	4
ACKNOWLEDGEMENTS	9
REFERENCES	9
APPENDICES	11
HISTORY	12
CONTRIBUTIONS OF AUTHORS	13
DECLARATIONS OF INTEREST	13
SOURCES OF SUPPORT	13

[Intervention Protocol]

Peer support interventions for family carers of adults with chronic mental or physical illness who are living at home

Karen Burnell¹, Georgina Charlesworth², Alexandra R Feast³, Juanita Hoe⁴, Fiona M Poland⁵, Martin Orrell⁶

¹School of Health Sciences and Social Work (SHSSW), University of Portsmouth, Portsmouth, UK. ²Research Department of Clinical, Educational, and Health Psychology, University College London, London, UK. ³Research and Development Department, North East London NHS Foundation Trust, Ilford, UK. ⁴UCL Mental Health Sciences Unit, University College London, London, UK. ⁵School of Allied Health Professions (AHP) and Health and Social Science Research Institute, University of East Anglia, Norwich, UK. ⁶Mental Health Sciences Unit, University College London, London, UK

Contact address: Karen Burnell, School of Health Sciences and Social Work (SHSSW), University of Portsmouth, James Watson Building (West), 2 King Richard 1st Road, Portsmouth, PO1 2FR, UK. Karen.Burnell@port.ac.uk.

Editorial group: Cochrane Consumers and Communication Group.

Publication status and date: New, published in Issue 11, 2012.

Citation: Burnell K, Charlesworth G, Feast AR, Hoe J, Poland FM, Orrell M. Peer support interventions for family carers of adults with chronic mental or physical illness who are living at home. *Cochrane Database of Systematic Reviews* 2012, Issue 11. Art. No.: CD010231. DOI: 10.1002/14651858.CD010231.

Copyright © 2012 The Cochrane Collaboration. Published by John Wiley & Sons, Ltd.

ABSTRACT

This is the protocol for a review and there is no abstract. The objectives are as follows:

To assess the effects of peer support interventions on health-related quality of life (i.e. mental and physical health) and wellbeing of family carers who care for an adult relative with a chronic mental or physical illness at home.

Secondary objectives are:

- to assess whether different features within each peer support intervention impact on its effects. These features could include: the facilitator (peer, versus peer and professional co-facilitators); format, duration, intensity of intervention; and quality of peer training.
- to assess the effects of simple and multifaceted interventions (interventions with more than one component), and the particular features that are most effective.
- to assess the effects of peer support interventions across different types of illness.

BACKGROUND

This review will assess the effects of peer support interventions on health-related quality of life and wellbeing of family carers supporting adult relatives living with progressive or relapsing chronic illness.

Description of the condition

A family carer is someone who cares for a relative with a chronic illness(es) that makes the relative unable to care for themselves. Family carers are defined as relatives, partners, or 'as close as kin' friends who provide or organise the majority of care. Being a fam-

ily carer to a person with a progressive or relapsing chronic illness such as dementia or terminal cancer can have a significant impact on mental and physical health (Ory 1999; Rivera 2009), and has been found to increase mortality rates in later life (Bowling 1998; Schulz 1999). The contribution that family carers make is vital to the broader economy and, when carers feel supported, is linked with lower levels of hospitalisation and residential care placement for the care recipient (Mittelman 2006). Family carers can often feel unrecognised or unsupported, but this is beginning to change, and the needs of family carers are gaining a higher profile internationally.

Description of the intervention

The World Health Organisation (WHO) has highlighted the importance of enhancing social relationships in order to promote quality of life and wellbeing for people with chronic illness and their carers (WHO 1998). Health-related quality of life is defined as an individual's perception of their position in life in relation to their goals, expectations, standards, and concerns, as affected by their mental and physical health (WHOQOL Group 1993). Mental wellbeing is defined as a "dynamic state, in which the individual is able to develop their potential, work productively and creatively, build strong and positive relationships with others, and contribute to their community. It is enhanced when an individual is able to fulfil their personal and social goals and achieve a sense

of purpose in society" (Forsight 2008, p.10). Traditionally, interventions to enhance wellbeing have been delivered by qualified healthcare professionals. However, support by peers has also been found to directly improve quality of life and wellbeing, by reducing feelings of isolation or encouraging more appropriate coping strategies (Dennis 2003). Examples of lay and peer support exist across a wide range of health conditions, and have been developed for individuals with chronic illness (Doull 2005) as well as family carers (Pillemer 2002).

Much of the literature in this area refers to 'lay support'. Peers and lay persons are similar, in that neither are professionally qualified to practice, but the difference between them is poorly defined. For the purpose of this review we define peers as lay people who are experientially similar to (have similar experiences of caring as) the carer they are supporting. This means they have experience of caring for a relative or partner with the same illness as the carer's relative or partner; for example, both care/cared for a relative with dementia. It is also usual for peer supporters to have more experience of caring than the carer they are supporting. In addition, peers are likely to have received training to help prepare them for their supporting role, which sets them apart from other friends and family providing support. As such, peer support interventions are social support interventions, in which an experienced carer provides support to a less experienced/newer carer.

The concept of social support may be usefully subdivided into four categories: emotional, informational, instrumental, and appraisal (Antonucci 1985), as follows:

Categories of social support	Description
Emotional	Involves provision of verbal or non-verbal communication to reduce negative emotions and promote positive emotions
Informational	Involves provision of advice and strategies of coping
Instrumental	Involves provision of physical help or resources
Appraisal	Generates positive future expectations through encouragement, problem solving, and assurance that attempts to cope are effective and appropriate (Wills 1985)

Peer support interventions tend to focus on delivering emotional, informational, and appraisal support rather than instrumental support. These different types of social support may be found in embedded or naturally-occurring support networks, or in both. However they might not be accessed by carers in times of stress. Peer support interventions aim to fill this potential gap in support, by providing access to a peer through health care and volunteer services (Dennis 2003).

There are different formats of, and approaches to, peer support. Peer support interventions can be delivered on a one-to-one basis to provide support (Pillemer 2002) or supportive counselling (Toseland 1990). They may also be delivered on a group basis (Chien 2008; Gallagher 1996). As well as being conducted in person, peer support interventions may be delivered remotely via telephone (Goodman 1990), or the Internet (Marziali 2006). The

structure of the intervention also varies, with some interventions facilitated by a peer alone, and others co-facilitated by a professional and peer (Fung 2002). Finally, the level of training that peers undergo varies. Some peers receive in-depth training, particularly if the intervention they are providing is complex and includes counselling and other supportive elements.

How the intervention might work

Social support is known to improve quality of life (including health-related quality of life) and wellbeing, both in the short and long term, by reducing stress and anxiety (Cohen 1985), lowering blood pressure, increasing immunity, and reducing mortality (Hogan 2002). It is thought that the strength of peer support interventions in particular, above social support interventions more broadly, is that peers have similar caring experiences to the person(s) they support. This means they are able to empathise and deliver support based on their own experiences. This is referred to as 'homophily theory' (McPherson 2001), which suggests that people will associate and bond with similar others, particularly in stressful situations. In other words, we assume that those who have 'been there' are better able to understand and help. For this reason, peer support interventions may work on the basis that supported carers feel understood, and are more likely to listen and act on the information or guidance they receive, as they see it as relevant.

As with social support, peer support has been found to directly improve quality of life and wellbeing by decreasing feelings of isolation and improving mood, or by serving to inhibit maladaptive behaviour and promote more adaptive coping strategies (Dennis 2003). Peer support may also indirectly improve quality of life and wellbeing by encouraging changes in behaviour, emotions, and thoughts. This forms the basis of Social Cognitive Theory (Bandura 1989), which suggests that behaviours are modelled on those of role models in social interactions. This concept lends itself well to peer support interventions, because it is based on the extent to which an individual identifies with the role model. The more an individual identifies, the more likely they are to listen to, and act on, advice and guidance. In addition, having someone to talk to about worries associated with caring, and to help plan ways to cope with experiences, can improve feelings of self-efficacy (Bandura 1977), which has also been linked to improved quality of life and wellbeing (Gignac 1996). 'Self-efficacy' refers to the extent to which someone feels confident, in control of, and able to cope with, a potentially challenging situation such as caring.

Providing the intervention may also impact on the peer supporters themselves. Currently, little research looks specifically at the impact of volunteering as a peer supporter. Findings suggest that carers may be motivated to become peer supporters in order to help others and share their experiences (Pillemer 1996). Research looking at the impact of volunteering on a more generic level does suggest both positive and negative outcomes for volunteers. Volunteering can improve their access to social and psychological resources, resulting in fewer depressive symptoms (Musick 2003).

Older volunteers, in particular, may experience improved life satisfaction and mental and physical quality of life (Van Willigen 2000). However, negative outcomes have also been recorded. For example, people volunteering to support those with a chronic illness and their carers may experience greater levels of stress through being the recipients of negative emotions expressed by those they are supporting (Bakker 2006). Such negative outcomes may be exacerbated by poor training and support in the volunteering role (Ross 1999).

Why it is important to do this review

Family carers are often seen by governments and non-government organisations (NGOs) as a low-cost way to support people with chronic illness. As such, a number of peer support schemes have been developed to support family carers in low resource but high prevalence settings, such as caring for relatives with HIV/AIDS or dementia. However, peer support interventions for family carers have received less attention than programmes for the patients themselves, and research findings on effectiveness have been mixed, though qualitative evidence suggests that carers benefit from peer support (Chien 2008). Since some peer support schemes already operate, it is vital that we learn more about their effects, and identify the particular strategies that seem most beneficial. One of the difficulties in assessing the effects of such interventions is that the term 'peer' is not always used to describe interventions involving experientially-similar supporters, meaning that evidence is easily overlooked and not assimilated into the existing evidence base. Another reason may be that research is conducted by researchers and members of the voluntary sector or NGOs, and may not be readily available to researchers in health. There is a need for a systematic review and analysis of the evidence in order to establish a more informed model of peer support.

This review will complement planned and existing Cochrane reviews. Namely, it will complement the review by Doull 2005, which will focus on peer support strategies for people with chronic illness, rather than carers. In addition, it will expand on the review by Nelis 2007, which focuses on information and support interventions for carers of people with dementia. It will also complement the review by Lewin 2010, which focuses on lay support and may include some peer support interventions but does not focus exclusively on them. Finally, it will extend Candy 2011, by including carers caring for someone in the early stages of an illness, rather than in the terminal stages only.

OBJECTIVES

To assess the effects of peer support interventions on health-related quality of life (i.e. mental and physical health) and wellbeing of family carers who care for an adult relative with a chronic mental or physical illness at home.

Secondary objectives are:

- to assess whether different features within each peer support intervention impact on its effects. These features could include: the facilitator (peer, versus peer and professional co-facilitators); format, duration, intensity of intervention; and quality of peer training.
- to assess the effects of simple and multifaceted interventions (interventions with more than one component), and the particular features that are most effective.
- to assess the effects of peer support interventions across different types of illness.

METHODS

Criteria for considering studies for this review

Types of studies

We will include randomised controlled trials (RCTs). Due to the likelihood of limited research in this area, we will also include quasi-RCTs, controlled before and after studies (CBAs), and interrupted time series studies (ITs) (either with or without a control group). For RCTs, quasi RCTs and CBAs, we will include studies allocating to groups at both the individual and cluster levels.

For CBAs to be included they must have: at least two intervention sites and two control sites; comparable pre- and post-intervention periods of measurement for the intervention and control groups; and comparable key characteristics at baseline (Ryan 2011).

For ITs to be included they must have: a clearly-defined point in time in which the intervention occurs and is specified by the researchers; and a collection of at least three data points before and after the intervention (Ryan 2011).

Types of participants

Participants (intervention recipients) will be primary family carers, defined as adults (18 years and over) who:

- are relatives, partners, or people who are as close as kin, to the person they care for (including spouses, partners, adult children, parents of adult children, siblings, extended family members, or close personal friends); and
- provide or organise the majority of the care to an adult with chronic physical or mental illness(es), who lives at home (with or without their caring relative) and not in a formal care setting.

Chronic illness is normally defined as any illness which has persisted for a prolonged period (e.g. more than 3 months). People suffering some chronic illnesses, such as depression or diabetes,

often do not need help to care for themselves. For the purposes of this review, we are interested in peer support interventions to family carers of people suffering chronic illnesses (defined as an incapacitating progressive or relapsing illness or comorbidity, which may include a terminal phase (Rolland 1987)), which result in the individual being unable to care for themselves. Such chronic illnesses include (but are not limited to) dementia, terminal cancer, stroke, AIDS, motor neuron disease, psychiatric disorders such as chronic schizophrenia, or other combinations of conditions which are debilitating for the individual. The critical point, for this review, is that the person requires help to care for themselves, for a prolonged period.

Due to the diverse nature of caring populations, some studies may include carers or care recipients who are younger than 18. We will include studies in which the majority of carers or care recipients are over 18 years old, but will exclude studies that report interventions designed specifically for people aged less than 18. Such interventions are likely to be qualitatively different from interventions designed for adults on key elements such as nature of the intervention and, in particular, the outcomes measured, for example, impact on education.

We will exclude studies in which the care recipients have congenital impairments. This is because only carers of adult care recipients will be included. Carers of people with congenital impairments would have been undertaking the caring role for many years by the time the person they are caring for turns 18. In this situation, it would be difficult to match such a carer with a more experienced peer and therefore have an experiential gap, which is seen to be the defining feature of a peer support intervention.

Types of interventions

We will include peer support interventions, defined as interventions providing support, social support, or supportive counselling (on a formal (structured/facilitated) or informal basis), delivered or facilitated by peers. Peers are lay persons who are experientially similar to the carers they are supporting; that is, peers care or have cared for a relative with the same/similar illness as the relative of the family carer they are supporting. Peers are different from friends or family who may provide some level of informal support, because peers are usually more experienced in caring than the carer they are supporting, and they have usually received some training before providing support.

Interventions may be delivered to carers on a one-to-one or group basis, and may be delivered in a number of different ways such as face-to-face, or via phone or the Internet. We are particularly interested in sustained contact interventions, which are interventions that take place over six months or more. However, as there is likely to be limited research in this area, we will also include studies that feature shorter interventions. Interventions may differ in terms of whether the peers are trained. The intensity of the intervention may also vary in terms of length and frequency of contact.

Our primary focus will be on interventions delivered to peers only. However due to the likelihood of limited research in the area we will include studies which are facilitated by lay persons where peers (as defined above) comprise approximately 65% or more of the intervention providers. Where this information is not explicit within the study, we will seek further information from the study authors. If this information is not available, we will include these studies and conduct a sensitivity analysis of the trials that report the proportion of the peer component. If meta-analysis is not possible, we will discuss any differential effect of the intervention in trials which report the proportion of the peer component of the intervention, compared with those which do not report this. We will exclude studies in which interventions are facilitated exclusively by lay or professional persons who are not peers (i.e. not experientially similar to those they are supporting). Some interventions will be co-facilitated by a peer and a professional (defined as individuals who are trained and qualified to practice, i.e. psychologists, psychiatrists, nurses, and social workers, GPs, medical students, and healthcare specialists such as speech and occupational therapists). That is, interventions may be carried out by both a peer supporter(s) and professional(s) together. They may provide the entire intervention together, or each provide different elements separately within the same intervention. For these co-facilitated interventions, there is no particular proportion of the intervention providers that must be peer supporters for a study to be included because they are, by their very nature co-facilitated. We will include studies of co-facilitated interventions in the review, and will collect and report information on the proportion of peer supporters providing co-facilitated interventions, but will analyse these separately from studies assessing interventions delivered by peers alone.

We will include studies assessing the following comparisons:

- peer delivered interventions versus control/treatment as usual/waiting list condition;
- peer delivered interventions versus 'other' delivered interventions (professional or lay);
- co-facilitated peer and professionally-delivered interventions versus control/treatment as usual/waiting list condition;
- co-facilitated peer and professionally-delivered interventions versus professionally-delivered interventions;
- co-facilitated peer and professionally-delivered interventions versus peer delivered interventions;
- one peer-delivered intervention versus another;
- one co-facilitated peer and professionally-delivered intervention versus another.

We will exclude non-facilitated mutual support groups, as these groups are not facilitated by a more experienced peer, but rely on participants recruited to the study to support one another. We will also exclude interventions that are not support interventions, such as educational programmes that comprise no planned support element, along with respite, and psychotherapeutic interventions.

A psychotherapeutic intervention would involve "an interpersonal process designed to bring about modifications of feelings, attitudes and behavior which have proved troublesome to the person seeking help from a trained professional" (Strupp 1978).

Types of outcome measures

In order to increase this review's relevance to consumers we conducted a focus group with carers of people with dementia to identify which outcomes were most important to them when being offered a peer support intervention. We presented a list of outcome categories for family carers, and another list for care recipients. These lists were based on outcomes commonly reported in the peer support literature. Using a mix of small group and large group discussion we determined that improvements in quality of life and coping strategies were the most important carer outcomes. From a theoretical perspective we were also interested in quality of life as a primary outcome, as peer support is thought to improve quality of life through building supportive bonds with similar others and increasing feelings of self-efficacy. Therefore, we specify quality of life as a primary outcome, and coping strategies as a secondary outcome. In addition, we decided to include adverse events as a primary outcome along with the concept of wellbeing. We also found that the carers were keen to know the outcomes of peer support interventions on care recipients, particularly the changes in quality of life and neuropsychiatric symptoms. We will assess outcomes for the care recipient where these are available.

Primary outcomes

We will assess and report the following primary outcomes for family carers:

- Health-related quality of life
- Wellbeing
- Adverse effects (i.e. greater levels of stress/anxiety).

Secondary outcomes

In order to select one outcome measure for each relevant secondary outcome category, we will list the outcomes reported by each study and make a decision as to the most clinically important outcome.

Family carer

- Other psychological and psychosocial outcomes (i.e. coping strategies measured as changes in the number and types of strategies used, anxiety, depression, perceptions of carer burden and strain, self-efficacy, knowledge and skills acquisition, satisfaction with intervention).
- Social support outcomes (frequency of perceived and received support, or type of support, i.e. emotional, informational, instrumental, appraisal (where specified), or

change in support network i.e. numbers of people available to provide support and use of network by carer).

- Relationship outcomes (i.e. quality of relationship between carer and care recipient, or satisfaction with caregiving role).

In order to be included in the review, it is not essential that studies report outcomes for the care recipient or peer supporter, but data will be extracted where available.

Care recipient

- Psychological outcomes (i.e. health-related quality of life, wellbeing, associated distress and neuropsychiatric symptoms)
- Adverse effects i.e. levels of (re)hospitalisation/institutionalisation
- Physical outcomes (health problems i.e. change in use of medication/progression of illness)

Peer supporter

- Psychological outcomes (i.e. health-related quality of life, wellbeing, life satisfaction, depression, anxiety)

Economic outcomes

- Resource use and costs

We will not exclude studies based on the outcomes reported or not reported.

Search methods for identification of studies

The proposed search strategy recognises that there is no global consensus in terminology used to describe family carers. This is the case for both the research community and the carers themselves. For this reason, key words such as 'spouse', 'partner', 'child', and 'sibling' will be used alongside the terms 'caregiver' and 'carer'. In addition, due to the nature of the topic area the search strategy is intended to be highly sensitive, thus forsaking precision.

Electronic searches

We will search

1. The Cochrane Central Register of Controlled Trials (CENTRAL, *The Cochrane Library*) (latest issue).
2. MEDLINE (OvidSP; inception to present).
3. EMBASE (OvidSP; inception to present).
4. PsycINFO (OvidSP; inception to present).
5. CINAHL (EbscoHOST; 1982 to present).

We present the strategy for MEDLINE in [Appendix 1](#). We will adapt the strategy for each database. We will not restrict the search in terms of date or language.

We will pilot the strategies before running them, and report the strategies as run, in the review.

Searching other resources

We will search:

1. Grey literature - OpenGrey (inception to present).
2. Dissertation Abstracts (inception to present).
3. Conference abstracts/proceedings.

We will search the reference lists of all included studies and relevant reviews, and conduct forward citation searches (using Web of Science). In addition, we will search ClinicalTrials.gov, Current Controlled Trials *metaRegister* of Controlled Trials (*mRCT*) active and archived register, and the WHO International Clinical Trials Registry Platform, to identify ongoing studies. Finally, we will contact prominent researchers in the field of peer support interventions for family carers to enquire about ongoing or unpublished studies.

Data collection and analysis

Selection of studies

We will combine the results of each database search using reference management software, and remove duplicates. Two review authors (KB and AF) will review the titles and abstracts of all studies identified through the searches, against the criteria specified in [Criteria for considering studies for this review](#). We will obtain in full text those studies identified by either author as potentially meeting the criteria. We will pilot the screening tool on a sample of studies (between 10 and 12) to refine and finalise it. KB and AF will independently assess potentially-relevant papers against the inclusion criteria. We will identify and collate multiple reports from individual studies ([Higgins 2011a](#)).

If there are disagreements between KB and AF as to whether a study should be included, a third review author will be consulted. If necessary, we will request additional information from study authors to aid the decision making process. Until information is received, these studies will be classified as awaiting assessment. We will list those studies that do not meet the selection criteria after inspection of the full text in the 'Characteristics of excluded studies' table, giving the specific reason(s) for exclusion.

Data extraction and management

We will extract data from each included study using a data extraction form based on the data extraction template of the Cochrane Consumers and Communication Review Group, which will be piloted for the review. Two review authors (KB and AF) will extract data independently. All data will be cross-checked between the two forms before being entered into RevMan (by AF). If there are any discrepancies, authors will refer to the original paper. For any discrepancies remaining unresolved after this process, a third review author will be consulted. All data entered into RevMan by

AF will be checked against the agreed data extraction sheets by KB to ensure no errors have been introduced at this stage.

For each included study we will extract:

- study design;
- participant details (including number in each group, demographics and characteristics at baseline, type and definition of chronic illness, and relationship between carer and care recipient and whether they live together or not);
- details about the peer supporters (including demographics, and number of years of caring experience and type of illness);
- description of intervention (including cost, total number of groups and details of the control/comparison groups, duration, intensity, format, setting, length of follow-up, level of training of peer supporter, details of co-facilitators, and how the peer and carer have been matched in one-to-one interventions);
- outcome measures;
- outcome data;
- analysis methods;
- theoretical basis of intervention;
- integrity of the intervention (i.e. consistency of intervention, quality of intervention, and uptake of intervention).

Finally, we will extract methodological data in order to complete the Risk of Bias Assessment (see [Assessment of risk of bias in included studies](#)).

Assessment of risk of bias in included studies

We will assess and report on the methodological risk of bias of included studies in accordance with the Cochrane Handbook for Systematic Reviews of Interventions ([Higgins 2011b](#)) and the guidelines of the Cochrane and Communication Review Group ([Ryan 2011](#)), which recommends the explicit reporting of the following individual elements for RCTs: random sequence generation; allocation concealment; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data, selective outcome reporting; other sources of bias.

Whilst the nature of psychosocial interventions means that it is not possible to blind participants or intervention providers to allocation, this information will still be assessed and reported.

If cluster-RCTs, quasi-RCTs, controlled before and after studies and/or interrupted time series are included in the review, we will assess their risk of bias systematically by adapting the above tool in the following ways:

Cluster RCTs: we will report additionally on whether selective recruitment of cluster members was prevented (at 'other sources of bias').

Quasi-RCTs: we will assess all criteria as outlined for RCTs, rating random sequence generation as 'high risk' and reporting on how participants were allocated to the intervention and control groups.

CBAAs: we will assess the criteria as outlined for RCTs, rating CBA studies as 'high risk' for sequence generation and allocation con-

cealment. We will additionally assess (as an 'other' source of bias) protection against contamination between groups.

ITSs: we will assess whether the intervention is independent of other changes; shape of the intervention effect prespecified; likelihood of intervention affecting data collection; blinding (participants, personnel); blinding (outcome assessment); completeness of outcome data; selective outcome reporting; other sources of bias.

In all cases, two authors (KB and AF) will independently assess the risk of bias of included studies, with any disagreements resolved by discussion and consensus. We will contact study authors for additional information or clarification of the study methods as required. For each domain we will describe the relevant information provided by authors and judge each item as being at 'high', 'low' or 'unclear' risk of bias, as set out in the judging criteria provided by [Higgins 2011b](#). We will incorporate the results of the risk of bias assessment into the review through standard tables, and systematic narrative description and commentary about each of the elements, leading to an overall assessment of the risk of bias of included studies and a judgement about the internal validity of the review's results.

Measures of treatment effect

RCTs (quasi and cluster), and CBAs

RCTs: For dichotomous outcomes we will report risk ratios (RRs) and their 95% confidence intervals (CI), where events occur both in the intervention and control/comparison groups. For continuous outcomes, we will report mean difference (MD), standard deviations (SD), and 95% CI at the end point. When the selected studies measure the same outcome but on different scales, we will calculate the standardised mean difference (SMD) and 95% CI. CBAAs: For dichotomous outcomes we will report risk ratios (RRs). For continuous data we will report SMD.

ITSs

The following estimates and their P values will be reported from regression analyses, which we will adjust for autocorrelation: change in level of the outcome at the first point after the introduction of the intervention; and the post-intervention slope minus the pre-intervention slope. The first gives the immediate effect of the intervention whilst the second gives the long-term effect of the intervention.

Economic data

We will extract data on cost-effectiveness and resource use where available, and present a narrative summary of results. This is for three reasons: first, we do not expect a large proportion of studies to have collected or reported economic data; second, assessing

economic data is a secondary aim of this review; third, there is no agreed method for conducting meta-analyses of economic data (Shemilt 2009).

Unit of analysis issues

We will take into account the level at which randomisation occurred in each included study. In the majority of included studies, we expect the number of observations in the analysis to match the number of units randomised, as most will randomise and/or assess participants individually. However, we also expect to include cluster RCTs in the review. Studies in which clusters of individuals are randomised to groups, but where inference is intended at the level of the individual, need to be analysed taking account of intra-cluster correlation (ICC). Estimates of ICC will be obtained from contacting authors, or imputed using external estimates. If this is not possible we will report effect estimates and annotate 'unit of analysis error'.

Often, analyses of ITS studies do not account for autocorrelation of data points. Consequently, we will re-analyse results where data are available. Time series regression analysis will be used, which will take account of the first order autocorrelation. From this we will estimate the change in level of the outcome at the first point after the intervention is introduced, along with the post-intervention slope minus the pre-intervention slope. We will also calculate confidence intervals for these effect estimates.

Dealing with missing data

We will contact the study authors for missing data required for analysis. If data are supplied, we will carry out analyses on an intention to treat basis. If data are not available we will conduct an available case analysis using the known outcome data. We will report information regarding loss to follow up and assess this as a source of bias. If only SDs are missing, we will attempt to calculate these from the data available.

Assessment of heterogeneity

We anticipate that included studies will be clinically and methodologically heterogeneous, that is, they will differ in terms of interventions, type of illness, participants, study design and outcome measures. In this case, it may not be appropriate to conduct a meta-analysis. In addition to examining clinical heterogeneity through discussion, we will assess heterogeneity by visual inspection of forest plots and using the Chi^2 test to test for heterogeneity and the I^2 statistic to quantify it. An I^2 value of 50% or more will be considered to represent substantial levels of heterogeneity, but will be interpreted in light of the size and direction of effects and the strength of the evidence for heterogeneity, based on the P value from the Chi^2 test (Deeks 2011).

Assessment of reporting biases

We will follow Cochrane Collaboration guidelines for assessing reporting biases (Sterne 2009). The most pertinent types of reporting biases in this subject area are likely to include: publication bias; time lag bias; location bias; and language bias. If we identify sufficient (at least 10) studies for inclusion in the review we will construct a funnel plot to investigate publication bias and we will formally test for funnel plot asymmetry, with the choice of test informed by the advice outlined in Higgins 2011.

Data synthesis

We will compare included studies based on the type of intervention, setting, participants and delivery. Based on this assessment, if we consider the studies to be similar enough to conduct a meta-analysis, we will use a random-effects model. Meta-analysis will be conducted only for RCTs, cluster RCTs, and quasi RCTs. We will provide descriptive statistics for ITS and CBA studies, which will include, for instance median effect sizes and inter-quartile ranges. If meta-analysis is inappropriate, we will present a narrative review describing differences in effects between studies in each group. For each comparison we will report: the number of comparisons showing positive direction of effect; median effect size across comparisons; the median effect size across comparisons without unit of analysis errors; and the number of comparisons showing statistically significant effects.

For the narrative synthesis or meta-analysis, we will synthesise according to different types of interventions (i.e. grouping similar interventions together), then by outcomes.

We will prepare a 'Summary of findings' table to present the results of meta-analysis, based on the methods described in chapter 11 of the Cochrane Handbook for Systematic Reviews of Interventions Schünemann 2011. We will present the results of meta-analysis for the major comparisons of the review, for each of the major primary outcomes, including potential harms, as outlined in the 'Types of outcome measures' section. We will provide a source and rationale for each assumed risk cited in the table(s), and will use the GRADE system to rank the quality of the evidence using the GRADE profiler (GRADEpro) software (Schünemann 2011). If meta-analysis is not possible, we will present results in a narrative 'Summary of findings' table format, such as that used by Chan 2011.

Subgroup analysis and investigation of heterogeneity

Due to the varied nature of methodologies, participant groups, and interventions, it will be important to conduct subgroup analyses through narrative or statistical methods. Likely subgroup analyses will focus on the following groupings, depending on an adequate number of studies. All comparisons focus on the nature of the intervention because the current literature indicates that the effect of a peer support intervention may lie in the fine detail, such as:

- Short-term interventions (up to three months) versus long-term interventions (three months or longer) and number of contacts during the intervention.
- Type of support intervention such as support versus counselling.
 - One-to-one versus group interventions.
 - Medium of intervention (e.g. Internet versus telephone).

Sensitivity analysis

We will conduct sensitivity analyses on the primary outcomes to investigate the impact of including studies assessed as having a high or unclear risk of bias on the pooled effect estimates. Studies rated as at high or unclear risk of bias on the tool domains of sequence generation and allocation concealment will be considered at high or unclear risk of bias for the purposes of sensitivity analysis.

Consumer involvement

As previously mentioned, we contacted family carers via Dementia UK to take part in a focus group discussion to determine the primary and secondary outcomes for the review. We hope that one of these carers will be involved in the review process by providing feedback on the review to ensure that it is written in an accessible way, and to help check whether and how the findings and implications drawn from the review will be meaningful to consumer groups. Consumers have also been involved in the peer review of this protocol through standard procedures adopted by the Cochrane Consumers and Communication Group. They will also review the full review before publication.

ACKNOWLEDGEMENTS

The SHIELD CSP/RyCT programme (ISRCTN37956201) is part of the Support at Home - Interventions to Enhance Life in Dementia (SHIELD) project (Application No. RP-PG-0606-1083) which is funded by the NIHR Programme Grants for Applied Research funding scheme. The grant holders are Professors Orrell (UCL), Woods (Bangor), Challis (Manchester), Moniz-Cook (Hull), Russell (Swansea), Knapp (LSE) and Dr Charlesworth (UCL).

This review presents independent research commissioned by the National Institute for Health Research (NIHR) under its Programme Grants for Applied Research scheme (RP-PG-060-1083). The views expressed in this publication are those of the author(s) and not necessarily those of the NHS, the NIHR or the Department of Health.

The authors would like to thank all the members of the Cochrane Consumers and Communication Review Group for their insightful and pragmatic support while developing this systematic review. In particular we thank Megan Prictor (Managing Editor), Sophie Hill (Coordinating Editor), John Kis-Rigo (Trials Search Coordinator), and Annie Synnot (Research Officer). We also thank the members of Dementia UK who gave their time to take part in the focus group discussion and to Joy Watkins for organising the focus group. Thanks also go to Janet Wale (of the Cochrane Consumer Network) for her encouragement and support of the focus group.

REFERENCES

Additional references

Antonucci 1985

Antonucci TC. Personal characteristics, social support, and social behavior. In: Binstock RH, Shanas E editor(s). *Handbook of Aging and the Social Sciences*. New York: Van Nostrand-Reinhold, 1985:94–128.

Bakker 2006

Bakker AB, Van der Zee KI, Lewig KA, Dollard MF. The relationship between the big five personality factors and burnout: a study among volunteer counselors. *The Journal of Social Psychology* 2006;**146**(1):31–50.

Bandura 1977

Bandura A. Self-efficacy: Toward a unifying theory of behavioural change. *Psychological Review* 1977;**84**:191–215.

Bandura 1989

Bandura A. Social cognitive theory. In: Vasta R editor (s). *Annals of Child Development, 6. Six Theories of Child Development*. Greenwich, CT: JAI Press, 1989:1–60.

Bowling 1998

Bowling A, Grundy E. The association between social networks and mortality in later life. *Reviews in Clinical Gerontology* 1998;**8**:353–61.

Candy 2011

Candy B, Jones L, Drake R, Leurent B, King M. Interventions for supporting informal caregivers of patients in the terminal phase of a disease. *Cochrane Database of Systematic Reviews* 2011, Issue 6. [DOI: 10.1002/14651858.CD007617.pub2]

Chan 2011

Chan RJ, Webster J, Marquart L. Information interventions for orienting patients and their carers to cancer care facilities. *Cochrane Database of Systematic Reviews* 2011, Issue 12. [DOI: 10.1002/14651858.CD008273.pub2]

Chien 2008

Chien WT, Thompson DR, Norman I. Evaluation of a peer-led mutual support group for Chinese families of

- people with Schizophrenia. *American Journal of Community Psychology* 2008;**42**(1-2):122–34.
- Cohen 1985**
Cohen S, Wills TA. Stress, social support, and the buffering hypothesis. *Psychological Bulletin* 1985;**98**:310–57.
- Deeks 2011**
Deeks JJ, Higgins JPT, Altman DG. Chapter 9: Analysing data and undertaking meta-analyses. *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org 2011.
- Dennis 2003**
Dennis C. Peer support within a health care context: a concept analysis. *International Journal of Nursing Studies* 2003;**40**:321–32.
- Doull 2005**
Doull M, O'Connor AM, Wells GA, Tugwell P, Welch V. Peer support strategies for improving the health and well-being of individuals with chronic diseases. *Cochrane Database of Systematic Reviews* 2005, Issue 3. [DOI: 10.1002/14651858.CD005352]
- Forsight 2008**
Forsight Mental Capital and Wellbeing Project. Final Project Report. The Government Office for Science, London 2008.
- Fung 2002**
Fung WY, Chien WT. The effectiveness of a mutual support group for family caregivers of a relative with dementia. *Archives of Psychiatric Nursing* 2002;**16**(3):134–44.
- Gallagher 1996**
Gallagher EM, Hagen B. Outcome evaluation of a group education and support program for family caregivers. *Gerontology & Geriatrics Education* 1996;**17**(1):33–50.
- Gignac 1996**
Gignac MAM, Gottlieb BH. Caregivers' appraisals of efficacy in coping with dementia. *Psychology and Aging* 1996;**11**:214–25.
- Goodman 1990**
Goodman CC. A model telephone information and support program for caregivers of Alzheimer's patients. *The Gerontologist* 1990;**30**(3):399–404.
- Higgins 2011a**
Higgins JPT, Deeks JJ (editors). Chapter 7: Selecting studies and collecting data. In: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.
- Higgins 2011b**
Higgins JPT, Green S (editors). Chapter 8: Assessing risk of bias in included studies. In: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions*. Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.
- Hogan 2002**
Hogan BE, Linden W, Najarian B. Social support interventions: do they work?. *Clinical Psychology Review* 2002;**22**:381–440.
- Lewin 2010**
Lewin S, Munabi-Babigumira S, Glenton C, Daniels K, Bosch-Capblanch X, van Wyk BE, et al. Lay health workers in primary and community health care for maternal and child health and the management of infectious diseases. *Cochrane Database of Systematic Reviews* 2010, Issue 3. [DOI: 10.1002/14651858.CD004015.pub3]
- Marziali 2006**
Marziali E, Damianakis T, Donahue P. Internet-based clinical services: virtual support groups for family caregivers. *Journal of Technology in Human Services* 2006;**24**(2-3): 39–54.
- McPherson 2001**
McPherson M, Smith-Lovin L, Cook J. Birds of a feather: homophily in social networks. *Annual Review of Sociology* 2001;**27**:415–44.
- Mittelman 2006**
Mittelman MS, Haley WE, Clay OJ, Roth DL. Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. *Neurology* 2006;**67**: 1592–9.
- Musick 2003**
Musick MA, Wilson J. Volunteering and depression: the role of psychological and social resources in different age groups. *Social Science and Medicine* 2003;**56**(2):259–69.
- Nelis 2007**
Nelis S, Quinn C, Clare L. Information and support interventions for informal caregivers of people with dementia. *Cochrane Database of Systematic Reviews* 2007, Issue 2. [DOI: 10.1002/14651858.CD006440]
- Ory 1999**
Ory MG, Hoffman RR, Yee JL, Tennstedt S, Schulz R. Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *The Gerontologist* 1999;**39**:177–85.
- Pillemer 1996**
Pillemer K, Landreneau LT, Suito J. Volunteers in a peer support project for caregivers: what motivates them?. *American Journal of Alzheimer's Disease & Other Dementias* 1996;**11**(5):13–9.
- Pillemer 2002**
Pillemer K, Suito J. Peer support for Alzheimer's caregivers: is it enough to make a difference?. *Research on Aging* 2002;**22**:323–7.
- Rivera 2009**
Rivera HR Jr. Depression symptoms in cancer caregivers. *Clinical Journal of Oncology Nursing* 2009;**13**(2):195–202.
- Rolland 1987**
Rolland JS. Chronic illness and the life cycle: a conceptual framework. *Family Process* 1987;**26**(2):203–21.

Ross 1999

Ross MW, Greenfield SA, Bennett L. Predictors of dropout and burnout in AIDS volunteers: a longitudinal study. *AIDS Care* 1999;**11**(6):723–31.

Ryan 2011

Ryan R, Hill S, Pricor M, McKenzie J, Cochrane Consumers and Communication Review Group. Study Quality Guide. <http://www.latrobe.edu.au/chcp/cochrane/resources.html> (accessed 23 November 2011) May 2011.

Schulz 1999

Schulz R, Beach SR. Caregiving as a risk factor for mortality - the caregiver health effects study. *JAMA* 1999;**282**: 2215–9.

Schünemann 2011

Schünemann H, Oxman A, Higgins J, Vist G, Glasziou P, Guyatt G. Chapter 11: Presenting results and 'Summary of findings' tables. In: Higgins JPT, Green S editor(s). *Cochrane Handbook for Systematic Reviews of Interventions. Version 5.1.0*. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org, [updated March 2011].

Shemilt 2009

Shemilt I, Mugford M, Byford S, Drummond M, Eisenstein E, Knapp M, et al. Chapter 15: Incorporating economics evidence. In: Higgins JPT, Green S (editors). *Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0* [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.

Sterne 2009

Sterne JAC, Egger M, Moher D (editors). Chapter 10: Addressing reporting biases. In: Higgins JPT, Green A (editors). *Cochrane Handbook for Systematic Reviews*

of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration, 2011. Available from www.cochrane-handbook.org.

Strupp 1978

Strupp HH. Psychotherapy research and practice: an overview. In: Bergin AE, Garfield SL editor(s). *Handbook of Psychotherapy and Behavior Change*. 2nd Edition. New York: Wiley, 1978:3–22.

Toseland 1990

Toseland RW, Smith GC. Effectiveness of individual counselling by professional and peer helpers for family caregivers of the elderly. *Psychology and Aging* 1990;**5**(2): 257–63.

Van Willigen 2000

Van Willigen M. Differential benefits of volunteering across the life course. *The Journals of Gerontology Series B: Psychological Sciences and Social Sciences* 2000;**55**:S308–18.

WHO 1998

WHO. *Health Promotion: Milestones on the Road to a Global Alliance*. Geneva: WHO, 1998.

WHOQOL Group 1993

WHOQOL Group. *Measuring Quality of Life: The Development of the World Health Organization Quality of Life Instrument (WHOQOL)*. Geneva: WHO, 1993.

Wills 1985

Wills TA. Supportive functions of interpersonal relationships. In: Cohen S, Syme LS editor(s). *Social Support and Health*. San Diego, CA: Academic Press, 1985: 61–82.

* Indicates the major publication for the study

APPENDICES

Appendix I. MEDLINE search strategy

1. exp family/
2. (family or families or parent\$2 or relative? or spous\$2 or partner? or husband? or wife or wives or child or children or grandchild* or son? or daughter? or sibling? or brother? or sister? or mother? or father?).tw.
3. 1 or 2
4. (care* for or caring).tw.
5. 3 and 4
6. caregivers/
7. (carer* or caregiv* or care giv*).tw.
8. exp home nursing/
9. or/5-8
10. peer group/
11. (peer? or lay).tw.
12. voluntary workers/
13. (voluntary worker* or (trained adj3 volunteer*)).tw.

14. community health aides/
15. self help groups/
16. community networks/
17. (self help group* or ((support* or carer or caregiver) adj (group* or network*)) or (mutual adj (aid or support)) or ((support or community) adj network*)).tw.
18. mentors/
19. (mentor* or befriend* or buddy or buddies or companion*).tw.
20. or/10-19
21. 9 and 20
22. social support/
23. exp counseling/
24. psychotherapy, group/
25. family therapy/
26. exp "religion and psychology"/
27. (support* or befriend* or advice* or advis* or counsel* or help* or assist* or encourag* or pastoral* or spiritual* or meeting* or visit* or program* or ((family or group) adj (therap* or intervention*))).tw.
28. or/22-27
29. 21 and 28
30. randomized controlled trial.pt.
31. controlled clinical trial.pt.
32. random*.tw.
33. placebo*.tw.
34. trial.tw.
35. groups.ab.
36. clinical trial.pt.
37. evaluation studies.pt.
38. research design/
49. follow up studies/
40. prospective studies/
41. cross over studies/
42. comparative study.pt.
43. (experiment* or intervention*).tw.
44. (pre test or pretest or post test or posttest).tw.
45. (preintervention or postintervention).tw.
46. time series.tw.
47. (cross over or crossover or factorial* or latin square).tw.
48. (assign* or allocat* or volunteer*).tw.
49. (control* or compar* or prospectiv*).tw.
50. (impact* or effect? or chang* or evaluat*).tw.
51. or/30-50
52. exp animals/ not humans.sh.
53. 51 not 52
54. 29 and 53

HISTORY

Protocol first published: Issue 11, 2012

CONTRIBUTIONS OF AUTHORS

Writing the protocol: KB and AF with comments from GC, JH, FP, and MO

Developing the search strategy: John Kis-Rigo, KB, AF, GC, and FP

For the review:

Search for trials: KB and AF

Obtain copies of trials: AF

Select which trials to include: KB and AF (with GC)

Extract data from trials: KB and AF (with GC)

Enter data into RevMan: AF and KB

Carry out the analysis: KB and AF

Interpret the analysis: KB MO JH GC

Draft the final review: All

Update the review: KB/GC

DECLARATIONS OF INTEREST

Georgina Charlesworth and Fiona Poland were grant holders on the BECCA trial, which assessed the cost-effectiveness of lay befrienders on improving wellbeing and quality of life for family carers of people with dementia (ISRCTN08130075). Peers comprised a significant proportion of the lay befrienders in this trial and it may be included in the review. GC and FP will not be involved in assessing this study for inclusion, assessing its risk of bias, or extracting and entering data for this study if it is included.

SOURCES OF SUPPORT

Internal sources

- UCL Graduate School, UK.

Grant awarded to KB to provide assistance with travel costs to Melbourne to meet with the Review Group.

External sources

- National Institute for Health Research, UK.
Grant for Applied Research RP-PG-0606-1083.