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Interventions for adult family carers of people who have had a stroke: a systematic review

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Objective: A systematic review of the effectiveness of interventions for adult family carers of people with stroke, and an exploratory examination of the relationship between the conceptual basis of these interventions and their effectiveness.
Data sources: Seventeen electronic databases and grey literature sources were searched, including ASSIA, BNI, Cochrane Library, CINAHL, EMBASE, MEDLINE, PsycINFO, Social Science Citation Index and the Science Citation Index, HMIC and the National Research Register. Authors of unpublished material were contacted for data and additional publications. Reference and citation tracking was performed on included publications.
Review methods: Inclusion criteria: randomized controlled trials of interventions aimed primarily at adult family carers of people post stroke; carers were the primary sample; primary outcomes reported were for carers. Two independent reviewers screened titles and abstracts to identify publications and extract data. Quality assessment was performed to weight study findings.
Results: Eight papers were found reporting on six complex, generally heterogeneous, interventions: caregiver training; education and counselling; social problem-solving partnerships, delivered principally by telephone; a psycho-educational telephone support group; a nurse-led support and education programme; and a support programme, delivered either to groups in hospital or individuals during home visits. Half of the interventions were based on stress-coping theories; the remainder did not identify a conceptual basis for the intervention.
Conclusions: Some benefits were reported for all interventions, although trials were generally of low quality, preventing firm conclusions being drawn. The presence of a conceptual basis for interventions does not appear to influence effectiveness.

Introduction

Globally, family carers make an important contribution to community care.[1] Policy initiatives in the UK[2-6] mean that family carers now have the right to an independent assessment of their needs and should expect to become 'real partners' with services in care provision.[7] Consequently, it is becoming more urgent to develop appropriate and effective interventions to meet these carers' needs.

Developing appropriate and effective interventions for carers post stroke is particularly important as this is the greatest cause of long-term

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disability in the UK[8] and a sizeable number of people will unexpectedly find themselves adopting a caring role.[9] The number of people having a stroke will rise over the next 30 years purely as a result of the ageing population.[10]

Family members play an important role in care-recipients' recovery post stroke.[11] However, carers have little time to prepare for their role as policy initiatives require shorter inpatient hospital stays.[12] Much evidence exists suggesting that caring affects the carer's physical, psychological and social well-being.[13] UK National Clinical Guidelines for Stroke recognize family members' need for information and long-term practical, emotional, social and financial support to cope with the residual problems associated with stroke.[11] However, little evidence exists to assist in identifying the most useful interventions for carers.

This lack of evidence is not due to a lack of research in this field. Outcomes for adult family carers of people who have had a stroke have been examined by a sizeable body of research. Interventions aimed at both patients and carers together forms the largest body of work and includes new models of service delivery, such as community rehabilitation, the stroke family support worker, and multidisciplinary stroke teams.[14–17] To date there have been very few interventions developed specifically for carers. Those that have been developed include education and information,[18,19] skills training[20] and social support.[21] Although several reviews have focused in whole or in part on interventions designed specifically for adult family carers of people who have had a stroke,[18,20,23] there has only been one other systematic review.[24] However, this previous review evaluated the effectiveness only of education and information provision for patients and carers. It found that information combined with educational sessions was more effective than providing information alone for improving patients' and carers' knowledge.

This systematic review therefore aims to evaluate supportive interventions involving more than simple education or information giving, which are aimed at carers only and tested by randomized controlled trials. This has been done for several reasons. First, this review contributes to the synthesis of the existing evidence base and randomized controlled trials are widely acknowledged to be the most rigorous method for evaluating the effectiveness of interventions.[25,26] Second, the focus on carers is appropriate as the primary outcomes will be pertinent to this group, whereas interventions aimed at both patients and carers post stroke tend to report primarily on patient outcomes and would require consideration of the rehabilitation literature, which makes the task unwieldy. Third, there is currently no systematic review of research into interventions for adult family carers of people with stroke other than purely information-giving or educational interventions. This review aims to fill that knowledge gap.

Additionally, this paper will explore whether authors of included studies have reported any theoretical basis for their interventions, and will examine whether the presence of such a basis for the intervention influences its effectiveness. The Medical Research Council (MRC) framework document on the development of complex interventions has demonstrated the importance of having a theoretical basis for an intervention, 'to ensure the best choice of intervention and hypothesis and to predict major confounders and strategic design issues.'[27] Indeed, a randomized controlled trial for an intervention to help stroke carers was recently developed using this framework.[28] The intention is to contribute further to this debate on study design and methodology.

This review aims to answer the following questions:

1) Which, if any, interventions, specifically designed for carers of people who have had a stroke, are effective in improving carer outcomes?
2) Is there an association between the presence of a conceptual basis and the effectiveness of an intervention?

Method

Studies were included if they fulfilled the following criteria:

- Randomized controlled trial
- The intervention was primarily aimed at adult family carers of people who had had a stroke,

rather than being aimed at both people who had had a stroke and their carers, or only people who had had a stroke
- Carers were the primary sample
- The primary outcomes reported were for adult (defined as a person aged 18 or over) family carers of people who had had a stroke.

Studies were excluded if the intervention consisted only of education or information-giving, as these studies have already been the subject of a systematic review,[24] or if the only outcome was cost-effectiveness.

The electronic databases searched were AMED (1985–2005), ASSIA (1970–2005), BNI (1994–2005), C2-SPECTR (Campbell Collaboration Register of RCTs) (1950–2005), CDSR (Cochrane Library, Issue 4, 2005), CENTRAL (Cochrane Library, Issue 4, 2005), CINAHL (1982–2005), EMBASE (1980–2006), IBSS (1951–2005), MEDLINE (1966–2006), NHS DARE (Cochrane Library, Issue 4, 2005), NHS EED (Cochrane Library, Issue 4, 2005), NHS HTA (Cochrane Library, Issue 4, 2005), PreMEDLINE (2006), PsycINFO (1980–2005), Social Science Citation Index (1972–2005), Science Citation Index (1970–2005). Searches were also made of the following grey and unpublished literature sources: HMIC (1983–2005), King's Fund database (1979–2005), the National Research Register (1990–2005), and the Research Findings Register (1999–2005). Where relevant, authors of unpublished material were contacted for data and information about additional publications.

This review used a Cochrane Stroke Group stroke search strategy.[29] The Cochrane Highly Sensitive Search Strategy was used to identify randomized trials.[30] These strategies were combined with the search terms carer(s) and caregiver(s) both as free-text and database keywords, where they were available (see Appendix). The search filters were modified for different databases to take account of the thesaurus and limitations of each database. No limitations of language were applied in order to avoid known biases produced by language and location.[31,32] There were no limitations by date beyond the reported coverage of the databases themselves.

Results of the electronic searches were imported into Reference Manager software and duplicates were deleted. Titles and abstracts were screened using the inclusion/exclusion criteria to identify potentially relevant publications. A pilot sift was conducted by two reviewers (LB and CC) to test the study selection criteria form and to assess inter-rater reliability. In cases where there was disagreement, the two reviewers reached a consensus. Two reviewers (LB and CC) then each independently assessed half of the references. In cases where there was uncertainty about inclusion, the two reviewers reached a consensus, and in cases where there was insufficient information in the title or abstract to make a judgement on inclusion, the full publication was retrieved.

Data extraction was performed on references selected for inclusion using a form developed for this review and piloted on a sample of the studies. Double data extraction was performed on all included studies by two reviewers (LB and CC). This process also included quality assessment of studies using the Critical Appraisal Skills Programme (CASP) tool for randomized controlled trials.[33] Studies were not excluded on the basis of quality assessment, but the CASP tool was used to assist judgements on the relative quality of the studies, and thus to weight their findings. This is in accordance with developing systematic review methodology.[34–36] During data extraction, reference lists were checked for further relevant references and citation tracking was performed using ISI-Web of Science, CINAHL and Google Scholar on studies that satisfied the inclusion criteria.

Results

For details of the study identification and selection process, see the QUOROM flowchart in Figure 1. After the removal of duplicates, a total of 523 references were identified by the searches of the electronic databases and grey literature sources. The titles and abstracts of retrieved studies were then screened using the stated inclusion and exclusion criteria. A test sift of a sample of 100 titles and abstracts by two reviewers (LB and

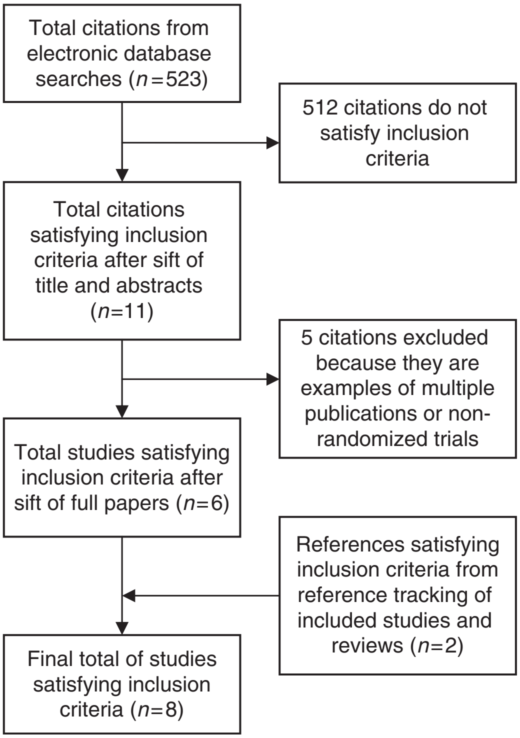

Figure 1 QUORUM flowchart: study identification and selection process.

CC) produced an inter-rater reliability coefficient of 0.9. The two reviewers then each screened half of the references for eligibility. Five hundred and twelve studies were rejected at this stage because they did not meet the required criteria. Attempts were made to retrieve the full papers of the remaining 11 references. Four of the citations were conference presentations of data from a single published paper (multiple publications) and one was an economic evaluation.[20] The result was six relevant papers.[37–42] Reference tracking both of these papers and the reviews cited above yielded two additional references which satisfied the inclusion criteria.[43,44] Citation tracking of these eight studies produced no more relevant references. Overall, therefore, eight studies were identified which satisfied the inclusion criteria (Table 1).

Despite the comprehensiveness of the multimethod information retrieval techniques employed by this systematic review, this study only found three papers[39–41] not included in any previous review. One of the studies included here[44] also appeared in the only other systematic review in this field,[24] but is included here because one of the interventions examined was not education or information-giving alone, but included counselling. Study results were not pooled statistically as there was heterogeneity in the context, interventions and outcomes of the included studies. Conclusions were drawn based on the quality and results of the studies.

Papers originated from the USA ($n=4$), UK ($n=1$), Sweden ($n=1$) and the Netherlands ($n=2$) and dated between 1988 and 2005. Two papers from the USA tested the same intervention (home and telephone social problem-solving partnerships (SPSP/SPTP)).[37,38] The two papers from the Netherlands reported on the short- and long-term effects of the same nurse-led support programme.[42,43] Six complex interventions were therefore tested in these randomized controlled trials: caregiver training[41]; SPSP/SPTP[37,38]; a psycho-educational telephone support group[39]; a nurse-led support and education programme[40]; a support programme, delivered by nurses either to groups at a hospital or individuals at home[42,43]; and a combination of education and counselling[44] (Table 2).

Effectiveness of interventions

The training of carers and a combination of education and counselling both had positive effects for carers, though these outcomes were quite different. Training improved carers' well-being and quality of life by reducing their depression, anxiety and burden[41]; education and counselling improved carer knowledge and resulted in significantly less deterioration in family functioning than either education alone or routine care.[44] Support groups and home visits led by health education nurses improved carers' coping skills, such as self-efficacy, confidence in knowledge of patient care and seeking social support, but had no significant beneficial effect on their well-being.[42,43]

Table 1 Intervention studies for carers post stroke

First author, year, country of origin	Carers sample size (m/f)	Carer characteristics recorded	Patients characteristics recorded	Conceptual/ Theoretical framework	Intervention (I) Control (C) Sham (S)	Data collection	Outcomes and measures (see key below)	Findings (Statistically significant at: * $P<0.05$ ** $P<0.01$)
44 Evans, 1988, USA	188 (17/171)	Age, education, income, gender, two-person household	Age, education, income, gender, two-person household, depression, self-care (BI), hospital days, employment, cognitively intact, marriage, hospitalization, discharge by service	None stated	I(1) = Education and supportive counselling ($n=61$). I(2) = Education alone ($n=64$). C = Routine medical and nursing care (not described) ($n=63$)	Baseline, 6 months, 1 year post stroke	Caregiver knowledge of stroke care: SCIT; Family function: FAD; Use of social resources: ESCROW profile; Patient adjustment: PARS	At 6 months: Intervention groups had significant improvement in carer knowledge about stroke and 3 of 7 family function measures (problem-solving, communication, global family function) and patient adjustment** All 3 conditions showed worsening family functioning but intervention groups had significantly less deterioration** Education and counselling group showed significantly improved patient adjustment compared to controls.** No significant differences in use of social resources At 1 year: Intervention groups significantly better than the control on carer knowledge of stroke, 4 measures of family functioning (problem-solving, communication, affective involvement and global family functioning).** Family functioning had deteriorated significantly less in intervention groups than in the control group**
37 Grant, 1999, USA	30 (16/14)	Age, education, race, relationship to person with stroke, disability	FIM score, age, race	Yes – Lazarus and Folkman's (1984) stress-coping model. Other social problem-solving theories were also named (see text)	I = Home and telephone SPSP. S = brief telephone contacts – same schedule as the intervention groups. C = Usual discharge planning services	2, 5 and 13 weeks post discharge	General Health: SF-36; Problem solving skills: PSI; Satisfaction with health care services: CSQ; Depression: CES-D; Caregiver preparedness: PCS; Burden: CBS; Social support: ISEL	Telephone group had a significant reduction in depression, more positive problem-solving skills and greater caregiver preparedness at 2** and 5* weeks post intervention. Lower, but not significant results in these scores were found at 13 weeks. No differences were found in general health, caregiver burden and satisfaction with health care services

(continued)

Table 1 Continued

First author, year, country of origin	Carers sample size (m/f)	Carer characteristics recorded	Patients characteristics recorded	Conceptual/ theoretical framework	Intervention (I) Control (C) Sham (S)	Data collection	Outcomes and measures (see key below)	Findings (Statistically significant at: $*P<0.05$ $**P<0.01$)
43 Van den Heuvel, 2000, Netherlands	257 (102/155)	Age, relationship to patient, income, physical functioning, mental well-being, social support, perception of disability, resources and patient care	Mental health and well-being	Yes – Lazarus and Folkman's (1984) stress-coping model	I = nurse support group or home visit programme C = Not clearly described	Baseline, 1 month	Confidence in knowledge: new questionnaire; Coping: Utrecht Coping List; Caregiver strain: CSI; Physical and Mental well-being, vitality: SF-36; Social support and satisfaction with social support: SSL; Assertiveness: new questionnaire	Significantly raised confidence in knowledge of patient care,** carer self-efficacy** and seeking social support as a coping strategy* in both intervention groups No other significant effects of the interventions and no significant differences between the 2 interventions
42 Van den Heuvel, 2002, Netherlands	As ref. 43	As ref. 43	As ref. 43	Yes – as ref. 43	As ref. 43	Baseline, 1 month, 6 months	As ref. 43	Significantly increased confidence in knowledge of patient care** and carer self-efficacy** in both intervention groups, and seeking social support as a coping strategy* in the home visit group at 6/12 months only No other significant effects of the interventions and no significant differences between the 2 interventions
38 Grant, 2002, USA	74 (35/39)	As ref. 37	As ref. 37	Yes – as ref. 37	I = SPTP and usual rehabilitation discharge planning services. C = Usual discharge planning services only	2, 5 and 13 weeks post discharge	Outcomes as ref. 37	SPTP group were significantly better than controls in all aspects of general health,* 3 of 4 elements of problem-solving,** caregiver preparedness,** depression** No difference with health care satisfaction or caregiver burden

39 Hartke, 2003, USA	88 (21/67)	Age, education, race, years caregiving, help received, who provides help	FIM score	Yes – Stress-coping models	I = Psycho-educational telephone support group. C = Usual care and given the same stress management publication and a brief written description of caregiver stress and stroke	Baseline, immediately post intervention, 6 months	Depression: CES-D; Burden: Burden Interview; Loneliness: UCLA Loneliness Scale; Stress: PPI; Competence: CCS	Treatment group showed significant increase in competence* and decreased stress** over time although this was not significantly more than the control group. Control group showed a significant increase in burden*
41 Kalra, 2004, UK	300 (not reported)	Family support, social services' support, relationship to patient	BI, type of stroke, Frenchay Activity Index, EuroQoL, homeowner	None stated	I = Caregiver training. C = Conventional support and carer training in basic nursing and facilitation of personal care techniques	3 and 12 months	Functional status and social activities: Frenchay Activities Index; Psychological state: HADS and CBSh; Quality of Life: EuroQol; Carers' satisfaction: measure not stated	Significant reduction caregiver burden,** anxiety** and depression** at 3 and 12 months
40 Larson, 2005, Sweden	100 (20/80)	Age	Age, gender, number of strokes, time since last stroke	None stated	I = A nurse-led support and education programme. C = Received only regular information (not described) during the patient's hospitalization and at discharge	Baseline, 6 and 12 months	EuroQoL; Well-being: Bradley's Well-being questionnaire; Life Situation of Spouses: LISS	No significant differences in outcomes between the 2 groups, although well-being improved more among those who attended the most classes (5 of 6) in the intervention group

FIM, Functional Independence Measure; BI, Barthel Index; SPTP, social problem-solving telephone partnerships; SPSP, social problem-solving partnership; SCIT, Stroke Care Information Test; FAD, Family Assessment Device; PARS, Personal Adjustment and Role Skills scale; PSI, Problem Solving Inventory; CSQ, Client Satisfaction Questionnaire; CES-D, Center for Epidemiologic Studies Depression Scale; PCS, Preparedness for Caregiving Scale; CBS, Caregiving Burden Scale; ISEL, Interpersonal Support Evaluation List; CSI, Caregiver Strain Index; SSL, Social Support List-Interaction; PPI, Pressing Problem Index; CCS, Caregiver Competence Scale; HADS, Hospital Anxiety and Depression Score; EuroQol, EuroQoL visual analogue scale; LISS, Life Situation Among Spouses after Stroke event questionnaire.

Table 2 Characteristics of interventions

Study	Study setting	Intervention (I) Sham (S)	Control (C)
44 Evans, 1988	Recruited at medical centre. Follow-up at home	Two interventions for the principal carer: Education alone ($n=64$) and Education and supportive counselling ($n=61$) Education – 2 × 1-hour classes in 3rd week of hospitalization. Lecture and video 'Living with Stroke'. Details given about the session content – delivered by members of the multidisciplinary team. Second class within 3 days of 1st to explain treatment unique to the family and answer questions. Education and counselling – Education as described above and 7 individual 1-hour counselling sessions with 1 of 2 social workers trained in cognitive behaviour counselling. First counselling in 3rd week of hospitalization then bi-weekly sessions. All counselling completed by 3 months post discharge.	Routine medical and nursing care (not described) ($n=63$)
37 Grant, 1999	Recruited and trained in rehabilitation setting	Home and telephone social problem-solving partnerships I – Social problem solving partnerships (SPSP) and usual rehabilitation discharge planning services to improve carers' physical and psychological well-being. Initial 3-hour session with the trained nurse in a quiet conference room 1–2 days pre-discharge then 7 home visits or telephone contacts (weekly in the 1st month, bi-weekly in the 2nd monthly and monthly in the 3rd month) S – brief telephone contacts: same schedule as the intervention groups.	Usual discharge planning services
42, 43 Van den Heuvel, 2000 and 2002	Home for home visit group. Group support programme (not stated where held)	A support programme (same content delivered as a group programme or via home visits) Group programme: 8 weekly 2-hour sessions over 2 months (16 hours of education). Groups of 8–13 carers supervised by health education nurses from home care services Home visits: 4 × 2-hour visits (8 hours of education), over 8–10 weeks supervised by specialized district nurses All nurses attended a 1-day training programme and some were experienced in delivering interventions to carers	Not clearly described
38 Grant, 2002	Recruited at 2 rehabilitation facilities: 1 private and 1 state with similar family discharge planning services. Training and follow-up at home	Social problem-solving telephone partnerships (SPTP) and usual rehabilitation discharge planning services Carers trained to use social problem-solving skills to manage caregiving problems and cope with the stresses of caregiving. I – SPTP = initial 3-hour face-to-face session with a registered nurse at home within 1 week of discharge. Carers taught positive problem orientation and follow 4 systematic steps to solve problems. Initial session followed by telephone contacts – weekly for the 1st month post discharge; bi-weekly in 2nd month post discharge and monthly in 3rd month post discharge (i.e. weeks 2, 3, 4, 6, 8, 10 and 12 to develop and maintain skills over the 12-week period.) In subsequent telephone contacts, carers asked to identify 3 most common/stressful problems since last contact and how they were currently managing this. Research nurse helped carers to use effective social problem-solving skills to manage problem and gave feedback on appropriateness of techniques being used	Usual discharge planning services only. (In hospital carers observed and participated in the patient's physical, occupational and speech therapy and received literature from the American Heart Association and National Stroke Association)

39 Hartke, 2003	Home	Psycho-educational telephone support group 8 × 1-hour sessions followed a structured format using a group manual mailed to participants before the first meeting. Manuals included an audiotaped relaxation procedure and a stress management publication. Each carer was given a list of caregiving problems that they had identified at initial assessment 16 groups of 3–6 members were formed usually with 2 facilitators (clinicians in psychology and social work or nursing). Almost all groups were conducted only by telephone conference over an 8-week period. Participants were encouraged to have contact with each other outside group meetings	Usual care and given the same stress management publication and a brief written description of caregiver stress and stroke
41 Kalra, 2004	Rehabilitation hospital and at home	Caregiver training Conventional support and carer training in basic nursing and facilitation of personal care techniques	Conventional care: information on stroke; involvement in goal-setting for rehabilitation and discharge; encouragement to attend nursing and therapy activities; advice on community services, benefits and allowances
40 Larson, 2005	Hospital	A nurse-led support and education programme Groups of 10 participants met in hospital, 6 times in 6 months. Participants could call the stroke specialist nurses between sessions for extra information or support Programme aims – to improve knowledge about stroke disease, provide opportunities for spouses to ask questions and discuss their experiences of caring with specialist nurses and people in similar situations	Received only regular information (not described) during the patient's hospitalization and at discharge. Could attend 1 open session for 1.5 hours led by a stroke physician on the ward. (Only 3 controls did so). No other support or education

Table 3 Summary of methodological elements of each study

Study	Response rate	Randomization and blinding	Power calculation	Carers control and experimental groups statistically the same at baseline	Numbers given in control and experimental groups at baseline and follow-up	Intention to treat
44 Evans, 1988	217 out of 233 (before drop-outs)	Randomized No blinding	No	Yes	Yes	No
37 Grant, 1999	Not given	Part randomized Single blinding (researchers)	No	Yes	No	No
43 Van den Heuvel, 2000	Not given	Randomized No blinding	Yes	No	Yes	Yes
38 Grant, 2002	Not given	Part randomized Single blinding (researchers)	No	Yes	No	No
42 Van den Heuvel, 2002	Not given	Randomized No blinding	Yes	No	Yes	Yes
39 Hartke, 2003	Not given	Randomized Single blinding (researchers)	No	No	Yes	No
41 Kalra, 2004	Not given	Randomized Single blinding (researchers)	Yes	Yes	Yes	No
40 Larson, 2005	40%	Randomized No blinding	No	Yes	Yes	No

A different nurse-led support group intervention also failed to have a significant positive effect on carers' well-being.[40] However, no form of coping skill was measured by this study to compare with the success of the other hospital-based support group intervention.[43] The two telephone-based interventions found different results.[37–39] One intervention had a significant positive effect on carers' health, as well as their problem-solving and preparedness,[37,38] while the other also measured aspects of well-being and competence, but showed no significant effect on either compared to the control group.[39] The former intervention involved telephone support to individuals, the latter to groups, and this may explain the different levels of success.

All of the interventions therefore had some positive outcome for carers, but only the training of carers in nursing and personal care techniques,[41] and the provision of problem-solving partnerships and support (SPSP/SPTP),[37,38] had any positive effect on aspects of carers' quality of life and well-being. Telephone-based partnerships were only one of two interventions, the other being the group or home visit support programme,[42,43] which had a significant positive effect on carers' coping skills.

Quality assessment of studies

Despite the positive effects attributed to certain interventions, however, the overall quality of the eight randomized controlled trials reviewed here was low (Table 3). The interventions did not permit blinding of participants in any of the studies, but four failed to employ blinding of the researchers responsible for data collection.[40,42–44] Only two studies reported response rates to their recruitment measures.[40,44] The unit of randomization for all trials was the individual but, in the SPSP/SPTP intervention, some participants, on account of the distance they lived from the hospital providing the intervention, were randomized only to two of the three study conditions.[37,38] This produced a bias in the randomization process. Only three of the eight studies performed a power calculation to determine the minimum sample size to minimize the role of chance in establishing the effect of an intervention.[41–43] This is particularly important in the case of small sample and cell sizes, such as in these studies. What is more, only one of these three studies actually generated cell sizes of sufficient size to evaluate the effectiveness of the intervention in relation to the outcomes being examined.[41] The other two studies did not generate sample sizes big enough to show even medium effects across the designated outcomes for all of their experimental and control groups. Also, the control intervention was rarely described.

The SPSP/SPTP intervention failed to report the number of participants in the control and experimental groups both at baseline and follow-up.[37,38] Rates of attrition and loss to follow-up were also omitted from one of the studies of this intervention.[37] Four of the seven studies that did report these data offered no reference at all as to how withdrawals were analysed. One trial simply removed withdrawals from all the analyses.[44] Only the studies examining the nurse-led group and home visits support programme reportedly countered participant attrition bias by performing analyses on the basis of intention-to-treat.[42,43] However, there were statistically significant differences in the age, physical health and knowledge of patient care of the control and experimental groups in these two studies, which in turn compromises the results, especially the last-named confounder. In this case, the control group had much better knowledge of patient care than the experimental groups. This may explain why the improvement over time was not significant for this group, unlike the intervention groups. The relative significant improvement demonstrated here may therefore be without basis.

The trial of a psycho-educational support group also demonstrates statistical differences in the baseline characteristics of the control and experimental groups.[39] In this study, the carers in the intervention group received significantly more help with care, and their care-recipients had significantly better motor scores than the control group. Again, this may confound the results for the carer outcomes in this study in favour of the intervention. The overall standard of the trials is therefore quite low, regardless of the limitations known to afflict studies of carers of people who have had a stroke, especially recruitment.[42,45]

Do the interventions have an underlying conceptual framework?

Three of the eight studies did not identify the underlying conceptual framework supporting their interventions.[40,41,44] The remaining interventions were underpinned by stress-coping theories. Four specifically stated that their interventions were based on Lazarus and Folkman's (1984) transactional model of stress.[37,38,42,43] A fifth study also cited stress-coping theory as the basis for its intervention but used a different model.[39] The intervention in one set of studies[37,38] was also underpinned by a number of other theories, including social problem-solving,46 family carer social problem-solving[47–50] and the concerns of caregivers.[51]

The outcomes reflected the orientation to stress-coping theories: one intervention measured strain and coping,[42,43] one burden and problem-solving skills,[37,38] and one stress and burden.[39] However, these studies did not clearly state how the outcome measures related to the intervention or its theoretical basis. Also, there is no apparent link between interventions and outcomes in some of the other studies. For example, one study focused on training carers,[41] but then did not measure role preparedness, confidence or competence, while the aim of another intervention was to improve knowledge, but did not measure whether or not an increase in knowledge was achieved.[40]

Given the small number of studies reviewed, caution needs to be exercised when stating whether there is a relationship between the existence of a conceptual basis for an intervention and benefits for carers. Also, results in this sample were inconsistent: all authors reported some benefits associated with the intervention, irrespective of whether interventions were underpinned by a conceptual basis or not. For example, despite the existence of a conceptual framework underpinning the intervention, telephone support groups found only limited benefits,[39] while benefits were found by some heterogeneous interventions with no identified underpinning conceptual framework[40] and at times these findings were significant.[41,44]

Discussion

Some of the interventions reviewed here appear to have a more positive effect on carer's well-being and skills than the information or information and education interventions examined by a previous systematic review.[24] However, it is not possible to draw conclusions on the effectiveness of these interventions for informal carers of people who have had a stroke based on this sample of studies. This is the case for several reasons. First, the interventions are quite heterogeneous. There are even substantial differences between the most apparently similar interventions (see Table 2). The two telephone-based support interventions provide an example. In the SPSP/SPTP intervention,[37,38] the support was delivered by a single nurse, and in the psycho-educational support intervention by a two-person combination involving nurses, social workers and clinicians.[39] The SPSP/SPTP intervention was delivered one-to-one to carers who were caring for a person who had only recently had a stroke[37,38]; the psycho-educational support intervention was delivered teleconference-style to a group of carers, who had been caring for an average of three years.[39] Similar, vital differences also afflict the group elements of the apparently comparable nurse-led support programmes.[40,42,43]

Second, these trials examine the impact of their six interventions on more than 20 different outcomes. Only carers' depression and burden are measured in relation to more than one intervention,[37–39,41] and burden is only measured by the same instrument, the Caregiving Burden Scale (CBS), in two of these studies.[38,41] These two studies trial quite different interventions and also find different effects. A systematic review of purely information-giving interventions for carers of people who have had a stroke found a similar variety and inconsistency in the outcomes studied.[24]

Third, even if there was sufficient homogeneity between these studies to aggregate their findings in some way, the critical appraisal conducted above suggests that great caution must be exercised when attempting to draw any conclusions from this sample. The SPSP/SPTP intervention, for example, is the only one to demonstrate a significant effect both on carers' well-being and their skills.[37,38] However, as described above, these studies are also by far the weakest in terms of methodology. The trials of carer training[41] and nurse-led support groups[40,42,43] are much better studies, but their results are much more inconsistent and they have their own weaknesses. A previous systematic review of information-giving interventions for carers of people who had had a stroke also found the quality of trials to be variable, and generally low.[24]

A further, typical weakness of all of these studies concerns the measurement of the baseline characteristics of carers and patients (Table 1). All of these studies record the characteristics of the carers by age and gender and all but three record the relationship of the carer to the patient.[39,40,44] However, there is very little agreement about the other factors which need to be controlled when establishing that the experimental and control groups are sufficiently similar for study results to be meaningful. A carer's physical or mental well-being, as well as the existence of formal and informal support networks, have all been demonstrated to have a significant effect on their level of need, burden, quality of life, psychosocial health and ability to cope.[52–54] However, only two studies take into account these issues,[42,43] and four studies do not control for any of these factors at all, even though they measure some of these outcomes.[37,38,41,44] Other known potential moderators not controlled for here include carers' familiarity with their role, their relationship with the care-recipient, biographical factors such as usual coping capacity, and other coexisting stressors, such as financial constraints and emotional responses to caring.[55–58] It may be argued that the findings of these studies are compromised as a result of their failure to control for known, significant confounders. By contrast, age and gender are recorded by all of these trials, but have been shown not to predict or have any effect on outcomes such as carers' quality of life or burden.[60]

The same problem exists for the data recorded about the patients assigned to experimental and control groups in these trials. Research has demonstrated that care-recipients' cognitive impairment can prove as demanding as physical impairment for adult family carers of people who have had a stroke,[54] but only three of the eight studies measure this.[42–44] Also, carers' willingness or ability to cope can be affected by the emotional, cognitive and behavioural disturbances that care-recipients experience post stroke.[59–61] Once again, these factors could potentially moderate the effect of any intervention to help carers unless it is controlled for and experimental and control groups are demonstrated to be statistically similar. However, the vast majority of these studies do not control for these factors.

The interventions varied in their content, delivery time and context but emphasis appears to be on providing support to carers, which potentially satisfies UK National Clinical Guidelines.[11] Most interventions were delivered whilst the care-recipient was in hospital or within six months of their discharge home. Such limits on the timing and duration of interventions potentially ignore the need for these to be stage-specific,[62] especially as carers' needs and responses change over time post stroke.[63] It is not surprising that these interventions do not reflect the longevity of caring post stroke since few longitudinal studies have focused on carers' experiences post stroke.[64] This means the needs of experienced or expert carers are being ignored.

Almost half of the interventions examined by this review had no theoretical basis for their design. The remainder were all underpinned by stress-coping theories. Despite the low quality of studies reviewed, the evidence suggests that interventions for family carers have some benefit irrespective of whether these are underpinned by a conceptual framework or not. One explanation for this may be that benefits occur because such interventions meet carers' reported need for recognition.[65] The emphasis on stress and coping as a conceptual foundation for the interventions reviewed here is perhaps not surprising given that these frameworks underpinned much of the early empirical work conducted in the field of family caring generally.[66] However, there remains an issue about the choice of stress-coping theory as the basis for developing interventions to help carers. Despite the existence of some support, stress-coping theories have been criticized on the basis that such an approach 'pathologizes' care[67] and is insufficiently developed to capture the complexities of individual caregiving contexts.[54,68] The studies included in this review have also ignored the potential contribution of other theoretical frameworks drawn from the wider caregiving literature, such as dyad or triad relationships,[69–72] biography[73,74] and carers' experience or expertise within the chronic illness trajectory.[75–78] Most studies do not make it clear who was responsible for designing the intervention. Only one study refers to input into this from a focus group of carers.[39] This is an area worthy of attention given directives for professionals to increase the involvement of service users and carers,[2,79] especially if interventions are to be relevant to carers' needs and of acceptable quality to caregivers.[80,81]

Finally, given the importance of establishing the theoretical basis of interventions to identify 'mechanisms of action' and expected effects,[25] it is uncertain whether the outcome measures used in these studies are valid and reliable determinants of the intervention's effects. For example, five of the eight studies in this review used interventions underpinned by stress-coping theory,[37–39,42,43] but questions have been raised about the capacity of this theory to determine outcomes for interventions.[54] The remaining three studies have no reported theoretical basis for their intervention at all,[40,41,44] which makes it almost impossible to determine the appropriateness of the outcome measures used. What is more, despite the known importance of selecting appropriate and sensitive outcomes related to the intervention,[82] there is little, if any, justification of the outcome measures used in these studies.

In summary, some benefits were reported as being associated with almost all interventions, but insufficient evidence exists to confirm the efficacy of the interventions for carers, since the studies reviewed here were generally of low quality. Nor is it possible to determine whether an association exists between the presence of a conceptual foundation for the intervention and its effectiveness.

Strengths and limitations of this review

This systematic review has addressed a gap in the evidence base by focusing on non-information giving interventions designed specifically for adult carers of people who have had a stroke. The comprehensive search, retrieval and review strategies used and reported in this review address some of the limitations of previous reviews. However, due to constraints of time and resources, the review did not hand-search any journals and focused principally on English language databases. As well as adding to the findings of previous reviews about the actual effectiveness of interventions to help carers, this review offers a new perspective on this research by looking at the conceptual basis of the interventions tested and existing study methodologies.

Recommendations

More, higher quality research into interventions to help carers of people who have had a stroke is needed. First, interventions should be underpinned by an appropriate conceptual framework in order to identify potential confounders and to inform the intervention and choice of outcomes. Studies need to control for the full range of factors that may moderate the effect of an intervention to support carers of people who have had a stroke, such as carer well-being, social support and relationship with the care-recipient. There is also an argument for involving carers in the development of interventions.[80,83] Only one of the studies reviewed here did this.[39] The involvement of carers in the development of interventions would also ensure that they are 'real partners' with professionals. This will help to ensure that interventions are acceptable and of appropriate quality. Finally, given the protracted nature of family caring post stroke there is a need to measure outcomes repeatedly over long periods of time.

Clinical messages

- Some interventions may have a positive effect on carers' well-being and skills, but this evidence must be treated with caution.
- More, higher quality research is needed.
- Interventions for family carers appear to have some benefit irrespective of whether or not these are underpinned by a conceptual framework.

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Competing interests

None.

Contributors

LB conceived the study. CC led on the review process. LB and CC conducted the review and wrote the paper. SB contributed to the review process and provided expert input and guidance on the review's perspectives.

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Appendix – Search strategies

Database: Ovid MEDLINE, 1966 to November Week 3 2005

Search strategy

1) cerebrovascular disorders/or exp basal ganglia cerebrovascular disease/or exp brain ischemia/or exp carotid artery diseases/or exp cerebrovascular accident/or hypoxia-ischemia, brain/or intracranial arterial diseases/ or exp 'intracranial embolism and thrombosis'/or exp intracranial hemorrhages/or exp vasospasm, intracranial/or exp Ischemic Attack, Transient/(145852)
2) (stroke or apoplexy or cerebral vascular or cerebrovascular or cva or TIA).tw. (87375)
3) ((brain or cerebr$ or cerebell$) adj5 (ischemi$ or ischaemi$ or infarct$ or thrombo$ or emboli$)).tw. (43122)
4) ((brain or cerebral or intracranial or subarachnoid) adj5 (hemorrhage or haemorrhage or hematoma or haematoma or aneurysm or bleed$)).tw. (23401)
5) hemiplegia/or exp paresis/or brain injuries/or brain injuries, chronic/or deglutition disorders/(42523)
6) (hemipleg$ or hemipar$ or paresis or paretic or dysphag$).tw. (24943)
7) or/1–6 (244511)
8) exp CAREGIVERS/(8931)
9) caregiver$.tw. (11431)
10) carer$.tw. (3232)
11) or/8–10 (18075)
12) randomized controlled trial.pt. (208988)
13) controlled clinical trial.pt. (69859)
14) Randomized Controlled Trials/(39966)
15) Controlled Clinical Trials/(3005)
16) Random Allocation/(54141)
17) Double-Blind Method/(84061)
18) Single-Blind Method/(9446)
19) or/12–17 (354671)
20) clinical trial.pt. (420410)
21) exp Clinical Trials/(171709)
22) (clin$ adj25 trial$).tw. (115946)
23) ((singl$ or doubl$ or trebl$ or tripl$) adj25 (blind$ or mask$)).ti,ab. (83425)
24) PLACEBOS/(24212)
25) placebos.tw. (1136)
26) random.tw. (82442)
27) Research Design/(42218)
28) or/20–27 (675816)
29) 19 or 28 (703917)
30) 7 and 11 and 29 (136)