

What are the key elements of educational interventions for lay carers of patients with advanced disease? A systematic literature search and narrative review of structural components, processes and modes of delivery.

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Abstract

Context:

Educating carers about symptom management may help meet patient and carer needs in relation to distressing symptoms in advanced disease. Reviews of the effectiveness of carer interventions exist but few have focussed on educational interventions, and none on the key elements that comprise them but which could inform evidence-based design.

Objectives:

To identify the key elements (structural components, processes and delivery-modes) of educational interventions for carers of patients with advanced disease.

Methods:

We systematically searched seven databases, applied inclusion and exclusion criteria, conducted quality appraisal, extracted data, and a narrative analysis.

Results:

62 included papers related to 49 interventions. Two main delivery-modes were identified: personnel-delivered interventions and standalone resources. Personnel-delivered interventions targeted individuals or groups: the former conducted at single or multiple time-points, the latter delivered as series. Just over half targeted carers rather than patient-carer dyads. Most were developed for cancer; few focussed purely on symptom management. Standalone resources were rare. Methods to evaluate interventions ranged from post-intervention evaluations to fully-powered randomised controlled trials, but of variable quality.

Conclusion:

Published evaluations of educational interventions for carers in advanced disease are limited, particularly for non-cancer conditions. Key elements for consideration in developing such interventions were identified, however lack of reporting of reasons for non-participation or drop-out from interventions limits understanding of the contribution of these elements to interventions' effectiveness. When developing personnel-delivered interventions for carers in advanced disease consideration of the disease (and therefore caring) trajectory, intervention accessibility (timing, location and transport) and respite provision may be helpful.

Key words

Informal carers; education; intervention; symptom management; advanced disease; narrative review

Running title

Key elements carers educational interventions

Introduction

Despite a substantial and growing literature on lay carer experiences and needs in advanced disease (1) the evidence-base for carer interventions remains limited and few existing carer-interventions are supported by rigorous research (2,3).

Bee et al's systematic review of carers' needs in providing home-based end of life care to people with cancer suggested that home-based palliative care services have been insufficiently focussed on assisting carers acquire information and practical skills (4). The review highlighted the lack of practical support, often related to inadequate information exchange, which resulted typically in carers adopting a 'trial and error' approach to caring. The authors concluded that health providers could better assist carers by providing the information and skills-training necessary to facilitate increasing the confidence of carers in their ability to undertake practical aspects of care (4). While a number of reviews have focussed on the effectiveness of various types of carer interventions in chronic disease and cancer (e.g. 5-9), few have focussed on educational interventions (e.g. 10,11). Educating carers about symptoms, and in particular about evidence-based non-pharmacological interventions for symptom management (e.g. what patients can be expected to do, what to do in an acute symptom episode), may be an effective approach to meeting both patient and carer needs in relation to distressing symptoms in advanced disease such as breathlessness.

Breathlessness is a distressing, disabling symptom of advanced disease (12-15): it is a frequent symptom of advanced cancer and cardio-respiratory disease, such as chronic obstructive pulmonary disease (COPD) and heart failure, and complicates neurological and neuromuscular conditions. It is a difficult, frightening symptom for both patients and their carers (16). Carers of patients with breathlessness experience anxiety and emotional distress (16-21), isolation (16,22) and restrictions (16-18,20-23), they lack support and assistance (16,21,23), knowledge and strategies, and they experience helplessness and powerlessness (16,21,22). The development of evidence-based interventions to support carers of patients with breathlessness is therefore warranted.

This review forms part of a programme of work to develop an evidence-based educational intervention for lay carers on the symptom of breathlessness in advanced disease. In the absence of an existing systematic review on the key elements that comprise such interventions we sought to establish the key elements of educational interventions for lay carers of adult patients with advanced disease e.g. the structural components of the intervention, the processes of the intervention or its mode of delivery. However scoping work suggested that literature on educational interventions for carers of patients with breathlessness in advanced disease would be scant. For example Caress et al's review of the information and support needs of family carers of patients with COPD found no studies which described or evaluated interventions designed to enhance caregiving capacity (24). Thus, despite our ultimate goal of developing an evidence-based educational intervention for carers on breathlessness in advanced disease, we chose not to limit our review to this symptom but to include educational interventions for a range of advanced and chronic cancer and non-cancer conditions.

We anticipated differences in the key elements of educational interventions for carers of patients with cancer compared to those with non-cancer disease due to the differing disease (and therefore caregiving) trajectories: the temporal context of the cancer caregiving role differs from that in non-cancer diseases in that it is usually shorter, and the trajectory

steeper. Thus we sought to structure the review findings by broad disease group.

The objective of our review was therefore not confined to the symptom of breathlessness but sought to understand the structural components, processes and modes of delivery of such interventions which could usefully inform the development and format of an educational intervention for carers on breathlessness in advanced disease.

Methods

We conducted a systematic search and narrative review. The five authors brought a range of perspectives to the review, including health services research (MF, CP, FW, JB), nursing (MF), general practice (FW, JB), information specialism (IK) and education (JB).

Inclusion criteria:

The inclusion criteria are outlined in Box 1 and described below.

[INSERT BOX 1 ABOUT HERE]

Types of intervention:

For their meta-analysis of the effectiveness of interventions for carers of older adults, Sørensen et al (25) developed a useful classification of seven carer intervention types: 1- psycho-educational, 2- supportive, 3- respite/adult day care, 4- psychotherapy, 5- interventions to improve care-receiver competence, 6- multicomponent interventions, and 7- miscellaneous interventions. Pasacreata and McCorkle's review of the cancer literature (26) used a simpler framework categorising interventions into three types: 1-educational, 2-support, counselling and psychotherapy, and 3- hospice and palliative home care services.

For this review, interventions of interest included those that were educational, or contained a substantial educational element (i.e. Sørensen et al and Pasacreata and McCorkle's first type of intervention, and Sørensen et al's fifth type (25,26)), rather than those that are purely, or predominantly, supportive / coping / psychological interventions. The interventions we sought aimed to alter knowledge, skills, attitudes or behaviours of carers, either solely, or as a predominant component of a wider intervention. The interventions could be aimed directly at carers, or could seek to alter carer knowledge, skills, attitudes or behaviours through patient-focused intervention.

Types of participants:

The review considered all studies that involved human subjects who were adult (aged 18 years+) informal lay carers of patients with advanced cancer or non-cancer physical disease. Working with the NICE 2004 definition of carers (27) (based on Thomas et al 2001 (28): 'lay people in a close supportive role who share the illness experience of the patient and who undertake vital care work and emotion management') we excluded studies where the patient or carer was under 18 years of age, or where the patient's condition related to mental health. Thus "carers" could be family members, neighbours or friends of patients.

Types of outcomes:

We sought quantitative or qualitative data on the helpfulness and/or utility of the

interventions to carers.

Types of studies:

The review considered all studies reporting interventions that seek to alter knowledge, skills, attitudes or behaviours of carers, either solely, or as a component of a wider intervention. This therefore included randomised controlled trials and other research designs, such as non-randomised controlled trials, before and after studies, quasi- or pseudo-randomised controlled trials, and cohort studies. Studies had to be primary research and reporting the outcome of evaluations of interventions, rather than just the process of their development, and be published in peer-reviewed journals. All languages were included initially.

Search strategy:

The search strategy, developed with our information specialist (IK), comprised three stages:

- 1) an initial pilot search of Medline was undertaken followed by an analysis of the text words contained in a sample of papers' titles and abstracts, and of the MeSH or thesaurus terms (subject descriptors) used to describe the papers;
- 2) terms identified in this way, and the subject headings used by respective databases (e.g. MeSH terms), were then refined and used in an extensive search of the literature across multiple databases; and
- 3) reference lists of included papers in identified systematic reviews were then searched for additional papers.

These three stages of the search strategy comprised the "identification" step referred to on the PRISMA flow diagram (Figure 1) which summarises the systematic review process.

Electronic search:

The search terms are shown in Box 2. The freetext search terms for the intervention were limited to the abstract and title only, search terms for the population were limited to MeSH terms only (where databases allowed), and specific conditions were searched for using MeSH when possible, but other flag terms such as "end stage" were included to improve sensitivity of the search. Disease group search terms relevant to advanced chronic disease were added, including disease groups associated with breathlessness (to ensure identification of papers that might have particular relevance to the development of an educational intervention on breathlessness). Relevant disease group search terms were used rather than search terms for "breathlessness" as scoping work and the pilot search using the latter resulted in zero hits. The Stage 2 search terms were then applied to all papers published from the start date of the following electronic databases up to, and including, February 2014: Medline (OvidSP), EMBASE (OvidSP), PsychINFO (OvidSP), CINAHL (EBSCOhost), ASSIA (Proquest), Cochrane Library (www.thecochranelibrary.com) and TRIP (www.tripdatabase.com) (TRIP uses free text search, no MeSH).

[INSERT BOX 2 ABOUT HERE]

Manual search:

Reference lists of 23 relevant systematic reviews identified through this search were checked for further potentially relevant papers based on their titles or commentaries within the reviews.

Selection procedure:

Titles and abstracts of studies to be considered for retrieval were recorded on a RefMan database, along with details of where the reference was found. Duplicates were removed. Title and abstracts were then screened by the lead reviewer and those that clearly did not meet the inclusion criteria were excluded by the lead reviewer only. Non-English language papers were then excluded due to limited resources.

Full copies of papers identified by the search, and considered to potentially meet the inclusion criteria based on their title, abstract and subject descriptors, were obtained for further consideration. Two reviewers then independently selected articles against the inclusion criteria. Discrepancies in reviewer selection were resolved at a meeting between the reviewers prior to data extraction. Retrieved papers were labelled and filed according to inclusion / exclusion decisions.

Assessment of study quality:

Included papers were assessed for methodological validity by one reviewer (MF). Given the broad range of study types, the pragmatic nature of the review question and that we were seeking to produce a narrative review, we chose to apply Dixon-Woods et al's five-category rating to assess study quality using unprompted judgement (29): KP - key paper to be included in systematic review, SP - satisfactory paper to be included in systematic review, ? – unsure whether paper should be included, FF – paper to be excluded on the grounds of being fatally flawed, or IRR – paper to be excluded on the grounds that it is irrelevant. We chose to take an inclusive approach when apply this rating, thus papers in categories 1-3 were included. Any uncertainties were brought to consensus meetings with the aim of being inclusive.

Data extraction:

A data extraction tool (electronic proforma; one per paper) was developed and piloted specifically for this review and included details about the interventions, populations (e.g. patient disease group), study methods and outcomes of significance to the review question including adverse outcomes. Two reviewers performed data extraction (MF and CP); any issues were discussed at consensus meetings.

Data synthesis:

As the included papers had heterogeneous methods of data collection and analyses, it was not possible to conduct formal meta-analysis techniques, hence we chose to employ a narrative synthesis method (30). To facilitate the narrative synthesis a broad classification of intervention delivery-modes was developed based on the included papers. Two main delivery-modes were identified: personnel-delivered and standalone resources. Personnel-delivered interventions were grouped into three types, as outlined in Box 3.

[INSERT BOX 3 ABOUT HERE]

Papers were grouped into these intervention delivery-modes. Classification was based on the dominant delivery-mode used, as described in the original empirical paper. Papers were then sub-grouped by condition (cancer or non-cancer).

The methodologies and results of studies relating to the same intervention delivery-mode were then compared together with their key elements and targeting (e.g. patients and carers together or carers alone, and disease groups). The content of the narrative was discussed by the reviewing team. It was written by the lead reviewer and checked independently by three other reviewers who fed-back with comments. Any disagreements were discussed and resolved.

Findings

The PRISMA flow diagram (Figure 1) summarises the systematic review outcome. Two papers that were potentially for inclusion were excluded for not meeting the required methodological rigour (FF; fatally flawed) despite our aim to be inclusive: both described single case studies of individual carers' experiences of interventions but neither included any detail of case-sampling.

[INSERT FIGURE 1 ABOUT HERE]

Overview of included papers:

Sixty-two papers were included in the review. Most papers were from the USA (n=35), followed by Australia (n=9), Canada (n=5), and Sweden (n=4), with two papers each from The Netherlands and the UK and only single papers from Taiwan, Portugal, Japan and Norway and one Europe-wide paper. Many papers reported different aspects of the evaluation(s) of the same intervention (e.g. process or outcome data) or different applications of the same intervention (e.g. to varying cancer sites). The 62 papers reported 49 interventions, thus interventions (n=49), rather than papers (n=62), were used as the denominator for this review. Table 1a provides a description of interventions of included papers, classified by intervention delivery-mode type. Table 1b outlines the methodology of evaluation of included papers, classified by intervention delivery-mode type.

[INSERT TABLES 1a & 1b HERE, OR APPEND TO PAPER, OR AS ONLINE CONTENT ONLY]

More than two-thirds of interventions related to cancer (35/49), and ten interventions focused on non-cancer conditions. There was one intervention aimed at a mixed cancer and non-cancer group no stated disease category for three interventions. Most were personnel-delivered interventions (44/49) delivered primarily face-to-face; there were a greater number of personnel-delivered interventions delivered to individuals compared to groups (27:17). Most interventions included an element of problem-solving; four of the individual (two one-off; two series) and one of the group interventions were based on the COPE (Creativity, Optimism, Planning and Expert information) problem-solving model (31). A focus purely on symptom management was less common (n=9: four individual one-off, four individual series, and one group intervention). The most commonly addressed single symptom was pain (n=5: two individual one-off and three individual series), followed by multiple symptoms (n=2), aphasia (n=1) and delirium (n=1). Half the interventions were targeted at both patients and carers/family members (n=24); the other interventions were targeted specifically at carers or family members only.

A number of interventions used written materials developed within the study teams, most often by the study Principal Investigator (PI). Three interventions used the same written resources developed independently by the American College of Physicians: Houts et al (1994) ACP Home Care Guide for Cancer (32), and Houts et al (1997) ACP Home Care Guide

for Advanced Cancer (33). A fourth intervention used handouts developed by the American Heart Association.

Over a third of the interventions were evaluated using randomised controlled trial (RCT) methodology (n=18). The majority of the interventions were evaluated using some form of before-after design (n=23). Five interventions were evaluated using some sort of control condition and four were evaluated using post-intervention only. As noted above, separate interventions were often reported in more than one paper, hence these interventions had sometimes been subjected to more than one methodology e.g. one paper reported on a process evaluation linked to an RCT reported in another paper. The quality of RCT reporting was variable.

There were a wide variety of outcome measures and both quantitative and qualitative data, with resulting sample sizes ranging from seven to more than 2,000 (carers or patients and carers combined). All reported some form of positive data on the helpfulness of the intervention for carers. A number of papers (either qualitative or quantitative) reported carers' perception of knowledge-gains rather than directly testing for knowledge-gains.

The papers were of variable quality, regardless of study design or data type. Many suffered from attrition due to the inevitable trajectory of advanced disease: this not only impacted on interventions conducted over more than one time-point, but also on one-off interventions where follow-up data collection was planned. The potential for bias was identified in many studies due to investigators either designing or delivering (parts of) interventions, or data collection being conducted by intervention-deliverers. Further, many lacked intervention fidelity monitoring, and few reported reasons for non-participation in interventions.

Further detail on the key elements of each of the identified broad delivery-modes is given below, together with their predominant evaluation methods.

Personnel-delivered educational interventions:

Type 1 - Individual one-off:

Ten papers reported individual one-off interventions. Two papers related to the same intervention: one reported on the feasibility of the intervention (34), and the other was a pilot study of the intervention (35). Of the nine interventions covered by the ten papers, all nine were conducted face-to-face, and eight were for cancer. Six were targeted at carers (34-40), the remainder were for patients and carers.

Most individual one-off face-to-face interventions lasted for 90 minutes or less: the shortest was just 5-10 minutes long (37) and the longest 3-6 hours long (34,35). Three papers provided no data on the duration of the intervention (39-41). Only two of the interventions were delivered in the home setting (38,39); the remainder were delivered in clinical settings, with one being delivered in a librarian's office (42). Interventions were often delivered opportunistically, when a patient was attending for care. Three of the interventions were explicitly delivered by research staff (36,41,43), four by nurses (34,35,37-39), one by a clinician (physicians and nurses) (40) and one by a librarian (42).

All nine individual one-off interventions described using additional resources to support the face-to-face intervention. All used written materials (either specific to the intervention or independent of the intervention), and two also reported using audio-visual or visual pre-

recorded material in the form of a slideshow on a laptop or flipchart (36) or DVD (38).

Individual one-off face-to-face interventions were most commonly evaluated using before-after designs, with just one paper reporting on a RCT (41).

Type 2 - Individual series:

Twenty-four papers described 18 interventions for individuals delivered over a series of time-points. Several sets of papers in this category related to the same interventions, either reporting different aspects of the same study or applying the intervention to a different diagnostic group. McMillan et al (44) and McMillan & Small (45) evaluated a coping skills training intervention: one paper addressed patient outcomes, the other carer outcomes. Two more recent papers (46,47) looked at carer outcomes and experiences for the coping skills training intervention adapted for heart failure patients. Similarly, Ferrell et al (48,49) evaluated a pain education programme with one paper addressing patient outcomes, the other carer outcomes. And Northouse et al (50-52) and Harden et al (53) evaluated the FOCUS (Family involvement, Optimistic Attitude, Coping effectiveness, Uncertainty reduction and Symptom management) program for breast cancer and prostate cancer, covering different aspects of the evaluations of each.

Sixteen interventions were conducted face-to-face but nine had an additional telephone element, including those relating to COPE and FOCUS interventions. Two were delivered by telephone alone (54,55). Twelve of the 18 interventions were for cancer only; of the remainder, one was for Parkinson's disease (56) and five were for heart failure (46,54,57-59). Nine were targeted at both patients and carers, and nine at carers alone.

Seven of the individual series interventions consisted of two to three face-to-face contacts. Contacts were usually weekly or fortnightly. Each individual face-to-face contact was between 45 minutes and two hours in duration, where stated. Two interventions evaluated using three-arm RCT designs sought to investigate differences in effect according to intervention delivery-mode (balance of face-to face versus telephone contact (60)) or dose (brief versus extensive versions (61)). Only two interventions involved contact by telephone only (54,55).

Thirteen of the 18 interventions were delivered in the home setting; one was delivered either in the home setting or clinic (58) and three were delivered in clinical settings (57,62,63); in two of these were supplemented with telephone calls to the home setting (62,63). One paper did not report the intervention setting (64). Fifteen interventions were delivered by nurses (in one case by a nurse and a dietician); one by a psychologist (64) one by a social worker (62), and one by an unspecified "interventionist" (likely to be clinical) (56).

Fourteen of the 18 individual series interventions described using additional resources to support the face-to-face intervention; all used written materials (either specific to, or independent of, the intervention), three also reported using audio pre-recorded material (i.e. audio cassettes for home use: 48,49,65,66), and two used visual pre-recorded material (i.e. video cassettes: 57,66). One intervention used a CD-ROM for computer-based education (58). One intervention, focussed on pain management, also provided participants with a payment of \$50 to buy non-drug equipment (48,49), and another reported providing respite care to the patient while the carer participated (44,45).

Individual series face-to-face interventions were most commonly evaluated using RCT

designs (15 of the 18 interventions evaluated by RCTs were in this category of intervention), with one paper reporting on a process evaluation (53) within an already reported RCT (52), and the remainder described before-after studies.

Type 3 - Group series:

Twenty-three papers reported 17 group interventions. Again, several sets of papers in this category related to the same interventions, usually reporting different aspects of the same evaluation: Hudson et al 2008 (67) and Hudson et al 2009 (68) reported on the evaluation of a Caregiver Group Education Programme (CGEP); Robinson et al (69) evaluated the Family Caregiver Education Program (FCCEP) across four contractors, whilst Pasacreta et al (70) reported on one FCCEP contractor; Roberts et al (71) and Sutherland et al (72) reported on different aspects of the Living with Cancer Education Programme (LWCEP); Simons et al (73), A'Campo et al (74,75) evaluated the Patient Education Program for Parkinson's (PEPP; formerly known as EduPark); and Hinckley et al (76) and Hinckley & Packard (77) evaluated the Opening Doors family education seminars.

All 17 group interventions were conducted face-to-face and all were delivered over a series of time-points. Ten of the 17 group interventions were for cancer only and four were for specified non-cancer groups. Two were for aphasia/stroke: the Opening Doors intervention (76,77) and CLASSiC, Community Living After Stroke for Survivors and Carers (78); one was for Parkinson's disease PEPP/EduPark (73-75), and one was for heart failure (79). Of the remaining three, all were for life-limiting illness or for during palliative care, but only one reported the diagnoses of participants (mainly cancer) (80); the other two provided no diagnostic data (81,82). Half of the 17 interventions were targeted at carers alone.

Most of the group interventions consisted of two to three group sessions, although three described six to eight sessions (LWCEP (71,72,83), PEPP/EduPark (73-75) and Lofvenmark et al (79), and another reported fortnightly sessions over an 18-month period (although this latter intervention was more supportive in nature) (84). Sessions were usually held weekly or fortnightly, although a couple of interventions had sessions held on consecutive days (Opening Doors (76,77) and Cashman et al (85)); the Opening Doors intervention also used a conference-style format (76,77). Each individual session was between one hour and half a day in duration, where stated, most being between 90 minutes (n=5) and two hours (n=4) long. Those longer than one hour usually included a refreshment break.

The setting was described for only ten of the 17 group interventions, and mainly included clinical settings, but some were also delivered in non-clinical settings such as a church hall or hotel (69,86).

Eight of the group interventions were delivered by multidisciplinary teams, with different professionals leading different sessions depending on their area of expertise; one of these interventions referred to the delivery team as including the study investigators (78). A further five group interventions were delivered by health care professionals (n=4) or "instructors" who had received some form of intervention-specific training ranging from a couple of hours to 5-day workshops with certification (26,67-69,71,72,81,87). One was delivered by massage therapists (86) reflecting the predominant content of the intervention. The intervention deliverer could not be identified for just one intervention (82). Group interventions also provided opportunities for peer support either explicitly or implicitly, but only one intervention referred to sessions (group discussions) being led by patients or carers themselves (Opening Doors (76,77)).

Most (14/17) of the group interventions described using additional resources to support their face-to-face component. Of those that used additional resources 12 used written materials (either specific to the intervention or independent of the intervention). Five of these also reported using visual pre-recorded materials: three used video (69,70,81,88) and two used slides (76,85). One intervention used videos only (71,72) and another used multimedia materials, although the types of resources were not specified (86). None reported using pre-recorded audio material. One group intervention reported offering respite care to patients while their carers participated (70) and another described providing free parking (85). Reasons for non-participation in group interventions were reported for carers in relation to two group interventions, including being too busy with work or caring, patient being too unwell to leave, time or location not suitable, already coping or supported, lack of interest, and transport difficulties in evenings (67,68,83). Transport issues were also given as a reason for drop out for one group intervention (89), but it was very rare for authors to report such data.

Group interventions were most commonly evaluated using before-after designs (n=8). There were just three papers reporting RCTs (75,78,87) and two further papers reporting studies with some other form of control condition (86,89). Four interventions were evaluated post-intervention only (80,83,84,88).

The key elements of all three types of personnel-delivered interventions (individual one-off, individual series and group series) are summarised in Table 2.

[INSERT TABLE 2 ABOUT HERE]

Resources (standalone):

Five papers described four standalone resource interventions: one was an audio-visual resource (four short films) (90), one written (91-92), one audio-visual (DVD) with manual (93), and one interactive website (94). All were for patients with cancer and three targeted both patients and carers while one was for carers alone. None of the standalone resource interventions was focused purely on symptom management. Two standalone resources were evaluated using RCT designs, and two were evaluated using non-randomised designs.

Discussion

We identified 62 papers relating to 49 interventions with multiple papers either reporting different aspects of the same evaluation or the application of the intervention to differing disease groups; the latter suggesting that programmes of work have been conducted on some interventions. All papers were from the developed world, with most emanating from the USA, Australia and Canada; only two were from the UK. The reason for the lack of UK presence in this field is unclear.

There was also a predominance of interventions relating to cancer, which mirrors the predominance of cancer in both the uptake of palliative and end of life care services and in publications in the field of palliative and end of life care. It may also reflect the more acute disease trajectory in cancer, and potentially the caring trajectory, as the need for adjustment to the caring role and its related skill acquisition may be more urgent. It is possible that in other non-cancer and chronic conditions there may be more opportunity for trial and error learning by carers, or more opportunities to pick up information relating to the caring role

from across a variety of sources over a period of time. It may be worth noting that those interventions delivered at one time-point only and resource-only interventions were all for carers of patients with cancer, again perhaps reflecting the more limited opportunity for intervention on the cancer trajectory and the need for interventions to be brief. The only interventions for non-cancer conditions were for Parkinson's disease, aphasia (usually due to stroke) and heart failure; none was identified on chronic respiratory disease reflecting the finding of Caress et al (24).

Most interventions sought to educate carers on a number of symptoms or topics rather than on single symptoms, which may explain the high number of individual or group interventions that were series designs and that were delivered by multi-disciplinary teams. The latter may also have been a function of the palliative field in which most of these interventions were set i.e. its holistic approach to care. Further, the predominance of pain as the most commonly addressed single symptom most likely reflects the predominance of interventions for cancer. Most interventions targeted patients and carers, rather than just carers.

Individual interventions were more common than group interventions, although there were roughly equal numbers of individual and group interventions designed as a series (as opposed to one-off). This may reflect a bias in either the evaluation of interventions, the submission of papers on evaluations, or a publication bias. A limiting factor in group interventions is the lack of flexibility in responding to individual participant's needs. It worth noting that attrition or dropout was rarely referred to in individual series interventions, but was described in a number of group intervention papers. Further, group settings may not appeal to everyone, thus participants may differ from those accessing interventions aimed at individuals, or resource-based interventions.

Interestingly, there was a trend for both individual series and group series interventions to consist of two to three contacts occurring on a weekly or fortnightly basis. Most contacts (whether one-off or series) were less than two hours long. The number and length of contacts reflected the content of the intervention i.e. an intervention on a single symptom (e.g. delirium) could be as short as a single 5-10 minute contact. Most personnel-delivered interventions reported using at least one additional resource; all were written materials but some also used pre-recorded visual or audio resources. It is possible that more interventions used these resources than was reported in the papers.

Individual series interventions were the only personnel-delivered interventions delivered in the home setting and, indeed, this was the most likely setting for individual series interventions. This may reflect the fact that most of these were nurse-delivered interventions and that home-delivery might potentially reduce intervention attrition. Curiously, individual series interventions were also the most likely to have been subjected to RCT methodology. This may reflect the complex nature of randomised designs for groups (e.g. cluster trials). Neither of the standalone resources was evaluated by RCT. RCTs are usually considered the methodological gold standard but Schildmann and Higginson (95) have identified important limitations in RCTs in the context of carer intervention research including biased recruitment and low generalizability, and problems with blinding and attrition. They suggest that pre-test/post-test studies with a control group may be more generalizable and feasible.

By far the majority of interventions were delivered primarily as face-to-face interventions which may reflect their generally broad content, or again reflect some sort of submission or publication bias. By contrast we found few papers reporting non-face-to-face interventions.

It may be that apparently “simpler” interventions (such as non-personnel delivered interventions or resources) are less likely to undergo formal evaluation and publication. In addition, there are recent technological innovations that are currently being evaluated, such as online interventions (webinars or online information pages with/without video content), interventions using mobile phone technology (texts or apps) and tablet devices.

A limitation to this review (and common to any intervention evaluation), is the lack of knowledge on the contribution of mode of delivery to the final success of these interventions. All the interventions reported some sort of positive data on the helpfulness of the intervention to carers, but it is not known what role the delivery-mode played in relation to the intervention content in this success. The closest we can get to this data is perhaps the reported reasons for non-uptake of, or drop out from, offered interventions. Such reporting was rare in the included papers but where it was reported it provided useful insights into potential components of successful interventions. Carer-identified barriers such as being too busy with work or caring, the patient being too unwell to leave, the time or location of the intervention being unsuitable, and transport difficulties could all potentially inform future intervention design. This reporting only occurred in relation to personnel-delivered interventions.

This review of educational interventions for carers with advanced or chronic disease identified some sub-optimal description of evaluations of interventions and sub-optimal description of the interventions themselves, across the range of studies e.g. data was not always provided on who collected data, the diagnostic group of participants, the duration of interventions, their settings or the intervention deliverer. Our findings around the poor quality of reports of educational interventions is not surprising as Stiles et al’s systematic review (96) also identified common deficiencies in the reporting of educational intervention RCTs in cancer pain control targeted at health care professionals, patients or their families. Many were described as methodologically weak, and their results more difficult to interpret because of deficiencies in reporting. They identified seven domains for improving reporting of methods and results in educational interventions: introduction and background, outcome measures, sample selection, interventions, statistical plan, adverse events and results. Focussing on the descriptions of the interventions themselves, Pino et al (97) reported similar inadequacies for educational interventions developed for patients and recorded in trial registries. Only a minority of registry records (17%) reported an overall adequate description of interventions; for most (59%) important information about the content of the intervention was missing and the mode of delivery (48%), duration of sessions (55%), frequency of sessions (42%), overall duration (37%), and number of sessions (26%) was lacking.

Conclusion

Educational interventions for carers of patients with advanced or chronic disease that focus purely on symptoms are rare, and we found none focussed on breathlessness (our ultimate target symptom). Most interventions have been developed for carers of patients with cancer and most take the form of group interventions delivered over two to three sessions in a clinical setting by clinical staff, with sessions averaging around 90 minutes and supported with additional resources. Standalone resources were rare.

A number of key elements (structural components, processes and delivery-modes) for consideration in developing such interventions were identified but a lack of reporting of reasons for non-participation or drop-out from interventions limits our understanding of the

contribution of these elements to interventions' effectiveness. When developing personnel-delivered interventions for carers in advanced disease consideration of the disease (and therefore caring) trajectory, the accessibility of the intervention (timing, location and transport) and respite provision may be helpful.

Conflicts of interest

None known.

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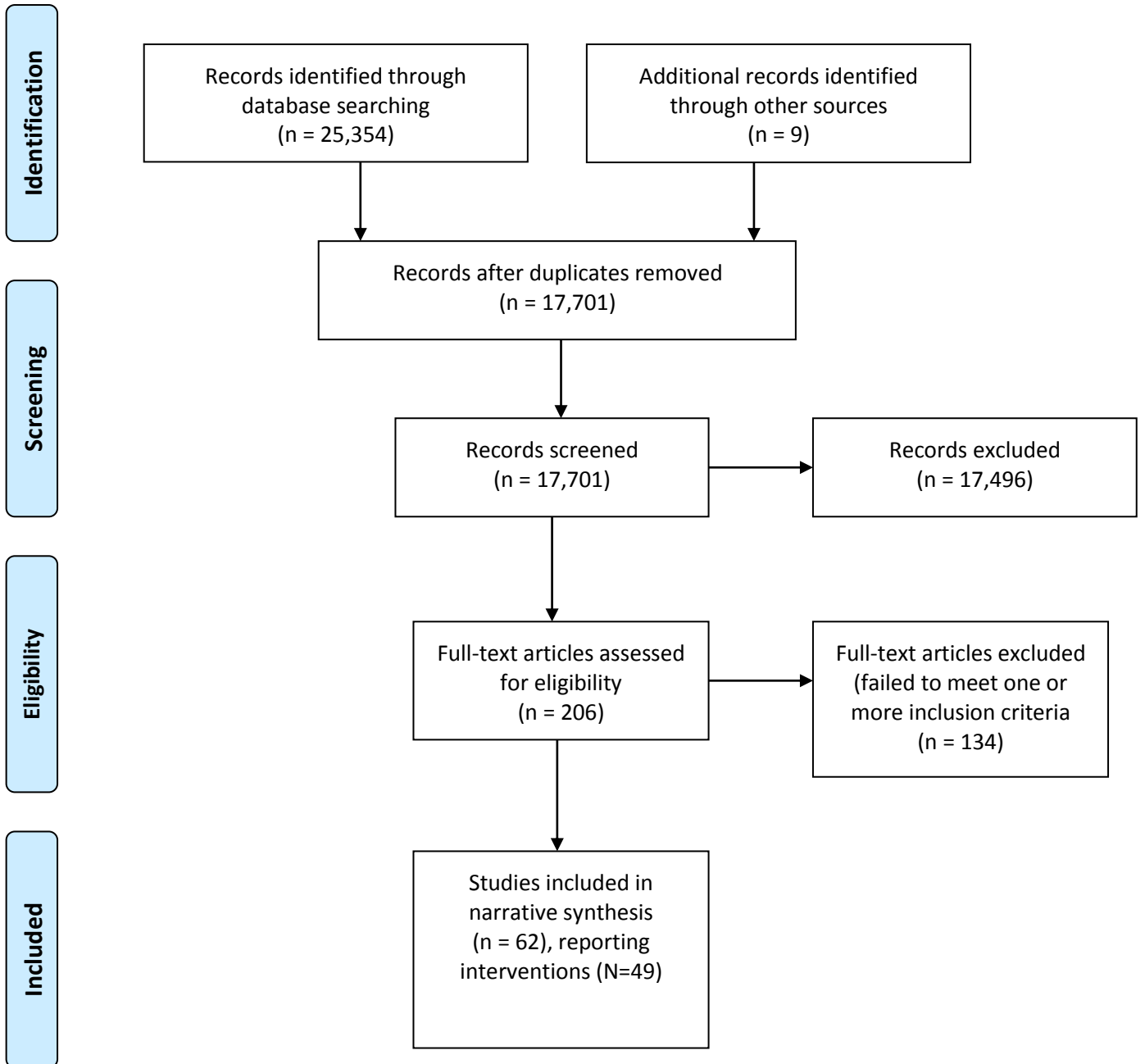
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Figure 1: PRISMA Flow Diagram



Box 1: Inclusion criteria

- 1) Does the paper focus on the evaluation of an intervention that is educational, or has an educational element?
- 2) Is this intervention one that is aimed at carers, or that seeks to alter carer knowledge, skills, attitudes or behaviours through patient-focused intervention?
- 3) Are the patients and carers adults?
- 4) Are they carers of patients with advanced cancer or advanced / chronic non-cancer physical disease?
- 5) Does the paper include data on the intervention's helpfulness to carers?
- 6) Is this a peer-reviewed journal or official report?
- 7) Is this a primary research paper?
- 8) Is the paper English language?

| Box 2: Search terms (multiple databases) | | | | | | |
|---|------------|-----------------------------|------------|-------------------|------------|---|
| INTERVENTION (<u>'OR'</u> between rows) | | POPULATION MeSH only | | AGE GROUP | | DISEASE GROUP (<u>'OR'</u> between rows) |
| Freetext against abstract & title only | | | | | | |
| educ* | <u>AND</u> | carer* MeSH only | <u>AND</u> | adult (18 years+) | <u>AND</u> | MeSH only: cancer; chronic; COPD; emphysema; neurodegenerative disease |
| skill* | | | | | | |
| knowledge | | | | | | |
| teach* | | | | | | Freetext against abstract and title only: COAD; |
| train* | | | | | | end-stage; advanced; failure |
| intervention* | | | | | | |
| program* | | | | | | |
| learn* | | | | | | |
| attitude* | | | | | | |
| behav* | | | | | | |

| Box 3: Educational intervention delivery-mode types | | |
|---|---|--------------------|
| Delivery-mode classification | | Label |
| Personnel-delivered | For individuals, delivered at one time-point | Individual one-off |
| | For individuals, delivered over a series of time-points | Individual series |
| | For groups, delivered over a series of time-points | Group series |
| Standalone resources (e.g. audio-visual/multimedia/written) | | Resources |

Table 1a: Description of interventions of included papers, classified by intervention delivery-mode type

| | | | | | | | | | |
|---|---|---|---------------|-----------------|-------------------|---|--|-------|---------|
| Authors (year) (reference) [country] - linked paper | Cancer / non- cancer | Intervention delivery-mode: ✓ = sole / primary delivery-mode (✓) = supporting / secondary delivery-modes | | | | Summary Intervention name / descriptor, patient diagnoses, intervention target, intervention setting, intervention deliverer, duration, additional resources | | | |
| | | Personnel-delivered: | | | Resources: | | | | |
| | | Individual | | Grou | | | | | |
| | | One | Series | | p | | | | |
| | | -off | Face | Tele- | series | | | Audio | Written |
| face- | -to- | phone | | - | | | | | |
| to- | face | | | visual | | | | | |
| face | | | | /multi media | | | | | |
| Individual one-off (n=10) | | | | | | | | | |

| | | | | | | | | |
|------------------------------------|--------|---|--|--|--|-----|-----|--|
| Cameron et al (2004) (36) [Canada] | Cancer | ✓ | | | | (✓) | (✓) | <p>Brief problem-solving intervention for family caregivers to individuals with advanced cancer (uses Family COPE problem-solving model)</p> <p>Diagnoses: advanced cancer (3-6 month prognosis)</p> <p>Target: carers</p> <p>Setting: oncology clinic whilst patient attending clinic</p> <p>Delivered by: study research assistant</p> <p>Duration: 1 hour</p> <p>Resources: Houts et al (1997) ACP Home Care Guide for Advanced Cancer (33); laptop slides / flip chart</p> |
| Edgar et al (2002) (42) [USA] | Cancer | ✓ | | | | | (✓) | <p>Internet lessons for oncology patients and family members</p> <p>Diagnoses: cancer (various sites and stages)</p> <p>Target: patients and family members</p> <p>Setting: librarian's office</p> <p>Delivered by: chief librarian</p> <p>Duration: more than one hour (total not given)</p> |

| | | | | | | | | |
|---|---------|---|--|--|--|-----|------------|---|
| | | | | | | | | Resources: librarian-prepared booklet |
| Gagnon et al (2002) (31) [Canada] | Cancer | ✓ | | | | | (✓) | <p>Psycho-educational intervention for family caregivers on delirium</p> <p>Diagnoses: cancer (no details of site or stage, but inpatients in a hospice that admits patients with a very short lifespan due to terminal cancer)</p> <p>Target: family caregivers</p> <p>Setting: palliative care hospice</p> <p>Delivered by: bedside nurse</p> <p>Duration: 5-10 minutes</p> <p>Resources: delirium brochure</p> |
| Healy et al (2013) (38) [Australia] | No data | ✓ | | | | (✓) | (✓) DVD | <p>Educational intervention to support carers to manage subcutaneous injections for symptom control</p> <p>Diagnoses: unspecified but inclusion criteria were palliative patients requiring subcutaneous injections for symptom control</p> <p>Target: lay carers</p> |

| | | | | | | | | |
|---|--------|---|--|--|--|--|-----|---|
| | | | | | | | | <p>Setting: home</p> <p>Delivered by: registered nurse</p> <p>Duration: one education session lasting 20-60 minutes</p> <p>Resources: suite of resources including step-by-step illustrated charts, booklet, DVD, colour-coded medication labels, fridge magnet</p> |
| <p>Hendrix & Ray (2006) (34) [USA]</p> <p>- linked to Hendrix et al, 2009 (35)</p> | Cancer | ✓ | | | | | (✓) | <p>Experiential caregiver training on home care and cancer symptom management prior to hospital discharge</p> <p>Diagnoses: older in-patients with cancer with planned discharge dates and homecare issues/cancer symptoms</p> <p>Target: carers</p> <p>Setting: hospital bedside</p> <p>Delivered by: experienced advanced practice nurse (PI)</p> <p>Duration: 3-6 hours</p> <p>Resources: pictorial PI-developed “A Manual for Informal Caregivers in Cancer Symptom Management”</p> |

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| <p>Hendrix et al (2009) (35) [USA]</p> <p>- linked to Hendrix & Ray, 2006 (34)</p> | <p>Cancer</p> | <p>✓</p> | | | | <p>(✓)</p> | <p>Experiential caregiver training on home care and cancer symptom management prior to hospital discharge</p> <p>Diagnoses: in-patients aged 50 yrs+ with cancer, likely to be discharged home</p> <p>Target: carers</p> <p>Setting: hospital bedside</p> <p>Delivered by: experienced advanced practice nurse (PI)</p> <p>Duration: unspecified (3-6 hours in related 2006 paper (34))</p> <p>Resources: pictorial PI-developed “A Manual for Informal Caregivers in Cancer Symptom Management”</p> |
| <p>Hoff & Haaga (2005) (41) [USA]</p> | <p>Cancer</p> | <p>✓</p> | | | | <p>✓</p> | <p>Education / orientation program for patients and family members</p> <p>Diagnoses: cancer (any: mostly breast and prostate)</p> <p>Target: patients and family members</p> <p>Setting: radiation oncology department</p> <p>Delivered by: “investigator”</p> |

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| | | | | | | | | Duration: no data on duration Resources: information pack of written information plus map |
| Hopkinson et al (2013) (39) [UK] | Cancer | ✓ | | | | | (✓) | MAWE (Macmillan Approach to Weight Loss and Eating) – complex psychosocial intervention for weight- and eating-related distress Diagnoses: advanced cancer Target: carers Setting: home Delivered by: MAWE trained nurse Duration: one MAWE consultation Resources: pack of leaflets |
| Lin et al (2006) (43) [Taiwan] | Cancer | ✓ | | | | | ✓ | Patient and family cancer pain education programme (based on below booklet) Diagnoses: cancer (sites unspecified, various stages) Target: patient and family dyads Setting: outpatients |

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| | | | | | | | | <p>Delivered by: research assistant</p> <p>Duration: 30-40 minutes</p> <p>Resources: Pain Education Booklet (developed by PI)</p> |
| Otani et al (2014) (40) [Japan] | Cancer | (✓) | | | | | ✓ | <p>Educational leaflet-based intervention in which clinicians communicated with families using a leaflet</p> <p>Diagnoses: cancer (terminally ill)</p> <p>Target: family members</p> <p>Setting: hospital</p> <p>Delivered by: clinicians</p> <p>Duration: not stated</p> <p>Resources: leaflet focusing on delirium in terminally ill patients with cancer</p> |
| Individual series (n=24) | | | | | | | | |
| Agren et al (2012) (58) | Non-cancer | | ✓ | | | (✓) | (✓) | <p>Education and psychosocial support for patient-caregiver dyads (problem solving and strategies for self-care)</p> |

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| [Sweden] | (CHF) | | | | | | | <p>Diagnoses: chronic heart failure</p> <p>Target: patients and caregivers</p> <p>Setting: home or heart failure clinic</p> <p>Delivered by: nurse</p> <p>Duration: three sessions of 60 minutes over 10 week period</p> <p>Resources: two booklets and CD-ROM for computer-based education</p> |
| Boele et al (2013) (64) [Netherlands] | Cancer | | ✓ | | | | | <p>Psycho-education covering disease-specific symptoms and resulting day-to-day problems and CBT to increase ability to cope</p> <p>Diagnoses: high grade (III or IV) glioma</p> <p>Target: caregivers</p> <p>Setting: not reported</p> <p>Delivered by: psychologist</p> <p>Duration: maximum of six one hour fortnightly sessions</p> <p>Resources: none reported</p> |

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| <p>Bucher et al (2001) (62) [USA]</p> | <p>Cancer</p> | | <p>✓</p> | <p>(✓)</p> | | | <p>(✓)</p> | <p>Problem-solving cancer care education for patients and caregivers (based on COPE problem-solving model)</p> <p>Diagnoses: advanced cancer (site unspecified)</p> <p>Target: patients and caregivers</p> <p>Setting: clinic setting</p> <p>Delivered by: social worker</p> <p>Duration: 90-minutes face-to-face (plus follow up reminder in clinic or by phone to use the intervention knowledge)</p> <p>Resources: Houts et al (1994) ACP Home Care Guide for Cancer (32) and Houts et al (1997) ACP Home Care Guide for Advanced Cancer (33)</p> |
| <p>Buck et al (2013) (47) [USA] - linked to</p> | <p>Non-cancer (CHF)</p> | | <p>✓</p> | <p>(✓)</p> | | | <p>(✓)</p> | <p>Psycho-educational intervention with focus on symptom management and caregivers' self-care (COPE-HF problem solving model)</p> <p>Diagnoses: heart failure</p> <p>Target: patients and caregivers</p> <p>Setting: home</p> |

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| McMillan et al 2013 (46) | | | | | | | | <p>Delivered by: nurse</p> <p>Duration: three visits of 45 minutes, each visit followed up with two phone calls (intervals between contacts not stated)</p> <p>Resources: manual (Home Care Guide for Advanced Heart Disease (COPE-HF)); symptom diaries for caregivers' to document symptom assessments</p> |
| Dunbar et al (2005) (57) [USA] | Non- cancer (CHF) | | ✓ | | | (✓) | (✓) | <p>Patient and family education intervention (EDUC) plus family partnership intervention (FPI) in heart failure</p> <p>Diagnoses: heart failure</p> <p>Target: patients and family members</p> <p>Setting: clinic</p> <p>Delivered by: research nurse and dietician</p> <p>Duration: EDUC 1-1.5 hour session + two 2-hour FPI sessions 3-5 weeks post baseline</p> <p>Resources: video and written material</p> |

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| <p>Ferrell et al (1993) (48) [USA]</p> <p>-linked to Ferrell et al, 1995 (49)</p> | <p>Cancer</p> | | <p>✓</p> | | | <p>(✓)</p> | <p>(✓)</p> | <p>Pain education program for elderly cancer patients and their family caregivers</p> <p>Diagnoses: elderly cancer patients (various sites)</p> <p>Target: patients (plus caregivers where included)</p> <p>Setting: home</p> <p>Delivered by: nurse</p> <p>Duration: three visits</p> <p>Resources: two audio cassettes, 10 page booklet, 19 instruction sheets on non-drug interventions, plus \$50 per patient for purchase of non-drug equipment</p> |
| <p>Ferrell et al (1995) (49) [USA]</p> <p>-linked to Ferrell et al, 1993 (48)</p> | <p>Cancer</p> | | <p>✓</p> | | | <p>(✓)</p> | <p>(✓)</p> | <p>Pain education program for elderly cancer patients and their family caregivers</p> <p>Diagnoses: elderly cancer patients with cancer-related pain for 3 months+ and using opioids (various sites)</p> <p>Target: patients and caregivers</p> <p>Setting: home</p> <p>Delivered by: experienced oncology nurse</p> <p>Duration: three one-hour visits</p> |

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| | | | | | | | | Resources: two audio cassettes, 10 page booklet, 19 instruction sheets on non-drug interventions, plus \$50 per patient for purchase of non-drug equipment |
| Habermann & Davis (2006) (56) [USA] | Non- cancer (PD) | | ✓ | (✓) | | | ✓ | Parkinson's disease caregiver psycho-educational intervention Diagnoses: Parkinson's disease (PD), aged 60yrs+ Target: caregivers Setting: home Delivered by: interventionist Duration: initial visit + project notebook with tip sheets (foundation for the skill training intervention) + series of phone contacts over next 6-weeks Resources: project notebook with tip sheets (intervention foundation) |
| Harden et al (2009) (53) [USA] | Cancer | | ✓ | (✓) | | | (✓) | FOCUS Program: family-based program of care for prostate cancer patients and spouses (included symptom management education) Diagnoses: prostate cancer (various phases) Target: patient and spouse |

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| -linked to Northouse et al 2002, 2005 and 2007 (50-52) | | | | | | | | <p>Setting: home</p> <p>Delivered by: masters-prepared nurse</p> <p>Duration: three initial phase home visits (90 minutes each) and two booster phase phone calls (30 minutes each) over a four month period</p> <p>Resources: symptom management cards</p> |
| Hudson et al (2013) (60) [Australia] | Cancer | | ✓ | (✓) | | | (✓) | <p>Psycho-educational intervention for caregivers including strategies to promote psychological well-being and focus on identifying positive aspects of caring</p> <p>Diagnoses: advanced cancer</p> <p>Target: caregiver</p> <p>Setting: home</p> <p>Delivered by: nurse (Family Caregiver Support Nurse)</p> <p>Duration: two versions of intervention delivered over four-week period; version one comprising one face-to-face visit and three phone calls, version two comprising two face-to-face visits and two phone calls</p> |

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| | | | | | | | | Resources: family caregiver guidebook |
| Hudson et al (2005) (65) [Australia] | Cancer | | ✓ | (✓) | | (✓) | (✓) | <p>Psycho-educational intervention for family carers of patients receiving palliative care</p> <p>Diagnoses: advanced cancer accessing a home-based palliative care service</p> <p>Target: caregivers</p> <p>Setting: home</p> <p>Delivered by: nurse</p> <p>Duration: two home visits, phone call in between (no data on length of visits)</p> <p>Resources: carer guidebook developed by PI and audio-tape</p> |
| Keefe et al (2005) (66) [USA] | Cancer | | ✓ | | | (✓) | (✓) | <p>Partner-guided cancer pain management training at the end of life</p> <p>Diagnoses: hospice-eligible advanced cancer patients (various sites: mainly lung, breast or prostate)</p> <p>Target: patients and partners</p> <p>Setting: home</p> |

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| | | | | | | | <p>Delivered by: registered nurse-level nurse educator</p> <p>Duration: three 45-60 minute sessions over one to two weeks</p> <p>Resources: video and audio tapes, and written materials</p> |
| Kurtz et al (2005) (51) [USA] | Cancer | | ✓ | ✓ | | | <p>Patient/ caregiver symptom control intervention</p> <p>Diagnoses: breast, lung and other cancers, early or late stage (67% late)</p> <p>Target: caregivers</p> <p>Setting: clinic and home (by telephone)</p> <p>Delivered by: nurse</p> <p>Duration: 10 fortnightly contacts alternating in-person / telephone over 20 weeks</p> <p>Resources: none reported</p> |
| McMillan & Small (2007) | Cancer | | ✓ | | | | <p>Coping skill training intervention using the Family COPE problem-solving model</p> <p>Diagnoses: community dwelling hospice patients with advanced cancer</p> |

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| <p>[USA] (45)</p> <p>-linked to</p> <p>McMillan et al, 2006 (44)</p> | | | | | | | | <p>Target: carer</p> <p>Setting: home setting, whilst Home Health Aide provided respite</p> <p>Delivered by: intervention nurse</p> <p>Duration: three visits</p> <p>Resources: respite</p> |
| <p>McMillan et al (2006) (44)</p> <p>[USA]</p> <p>-linked to</p> <p>McMillan & Small, 2007 (45)</p> | <p>Cancer</p> | | <p>✓</p> | | | | | <p>Coping skill training intervention using the Family COPE problem-solving model</p> <p>Diagnoses: community dwelling hospice patients with advanced cancer</p> <p>Target: carer</p> <p>Setting: home setting, whilst Home Health Aide provided respite</p> <p>Delivered by: intervention nurse</p> <p>Duration: three visits</p> <p>Resources: respite</p> |

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| McMillan et al (2013) (46) [USA] | Non-cancer (CHF) | | ✓ | (✓) | | | (✓) | <p>Psycho-educational intervention with focus on symptom management and caregivers' self-care (COPE-HF problem solving model)</p> <p>Diagnoses: heart failure</p> <p>Target: patients and caregivers</p> <p>Setting: home</p> <p>Delivered by: nurse</p> <p>Duration: three visits of 45 minutes, each visit followed up with two phone calls (intervals between contacts not stated)</p> <p>Resources: manual (Home Care Guide for Advanced Heart Disease (COPE-HF)); symptom diaries for caregivers' to document symptom assessments</p> |
| -linked to Buck et al 2013 (47) | | | | | | | | |
| Northouse et al (2002) (50) [USA] | Cancer | | ✓ | (✓) | | | (✓) | <p>FOCUS Program: family-based program of care for women with recurrent breast cancer and a family member (including symptom management education)</p> <p>Diagnoses: recurrent breast cancer (Stage 3 or 4)</p> <p>Target: patient and a family member</p> |

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| <p>-linked to Northouse et al 2005, 2007 (51, 52) and Harden et al 2009 (53)</p> | | | | | | | | <p>Setting: home</p> <p>Delivered by: master's-prepared nurse</p> <p>Duration: three initial phase home visits (90 minutes each) and two booster phase phone calls (30 minutes each) over a five month period</p> <p>Resources: symptom management cards</p> |
| <p>Northouse et al (2005) (51) [USA]</p> <p>-linked to Northouse et al 2002,</p> | <p>Cancer</p> | | <p>✓</p> | <p>(✓)</p> | | | <p>(✓)</p> | <p>FOCUS Program: family-based program of care for women with recurrent breast cancer and a family member (including symptom management education)</p> <p>Diagnoses: recurrent breast cancer (Stage 3 or 4)</p> <p>Target: patient and a family member</p> <p>Setting: home</p> <p>Delivered by: master's-prepared nurse</p> <p>Duration: three initial phase home visits (90 minutes each) and two booster</p> |

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| 2007 (50,52) and Harden et al 2009 (53) | | | | | | | | phase phone calls (30 minutes each) over a five month period Resources: symptom management cards |
| Northouse et al (2007) (52) [USA] -linked to Northouse et al 2002, 2005 (50,51) and Harden et al | Cancer | | ✓ | (✓) | | | (✓) | FOCUS Program: family-based program of care for prostate cancer patients and spouses (including symptom management education) Diagnoses: prostate cancer (various phases) Target: patient and spouse Setting: home Delivered by: masters-prepared nurse Duration: three initial phase home visits (90 minutes each) and two booster phase phone calls (30 minutes each) over a four month period Resources: symptom management cards |

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| 2009 (53) | | | | | | | | |
| Northouse et al (2013) [USA] (51) | Cancer | | ✓ | (✓) | | | | <p>Information and support provided to patient-carer dyads (FOCUS program)</p> <p>Diagnoses: advanced cancer (stage III or IV breast, colorectal, lung or prostate)</p> <p>Target: patients and their caregivers</p> <p>Setting: home</p> <p>Delivered by: mastered-prepared nurses</p> <p>Duration: two versions of intervention delivered over 10-week period; ‘brief’ comprising two 90-minute home visits and one 30-minute phone call, ‘extensive’ version comprising four 90-minute home visits and two 30-minute phone sessions</p> <p>Resources: none reported</p> |
| Piamjariyak ul et al (2013) (54) | Non- cancer (CHF) | | | ✓ | | | (✓) | <p>Caregiver telephone CHF home management coaching program</p> <p>Diagnoses: CHF</p> <p>Target: caregivers</p> |

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| [USA] | | | | | | | | <p>Setting: home</p> <p>Delivered by: nurses</p> <p>Duration: 4 telephone coaching sessions of approx. 1 hr</p> <p>Resources: 2 American Heart Association handouts and caregivers' guidebook</p> |
| Sebern et al (2012) (59) [USA] | Non- cancer (CHF) | | ✓ | | | | (✓) | <p>Shared Care Dyadic Intervention (SDCI) aimed at improving communication, decision-making and reciprocity</p> <p>Diagnoses: CHF</p> <p>Target: patient-carer dyad</p> <p>Setting: home</p> <p>Delivered by: PhD and master's prepared nurses with clinical background in CHF</p> <p>Duration: 7 weekly sessions of 60-120 minutes delivered in joint and mixed format</p> <p>Resources: worksheets supporting each session</p> |

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| <p>Sherwood et al (2012) (55) [USA]</p> | <p>Cancer</p> | | <p>✓</p> | | | <p>(✓)</p> | <p>Problem-solving symptom management intervention</p> <p>Diagnoses: advanced cancer (stage III or IV solid tumour)</p> <p>Target: caregiver</p> <p>Setting: home</p> <p>Delivered by: master's prepared nurse with experience in oncology</p> <p>Duration: 3 telephone contacts at weeks 1, 4 and 8 (no details on length of contacts); attention control received same number of contacts by research staff member</p> <p>Resources: toolkit containing symptom management strategies</p> |
| <p>Valeberg et al (2013) (98) [Norway]</p> | <p>Cancer</p> | | <p>✓</p> | | | <p>(✓)</p> | <p>Psycho-educational intervention to improve family carer's knowledge and attitudes regarding cancer pain management (PRO-SELF Pain Control Program)</p> <p>Diagnoses: cancer (bone metastasis)</p> <p>Target: family carer</p> <p>Setting: home</p> |

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| | | | | | | | | <p>Delivered by: specially trained oncology nurse</p> <p>Duration: coaching and reinforcing educational materials over 6-week period with home visits at weeks 1,3 and 6 and telephone contact at weeks 2, 4 and 5 (no details on length of contacts); control group contacted with same frequency but focused on monitoring level of adherence with completing pain management diary</p> <p>Resources: booklet about cancer pain management</p> |
| Group series (n=23) | | | | | | | | |
| A'Campo et al (2010a) (74) [7 European countries] | Non-cancer (PD) | | | | ✓ | | (✓) | <p>Patient Education Program Parkinson (PEPP; developed by EduPARK): psychosocial intervention for patients and their caregivers (teaches knowledge and skills)</p> <p>Diagnoses: Parkinson's disease (PD)</p> <p>Target: patients and caregivers</p> <p>Setting: unspecified</p> |

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| -linked to A'Campo et al 2010b (75); Simons et al, 2006 (73) | | | | | | | | Delivered by: "professional group leaders", mostly psychologists, who were knowledgeable about patient education and psychosocial problems of PD Duration: eight weekly 90-minute sessions Resources: handouts |
| A'Campo et al (2010b) (75) [Netherlands] -linked to A'Campo et | Non- cancer (PD) | | | | ✓ | | (✓) | Patient Education Program Parkinson (PEPP; developed by EduPARK): psychosocial intervention for patients and their caregivers (teaches knowledge and skills) Diagnoses: Parkinson's disease (PD) Target: patients and caregivers Setting: unspecified Delivered by: unspecified but trainers followed a 2-day training for PEPP Duration: eight weekly 90-minute sessions |

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| al 2010a (74); Simons et al, 2006 (73) | | | | | | | | Resources: handouts |
| Bucher et al (1999) (88) [USA] | Cancer | | | | ✓ | (✓) | (✓) | <p>Prepared Family Caregiver Course (based on the COPE problem-solving model)</p> <p>Diagnoses: cancer (no data on site or stage)</p> <p>Target: caregivers (but hospice volunteers, home health aides, nurses and patients also participated)</p> <p>Setting: unspecified</p> <p>Delivered by: “instructor” (structured approach allowed groups to be led by adults with minimal experience of leading groups or work in cancer care)</p> <p>Duration: three 2-hour sessions (or one-day workshop) using video-taped instruction with case studies and group exercises</p> |

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| | | | | | | | | Resources: video of instruction plus Houts et al (1994) Home Care Guide for Cancer (32) |
| Cashman et al (2007) (85) [Canada] | Cancer | | | | ✓ | (✓) | (✓) | <p>Educational program for the caregivers of persons diagnosed with a malignant glioma</p> <p>Diagnoses: malignant glioma</p> <p>Target: caregivers</p> <p>Setting: cancer support facility of hospital campus</p> <p>Delivered by: neuro-oncologist, advanced practice nurse, palliative physician, occupational therapist, social worker and neuro-physicist</p> <p>Duration: two consecutive half-days</p> <p>Resources: childcare and patient supervision available; free parking; lunch; handouts</p> |
| Chiquelho et al | Cancer | | | | ✓ | | (✓) | proFamilies (psycho-educational multi-family group intervention for cancer patients and their families) |

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| (2011) (89) [Portugal] | | | | | | | <p>Diagnoses: cancer: mainly breast (49%) and prostate (11%), no data on stage</p> <p>Target: patients and family members</p> <p>Setting: Cancer Institute</p> <p>Delivered by: multi-disciplinary, coordinated by two psychologists with participation of doctors, nurses and social workers</p> <p>Duration: six sessions (once a week for six weeks)</p> <p>Resources: handouts</p> |
| Collinge et al (2007) (86) [USA] | Cancer | | | | ✓ | (✓) | <p>Brief instruction in massage and touch therapy to build caregiver efficacy</p> <p>Diagnoses: cancer – mainly breast (27/50), no stage data, self-referred to intervention</p> <p>Target: caregivers and their patients</p> <p>Setting: various i.e. hospitals, community-based cancer support organisation and church parish hall</p> <p>Delivered by: community-based licensed massage therapists with dual training in therapeutic touch (plus preparatory workshop in oncology massage and</p> |

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| | | | | | | | <p>safety precautions); one trainer per two couples</p> <p>Duration: 6-hour workshop (plus audio-tape of contemplative practice to take home), home practice, plus three 2-hour refresher meetings</p> <p>Resources: unspecified “multi-media materials”</p> |
| <p>Grahn & Danielson (1996) (83) [Sweden]</p> | <p>Cancer</p> | | | | ✓ | (✓) | <p>Learning to live with cancer: education and support programme for cancer patients and their significant others</p> <p>Diagnoses: various recently diagnosed cancers, no data on staging</p> <p>Target: cancer patients and their significant others</p> <p>Setting: not specified</p> <p>Delivered by: not specified, but related paper (Grahn, 1996 (99)) states “staff members e.g. the nurse, physician, dietician, physiotherapist and social worker act as teachers in different sessions”</p> <p>Duration: not specified, but related paper (Grahn, 1996 (99)) describes eight 2-hour groups</p> <p>Resources: pocket-sized booklets and related paper (Grahn, 1996 (99)) refers to</p> |

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| | | | | | | | | extensive learning materials e.g. booklets, information sheets, memos etc. |
| Henriksson et al (2011) (89) [Sweden] | Mixed - most cancer | | | | ✓ | | (✓) | <p>Support Group Program during ongoing palliative care (including information / educational element)</p> <p>Diagnoses: patients with life-threatening illness receiving palliative care (2/29 non-cancer: amyotrophic lateral sclerosis and myelofibrosis)</p> <p>Target: family members</p> <p>Setting: one of three care units plus a library session at one unit (two units specialist palliative care , third haematology)</p> <p>Delivered by: multi-professional team caring for the patient led by two nurses (included dietician/ nutrition nurse, physician, social worker/ psychologist, occupational therapist, physiotherapist, hospital priest)</p> <p>Duration: 1.5-hours per week for six weeks</p> <p>Resources: library information</p> |
| Hinckley & | Non- | | | | ✓ | (✓) | (✓) | Opening Doors: family education seminars for adults with chronic aphasia and |

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| Packard (2001) (87) [USA] -linked to Hinckley et al, 1995 (76) | cancer (most CVA) | | | | | | | families Diagnoses: mainly CVA Target: patients and families Setting: unspecified Delivered by: as described in Hinckley et al, 1995 (76), below Duration: 2-day seminar style programme (as described in Hinckley et al, 1995 (76), below) Resources: handouts, slides, Resource Guide |
| Hinckley et al (1995) (76) [USA] -linked to Hinckley & | Non- cancer (CVA) | | | | ✓ | | | Opening Doors: family education programming for adults with chronic aphasia Diagnoses: CVA Target: patients and families Setting: unspecified Delivered by: topic sessions led by highly qualified professionals who specialise in topic area (e.g. speech pathology staff); patients and carers led the discussion groups |

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| Packard, 2001 (77) | | | | | | | Duration: conference format with breakout sessions and exhibit hall (corporate co-sponsors); duration unspecified but 2001 paper states 2-days; based on a pilot 3-day residential programme of individual and group meetings including group recreational outings and individualised community outings, plus individualised consultations with speech-language pathologists Resources: none reported |
| Horowitz et al (1996) (84) [USA] | Cancer | | | | ✓ | | Psycho-educational support group for spouses of patients with brain tumours Diagnoses: brain tumours (various stages) Target: spouses of patients Setting: cancer centre Delivered by: multi-disciplinary including neuro-oncologist, social worker, psychiatrist Duration: open-membership spousal support group met for 90 minutes twice a month for 18 months (no time limit at inception); first 30 minutes devoted to education and information, second 60 minutes to emotional needs |

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| | | | | | | | | Resources: none reported |
| Hudson et al (2008) (67) [Australia] | Cancer | | | | ✓ | | (✓) | <p>Caregiver Group Education Programme (CGEP; for family caregivers in home-based palliative care)</p> <p>Diagnoses: malignant disease requiring palliative care</p> <p>Target: family caregivers</p> <p>Setting: palliative care service</p> <p>Delivered by: “suitably qualified health care professionals (Education programme Facilitators)” - undertaken short training programme, plus multi-disciplinary team members (e.g. palliative care doctor, counsellor, social worker, palliative care nurse)</p> <p>Duration: three consecutive 1.5 hour weekly sessions at one of six home-based palliative care services</p> <p>Resources: Caregiver Guidebook developed by PI</p> |
| -linked to Hudson et al, 2009 (68) | | | | | | | | |
| Hudson et al | Cancer | | | | ✓ | | (✓) | Caregiver Group Education Programme (CGEP; for family caregivers in home- |

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| al (2009) (68) [Australia] -linked to Hudson et al, 2008 (67) | | | | | | | | <p>based palliative care)</p> <p>Diagnoses: malignant disease requiring palliative care</p> <p>Target: family caregivers</p> <p>Setting: palliative care service</p> <p>Delivered by: see Hudson et al, 2008 (67) pilot, above</p> <p>Duration: see Hudson et al, 2008 (67) pilot, above</p> <p>Resources: see Hudson et al, 2008 (55), pilot above</p> |
| Kwak et al (2007) (81) [USA] | No data | | | | ✓ | (✓) | (✓) | <p>Caregiving at Life's End (CGLE)</p> <p>Diagnoses: unspecified but refers to "life-limiting illness" and "in the last years of life"</p> <p>Target: family caregivers</p> <p>Setting: unspecified</p> <p>Delivered by: health/ human service professionals (n=142) who completed a</p> |

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| | | | | | | | <p>CGLE train-the-trainer 5-day workshop at hospice (55% then provided CGLE in their home community, returned rosters and survey data; average 26 caregivers per trainer)</p> <p>Duration: five 90-minute sessions covering nine modules over a few weeks (average of four sessions and 7.6 hours of training); can be delivered as group or individual sessions (95% of survey participants participated in group sessions)</p> <p>Resources: handouts and videos</p> |
| Lofvenmark et al (2012) (79) [Sweden] | Non-cancer (CHF) | | | | ✓ | | <p>Group-based multi-disciplinary educational programme to provide disease-related knowledge and forum for family members to interact with each other</p> <p>Diagnoses: CHF</p> <p>Target: family members</p> <p>Setting: hospital conference room</p> <p>Delivered by: multi-disciplinary team comprising cardiologist, specialist CHF nurse, dietician, physiotherapist and social worker)</p> |

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| | | | | | | | | Duration: 6 meetings of 2-hrs duration on monthly basis (8 participants per group) Resources: none reported |
| Manne et al (2004) (87) [USA] | Cancer | | | | ✓ | | (✓) | Psycho-educational group intervention for wives of men with prostate cancer Diagnoses: prostate cancer, stages I-IV (majority stage II) Target: wives of men with prostate cancer Setting: unspecified (likely to be cancer centre) Delivered by: sessions led by radiation oncologist, nutritionist, psychologist, and social worker; leaders trained in two 3-hour training sessions by PI Duration: 1-hour for 6 weeks (home practice assignments post sessions 3 and 4) Resources: handouts |
| Marsden et al (2010) (88) | Non-cancer (CVA) | | | | ✓ | | | CLASSiC (Community Living After Stroke for Survivors and Carers) – multi-disciplinary group programme in rural settings for patients and their carers Diagnoses: CVA |

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| [Australia] | | | | | | | <p>Target: patients and carers</p> <p>Setting: local public hospital (in rural communities)</p> <p>Delivered by: “a number of the investigators” who were members of the established rural-based stroke-specific multi-disciplinary team including a physiotherapist, social worker, dietician, clinical nurse consultant, speech pathologist and occupational therapist</p> <p>Duration: weekly 2.5-hour group session for seven weeks (1-hour physical activity and 1-hour education, with a “healthy options” morning tea between)</p> <p>Resources: none reported</p> |
| Pasacreta et al (2000) (26) [USA] -linked to | Cancer | | | | ✓ | | <p>Family Caregiver Cancer Education Program (FCCEP)</p> <p>Diagnoses: cancer, various sites, during / after transition points e.g. diagnosis, treatment cessation, recurrence, shift to palliative</p> <p>Target: caregivers</p> <p>Setting: not specified, facilitators from “agencies and hospitals”</p> <p>Delivered by: oncology nurses and social workers who participated in 1-day</p> |

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| Robinson et al, 1998 (69) report of full programme | | | | | | | intensive training for FCCEP facilitators (with ongoing mentoring) Duration: 6-hours taught over three 2-hour sessions Resources: respite care offered on later programmes |
| Roberts et al (2002) (71) [Australia] -linked to Sutherland et al, 2008 (72) | Cancer | | | | ✓ | (✓) | Living with Cancer Education Programme (LWCEP; an education and support programme for cancer patients and their family and friends) Diagnoses: cancer (site and stage unspecified) Target: patients, their family and friends Setting: 45 different locations (type unspecified) Delivered by: two facilitators who completed accredited training programme Duration: weekly two-hour sessions for eight weeks Resources: videos |

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| <p>Robinson et al (1998) (69) [USA]</p> <p>-linked to Pasacreata et al, 2000 (26) report on one of four contractors</p> | <p>Cancer</p> | | | <p>✓</p> | <p>(✓)</p> | <p>(✓)</p> | <p>Family Caregiver Cancer Education Program (FCCEP)</p> <p>Diagnoses: cancer (no data on sites or staging)</p> <p>Target: caregivers</p> <p>Setting: health care institutions, community organisations, hotels and churches; also sponsored by a variety of corporations as a lunchtime worksite programme</p> <p>Delivered by: oncology nurses and social workers from four contractors who participated in 6-hour Local Instructor Course (LIC)</p> <p>Duration: 6-hours taught over one to three sessions and at varying times of day depending on need (some content variation by contractor to reflect local needs)</p> <p>Resources: toll-free 800 number for cancer information; communication video; 1-page fact sheets on symptoms; patient and family newsletter; resource guide “Helping People Cope: A Guide for Families Facing Cancer”</p> |
| <p>Simons et al</p> | <p>Non-</p> | | | <p>✓</p> | | | <p>EduPark (early version of PEPP): an education programme for people with</p> |

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| <p>(2006) (73)</p> <p>[UK]</p> <p>-linked to</p> <p>A'Campo et al 2010a and 2010b (74,75)</p> | <p>cancer (PD)</p> | | | | | | | <p>Parkinson's disease and their carers</p> <p>Diagnoses: Parkinson's disease (PD)</p> <p>Target: patients and carers</p> <p>Setting: NHS Day Hospital within Department of Elderly Medicine</p> <p>Delivered by: unspecified</p> <p>Duration: eight 90-minute sessions (including 15 minute break)</p> <p>Resources: none reported</p> |
| <p>Sutherland et al (2008) (72)</p> <p>[Australia]</p> <p>-linked to</p> <p>Roberts et</p> | <p>Cancer</p> | | | | <p>✓</p> | | | <p>Living with Cancer Education Programme (LWCEP)</p> <p>Diagnoses: cancer (site and stage unspecified, mainly breast)</p> <p>Target: patients, their family and friends</p> <p>Setting: 46 different venues (unspecified)</p> <p>Delivered by: see Roberts et al, 2002 (71), above</p> <p>Duration: see Roberts et al, 2002 (71), above</p> <p>Resources: none reported</p> |

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| al, 2002 (71) | | | | | | | | |
| White et al (2008) (82) [Australia] | No data | | | | ✓ | | (✓) | <p>Learn Now; Live Well (LNLW): an educational programme for caregivers</p> <p>Diagnoses: unspecified but refers to “life-limiting illness”</p> <p>Target: caregivers</p> <p>Setting: inpatient and community settings (intervention delivered differently in each)</p> <p>Delivered by: unspecified</p> <p>Duration: six modules that can be offered as a full programme or stand-alone units; community settings combined six modules into three delivered over three Saturdays (or Wednesdays or Tuesdays when demand was high)</p> <p>Resources: module pack</p> |
| Resources (standalone) | | | | | | | | |
| Cassileth et | Cancer | | | | | ✓ | | Four audio-visual programmes about cancer and cancer treatment |

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| al (1982) (90) [USA] | | | | | | | | <p>Diagnoses: cancer, various sites (mainly breast, haematological, GI, lung), no staging</p> <p>Target: patients and caregivers</p> <p>Setting: cancer centre hospital (inpatients and outpatients)</p> <p>Delivered by: research assistant (shown on a television set with video player)</p> <p>Duration: approximately 14 minutes each covering one of four topics (chemotherapy, radiation therapy, common questions about cancer, and pain and sleep disturbances); 45 minutes with pre and post-testing</p> <p>Resources: four short films</p> |
| Chung et al (2009) (91) [Canada] -linked to Kitamura et | Cancer | | | | | | ✓ | <p>Informational stories for patients and caregivers with brain metastases</p> <p>Diagnoses: cancer (mainly GI); specifically excluding patients with brain metastases</p> <p>Target: patients and caregivers</p> <p>Setting: unspecified</p> <p>Delivered by: no information on who delivered but delivered in packs with</p> |

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| al, 2011 (92) | | | | | | | | <p>consent form and questionnaires (half ordered with stories first, half with fact sheets first)</p> <p>Duration: n/a</p> <p>Resources: four stories and four fact sheets on radiation therapy, treatment side effects, steroid tapering, and palliative care</p> |
| Collinge et al (2013) (93) [USA] | Cancer | | | | | ✓ | (✓) | <p>Multi-media home-based instructional program for family caregivers in touch-based techniques to provide comfort to cancer patients</p> <p>Diagnoses: cancer (any type or stage; over half sample had advanced cancer)</p> <p>Target: patient and caregiver</p> <p>Setting: home</p> <p>Delivered by: orientation meeting where intervention group viewed DVD together (no instruction or practice took place at meeting); control group instructed by phone</p> <p>Duration: instructed to practice massage for 5-20 mins at least 3 times a week for 4 weeks; control group instructed to read to patient for same duration and</p> |

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| | | | | | | | <p>frequency (reading companionship)</p> <p>Resources: 78-minute DVD and 66-page manual in English, Spanish, and Chinese</p> |
| DuBenske et al (2014) (94) [USA] | Cancer | | | | | ✓ | <p>CHESS (Comprehensive Health Enhancement Support System) eHealth System combined with Clinician Report</p> <p>Diagnoses: advanced lung cancer (non small cell stage IIIA, IIIB or IV)</p> <p>Target: caregiver</p> <p>Setting: home</p> <p>Delivered by: technical support and training on using internet or CHESS provided by telephone, laptops and internet access provided if needed</p> <p>Duration: up to 24 months, both groups encouraged to log into computer weekly</p> <p>Resources: CHESS interactive website comprising access to information, communication with peers, experts and social networks and interactive coaching to improve cognitive, behavioural and supportive coping skills;</p> |

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| | | | | | | | | control group received list of recommended lung cancer and palliative care websites |
| Kitamura et al (2011) (92) [Canada] | Cancer | | | | | | ✓ | <p>Combined story and fact-based educational booklet for patients with multiple brain metastases and their caregivers</p> <p>Diagnoses: newly diagnosed multiple brain metastases and less favourable life expectancy (less than one year) attending outpatients</p> <p>Target: patients and caregivers</p> <p>Setting: recruited in outpatients; no information on where booklet was read but post-booklet questionnaires were to be completed and returned within one week (suggesting home-completion)</p> <p>Delivered by: no information on who delivered by</p> <p>Duration: 12-page booklet (“Coping with Brain Metastases: a guide for patients and caregivers”) covering 11 topic areas (one page each); Grade 5 reading level and sensitive to multicultural and gender issues</p> <p>Resources: combined story and fact-based booklet</p> |
| -linked to Chung et al, 2009 (91) | | | | | | | | |

Abbreviations: RCT = randomised controlled trial; QoL = quality of life; PD = Parkinson's disease; CHF = chronic heart failure; CVA = stroke

Table 1b: Methodology of evaluation of included papers, classified by intervention delivery-mode type

| Authors (year) | Summary Study design, sample size, carer outcome, methodology notes (positive or negative) |
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| Individual one-off (n=10) | |
| Cameron et al (2004) (36) | <p>Brief problem-solving intervention for family caregivers to individuals with advanced cancer (uses Family COPE problem-solving model)</p> <p>Design: before-after study (baseline survey; telephone survey 4-weeks post-intervention)</p> <p>Sample size: 34 family caregivers</p> <p>Carer outcome: improved emotional tension, caregiving confidence and positive problem-solving orientation</p> <p>Methodology notes: intervention delivered by study research assistant (potential for bias)</p> |
| Edgar et al (2002) (42) | <p>Internet lessons for oncology patients and family members</p> <p>Design: before-after study (baseline; immediately post-intervention and 2-3 months later)</p> <p>Sample size: 28 patients and family members</p> |

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| | <p>Carer outcome: well-received, information helpful/ clear, participants attributed positive well-being 2-months later in large part to intervention</p> <p>Methodology notes: unclear who collected data</p> |
| Gagnon et al (2002) (37) | <p>Psycho-educational intervention for family caregivers on delirium</p> <p>Design: non-randomized comparative before – after design (baseline and 2-3 weeks post patient death)</p> <p>Sample size: 58 consecutive caregivers who did not receive the intervention and 66 caregivers who did</p> <p>Carer outcome: significant increase in caregiver confidence that they were making good decisions, significant and non-significant increases in various aspects of knowledge of delirium</p> <p>Methodology notes: randomisation felt to be impossible within the hospice setting due to risk of contamination between groups</p> |
| Healy et al (2013) (38) | <p>Educational intervention to support carers to manage subcutaneous injections for symptom control</p> <p>Design: before and after one-group design (immediately following education session and 4 weeks post experience of using resources)</p> <p>Sample size: 76 lay carers</p> <p>Carer outcome: on completion of the education session carers rated the package to be useful and this perception was maintained after they had experienced symptom management; carers felt confident they could assist with symptom management at both time points</p> |

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| | Methodology notes: outcome measures were specific to intervention (not validated) |
| Hendrix & Ray (2006) (34) | <p>Experiential caregiver training on home care and cancer symptom management prior to hospital discharge</p> <p>Design: before-after feasibility study (informal interview at end of intervention)</p> <p>Sample size: seven female informal caregivers</p> <p>Carer outcome: high interest from carers, individualised approach enabled particular needs to be met, flexibility in intervention timing was crucial, recruitment of carers through patients was challenging</p> <p>Methodology notes: intervention delivered by study PI and unclear if outcome assessed independently (potential for bias)</p> |
| Hendrix et al (2009) (35) | <p>Experiential caregiver training on home care and cancer symptom management prior to hospital discharge</p> <p>Design: before-after pilot study (baseline; immediately post-intervention and one week after discharge)</p> <p>Sample size: 20 informal caregivers</p> <p>Carer outcome: significant increase in mean Cancer Caregiver Self-Efficacy scores immediately post-intervention; non-significant increase at 1-week</p> <p>Methodology notes: small sample size for statistical significance</p> |
| Hoff & | Education / orientation program for patients and family members |

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| <p>Haaga (2005) (41)</p> | <p>Design: randomly assigned to intervention or control group (baseline; post-intervention assessments up to 8-weeks later)</p> <p>Sample size: 55 new cancer patients and 45 relatives/friends</p> <p>Carer outcome: positive programme evaluation and increased use of psychological counselling and external support sources but no significant difference in satisfaction with care, state anxiety, general distress, knowledge or use of other ancillary services</p> <p>Methodology notes: randomly assigned to experimental or control group but no details of randomisation procedure; research assistant delivered the intervention therefore no blinding (potential bias)</p> |
| <p>Hopkinson et al (2013) (39)</p> | <p>MAWE (Macmillan Approach to Weight Loss and Eating) – complex psychosocial intervention for weight- and eating-related distress</p> <p>Design: quasi-experimental before and after study with external control (baseline and 5 days post MAWE exposure)</p> <p>Sample size: 26 carers (12 intervention, 14 control)</p> <p>Carer outcome: median eating-related distress increased in the control group but decreased in the MAWE group, weight-related distress decreased in both groups but to greater extent in the MAWE group</p> <p>Methodology notes: authors note variability in support offered by nurses working with the control group including giving advice in common with the MAWE group; exposure of MAWE group to intervention prior to collection of baseline data may also have affected findings;</p> |

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| <p>Lin et al (2006) (43)</p> | <p>Patient and family cancer pain education programme (based on a Pain Education Booklet)</p> <p>Design: experimental longitudinal (baseline, two weeks and four weeks post-intervention)</p> <p>Sample size: 61 patient-family carer dyads (31 in experimental group, 30 controls)</p> <p>Carer outcome: significantly greater reduction in barriers to cancer pain management scores in experimental group</p> <p>Methodology notes: randomly assigned to experimental or control group, but no details of randomisation procedure; research assistant delivered the intervention therefore no blinding (potential bias); PI developed booklet</p> |
| <p>Otani et al (2014) (40)</p> | <p>Educational leaflet-based intervention in which clinicians communicated with families using a leaflet</p> <p>Design: historical control study</p> <p>Sample size: 357 family members (113 intervention, 242 controls)</p> <p>Carer outcome: family distress related to delirium remained high with no significant differences between two groups in levels of family-perceived distress or need for improvements in professionals' care for delirium; intervention group showed improvements in some aspects of knowledge</p> <p>Methodology notes: authors concluded need for comprehensive intervention program more focused on psychological support; all patients receiving specialised palliative care with adherence to recommended care practice generally high so sensitivity to intervention effects might have been low</p> |

Individual series (n=24)

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| <p>Agren et al (2012) (58)</p> | <p>Education and psychosocial support for patient-caregiver dyads (problem solving and strategies for self-care)</p> <p>Design: RCT (baseline; three months and 12 months post-intervention)</p> <p>Sample size: 155 patient-caregiver dyads (71 intervention, 84 controls)</p> <p>Carer outcome: neutral/limited effects, no change to perceived control for caregivers, and no difference in carer burden after 3 and 12 months.</p> <p>Methodology notes: Randomisation using random number table</p> |
| <p>Boele et al (2013) (64)</p> | <p>Psycho-education covering disease-specific symptoms and resulting day-to-day problems and CBT to increase ability to cope</p> <p>Design: RCT (baseline; two, four, six, eight and 10 months)</p> <p>Sample size: 56 patient-caregiver dyads (31 intervention, 25 controls)</p> <p>Carer outcome: modest effects; feelings of mastery increased over time in intervention group, but no significant effect for mental functioning (psychological morbidity and adaptation)</p> <p>Methodology notes: randomisation process not described; high attrition rate, especially in intervention group (over half dropped out in this arm due to intervention burden and death of patient)</p> |

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| <p>Bucher et al (2001) (62)</p> | <p>Problem-solving cancer care education for patients and caregivers (based on COPE problem-solving model)</p> <p>Design: before-after study (baseline; two months post-intervention)</p> <p>Sample size: 49 caregivers and 40 patients</p> <p>Carer outcome: Participants reported feeling more informed about community resources and achieved higher post-education scores for problem-solving ability; caregivers reported the written resource made a difference to their approach to home care</p> <p>Methodology notes: low response rate to follow up (35%: 14 patients & 17 caregivers; 13 patients died)</p> |
| <p>Buck et al (2013) (47)</p> | <p>Psycho-educational intervention with focus on symptom management and caregivers' self-care (COPE-HF problem)</p> <p>Design: qualitative descriptive study to assess acceptability of intervention</p> <p>Sample size: 7 carers</p> <p>Carer outcome: those newer to caring role valued the manual and visits were positively valued by some caregivers; caregivers recommended that intervention should be offered earlier in caring trajectory and a short pamphlet would be more useful than manual</p> <p>Methodology notes: sampling/ selection process not described</p> |
| <p>Dunbar et al (2005) (57)</p> | <p>Patient and family education intervention (EDUC) plus family partnership intervention (FPI) in heart failure</p> <p>Design: two-group randomised experimental pilot study (baseline; three-months)</p> |

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| | <p>Sample size: 61 patient and family member dyads (29 randomised to EDUC and 32 to EDUC+FPI)</p> <p>Carer outcome: significant increase in heart failure knowledge in both groups from pre- to post-education sessions with no difference in degree of knowledge change and both groups declined in knowledge by three months</p> <p>Methodology notes: limited information on RCT procedures; data collector not specified</p> |
| <p>Ferrell et al (1993) (48)</p> | <p>Pain education program for elderly cancer patients and their family caregivers</p> <p>Design: randomised trial (baseline; 1-week and 4-weeks post intervention)</p> <p>Pain education program for elderly cancer patients and their family caregivers</p> <p>Sample size: 40 patients and 29 caregivers</p> <p>Carer outcome: significant improvement in knowledge, fear of addiction reduction, adequacy of dose giving, round the clock medicating (as opposed to as-needed) and fear of respiratory depression reduction</p> <p>Methodology notes: limited information about randomisation process; control group just received the booklet</p> |
| <p>Ferrell et al (1995) (49)</p> | <p>Pain education program for elderly cancer patients and their family caregivers</p> <p>Design: quasi-experimental (baseline; 1-week and 3-weeks post intervention)</p> <p>Sample size: 50 family caregivers</p> |

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| | <p>Carer outcome: significant improvement in psychological and social well-being, total QoL score and pain knowledge</p> <p>Methodology notes: nurse present whilst participants completed data collection tools in the home setting</p> |
| <p>Habermann & Davis (2006) (56)</p> | <p>Parkinson's disease caregiver psycho-educational intervention</p> <p>Design: pre-test post-test pilot study (baseline; post-intervention)</p> <p>Sample size: "small" (data not given)</p> <p>Carer outcome: all aspects of intervention rated as helpful except for information about PD (as this was already readily available)</p> <p>Methodology notes: unclear if interventionist also collected data; no information on sample size; pilot study led to on-going RCT</p> |
| <p>Harden et al (2009) (53)</p> | <p>FOCUS Program: family-based program of care for prostate cancer patients and spouses (including symptom management education)</p> <p>Design: descriptive-correlational longitudinal process evaluation within Northouse et al 2007 RCT (baseline; on completion of program)</p> <p>Sample size: 263 patient-spouse dyads stratified by research site, phase of illness and treatment: 235 in final sample comprising 112 dyads in intervention group and 123 dyads in control group</p> <p>Carer outcome: spouses who reported positive changes following the intervention (less negative appraisal of caregiving and uncertainty, and better communication) reported higher satisfaction with the program (few baseline measures were related to this)</p> <p>Methodology notes: data collected by postal survey methods and returned to someone other than intervention deliverer</p> |

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| <p>Hudson et al (2013) (60)</p> | <p>Psycho-educational intervention for caregivers including strategies to promote psychological well-being and identifying positive aspects of caring</p> <p>Design: RCT (three-arm) (baseline; 1 week post intervention and 8 weeks post patient death)</p> <p>Sample size: 298 caregivers (57 intervention group 1, 93 intervention group 93, 148 control)</p> <p>Carer outcome: small non-significant improvement in psychological well-being of caregivers in the intervention condition; no reduction in unmet needs or improvements in positive aspects of caregiving</p> <p>Methodology notes: block randomisation process; research assistants responsible for data collection blinded to group allocation; authors highlight possible selection bias due to large proportion of eligible caregivers declining to participate; high attrition rate</p> |
| <p>Hudson et al (2005) (65)</p> | <p>Psycho-educational intervention for family caregivers of patients receiving palliative care</p> <p>Design: RCT (baseline; five-weeks later; eight-weeks post patient death)</p> <p>Sample size: 106 participants (54 intervention, 52 controls)</p> <p>Carer outcome: intervention group reported significantly more positive caregiver experience at five weeks and post-death measurement points; no impact on preparedness to care, self-efficacy, competence or anxiety</p> <p>Methodology notes: computer-generated randomisation sequence; random allocation by an independent person; data collected by researcher, but only 12 intervention and 15 controls completed all three assessments; carer guidebook developed by PI</p> |

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| <p>Keefe et al (2005) (66)</p> | <p>Partner-guided cancer pain management training at the end of life</p> <p>Design: preliminary RCT (mail or telephone baseline; post-intervention follow up at mean of 7.56 days, range 0-31 days)</p> <p>Sample size: 82 cancer patients and their partners, 78 randomised (41 intervention; 37 controls)</p> <p>Carer outcome: significant increase in ratings of self-efficacy for helping the patient control pain and other symptoms, plus a trend to report improvements in levels of caregiver strain</p> <p>Methodology notes: independent randomisation using concealed envelopes; data collected by researcher; single blinding</p> |
| <p>Kurtz et al (2005) (63)</p> | <p>Patient/ caregiver symptom control intervention</p> <p>Design: RCT (baseline; 10 week mid-point; 20 weeks at end of intervention)</p> <p>Sample size: 237 patient-caregiver dyads (118 intervention, 119 controls)</p> <p>Carer outcome: some trends, but no significant effect on caregiver depressive symptoms</p> <p>Methodology notes: high attrition particularly for late stage disease and lung cancers (59 dyads lost by 10 weeks, 39 further lost by 20 weeks; 139 remained); limited information about randomisation process</p> |
| <p>McMillan & Small (2007)</p> | <p>Coping skill training intervention using the Family COPE problem-solving model</p> <p>Design: three group RCT (baseline; 1-week and 2-weeks post-intervention); paper addresses impact on patient symptoms Sample size:</p> |

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| (45) | <p>329 patients</p> <p>Carer outcome: significant improvement in symptom distress</p> <p>Methodology notes: computerised randomisation; single-blinding; independent assessments</p> |
| <p>McMillan et al (2005)</p> <p>(44)</p> | <p>Coping skill training intervention using the Family COPE problem-solving model</p> <p>Design: three group RCT (baseline; one-week and two-weeks post-intervention); paper addresses impact on carers</p> <p>Sample size: 354 family caregivers</p> <p>Carer outcome: significantly greater improvement in caregiver QoL, burden of patient symptoms and caregiving task burden</p> <p>Methodology notes: computerised randomisation; single-blinding; independent assessments</p> |
| <p>McMillan et al (2013)</p> <p>(46)</p> | <p>Psycho-educational intervention with focus on symptom management and caregivers' self-care (COPE-HF problem solving model)</p> <p>Design: comparative experimental design (baseline, week 4 and 5)</p> <p>Sample size: 40 patient-caregiver dyads (19 intervention, 21 controls)</p> <p>Carer outcome: no significant differences on any caregiver outcomes (burden QOL, anxiety and depression, knowledge) at either week 4 or 5</p> <p>Methodology notes: group allocation process not described; high attrition reported but data relating to attrition published separately</p> |

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| <p>Northouse et al (2002) (50)</p> | <p>FOCUS Program: family-based program of care for women with recurrent breast cancer and a family member (including symptom management)</p> <p>Design: RCT (baseline; three months and six months later); paper reports different set of outcome measures to Northouse et al 2005 (51)</p> <p>Sample size: 134 patients and family members: 73 intervention group; 71 controls</p> <p>Carer outcome: higher mean scores for the intervention group carers on a series of items, but only reached statistical significance for “family involvement in discussions” item</p> <p>Methodology notes: researcher-developed handouts; questionnaire items reportedly geared towards the intervention; limited information on RCT procedures</p> |
| <p>Northouse et al (2005) (51)</p> | <p>FOCUS Program: family-based program of care for women with recurrent breast cancer and a family member (including symptom management)</p> <p>Design: RCT (baseline; three months and six months later); paper reports different set of outcome measures to Northouse et al 2002 (50)</p> <p>Sample size: 134 patients and family member dyads: 73 intervention group; 71 controls (182 dyads at baseline: 94 intervention and 88 controls)</p> <p>Carer outcome: significantly less negative appraisal of caregiving at three-months (not sustained at six months)</p> <p>Methodology notes: limited information on RCT procedures</p> |

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| <p>Northouse et al (2007) (52)</p> | <p>FOCUS Program: family-based program of care for prostate cancer patients and spouses (including symptom management)</p> <p>Design: RCT (baseline; four months; eight months and twelve months later) Sample size: 263 patient-spouse dyads stratified by research site, phase of illness and treatment: 235 in final sample comprising 112 intervention group and 123 controls</p> <p>Carer outcome: higher QoL, more self-efficacy, better communication and less negative appraisal of caregiving, uncertainty, hopelessness, and symptom distress at four months compared to controls; some effects sustained to eight and twelve months</p> <p>Methodology notes: single blinding, separate research nurses</p> |
| <p>Northouse et al (2013) (51)</p> | <p>Information and support provided to patient-carer dyads (FOCUS program)</p> <p>Design: RCT (three arm) (baseline; 3 months and 6 months)</p> <p>Sample size: 302 patient-carer dyads (99 brief intervention group, 99 extensive intervention group, 104 controls)</p> <p>Carer outcome: intervention effects limited in number and duration with most effects occurring at 3-month follow-up only; dyads in treatment groups had more improvement on study outcomes (use of healthy behaviours, coping more effectively, maintaining social QOL and emotional QOL) than dyads in the control group; authors unable to say which intervention dose was better than the other</p> <p>Methodology notes: sample power lower than desired; stratified randomisation process; data collected by research nurses blinded to dyads' group assignments [trial of revised FOCUS program to determine optimal dose]</p> |

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| <p>Piamjariyaku I et al (2013) (54)</p> | <p>Caregiver telephone CHF home management coaching program</p> <p>Design: mixed methods before and after one-group design (baseline; 3 months post-intervention)</p> <p>Sample size: 12 family caregivers</p> <p>Carer outcome: overall caregiving burden score lower at follow-up than at baseline with improvement for 9 of 10 caregivers completing program; around half indicated improved confidence and preparedness; qualitative findings included that the program and materials were considered helpful by caregivers and caregivers were satisfied with the telephone coaching method</p> <p>Methodology notes: small sample and no control group so unable to evaluate efficacy of intervention;; low participation rate (12 of 28 eligible caregivers participated)so possible selection bias</p> |
| <p>Sebern et al (2012) (59)</p> | <p>Shared Care Dyadic Intervention (SDCI) aimed at improving communication, decision-making and reciprocity</p> <p>Design: one-group quasi experimental design (baseline; week 12)</p> <p>Sample size: 9 patient-caregiver dyads and 1 caregiver</p> <p>Carer outcome: caregiver effect sizes strongest for relationship quality, emotional well-being, caregiver pain and fatigue; both care partners reported that they benefited from learning about their condition, mutual discussion of care values and preferences and the care planning sessions</p> <p>Methodology notes: no control group</p> |

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| <p>Sherwood et al (2012) (55)</p> | <p>Problem-solving symptom management intervention</p> <p>Design: RCT (baseline; 10 and 16 weeks)</p> <p>Sample size: 225 dyads (112 intervention, 113 attention controls)</p> <p>Carer outcome: no significant increase in amount of caregiver assistance and no significant effect on any caregiver measure (depression, burden, mastery and caregiver-patient communication)</p> <p>Methodology notes: randomisation performed using a minimisation approach – no further details; no discussion of potential limitations of design (i.e. attention control); authors note that caregivers with depressive symptoms were resistant to intervention suggesting need to address caregiver depressive symptoms</p> |
| <p>Valeberg et al (2013) (98)</p> | <p>Psycho-educational intervention to improve family carer’s knowledge and attitudes regarding cancer pain management (PRO-SELF Pain Control Program)</p> <p>Design: RCT (baseline and post-intervention)</p> <p>Sample size: 112 family carers (58 intervention, 54 attention controls)</p> <p>Carer outcome: family carers in the PRO-SELF group had significant increases in their knowledge for 8 of 9 items and total score on Family Pain Questionnaire; however need for further education in relation to use of pain medicine for less severe pain, addiction, and link between pain and disease progression</p> |

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| | Methodology notes: caregivers assigned to same group as patients but process for randomisation of patients not described |
| Group series (n=23) | |
| A'Campo et al (2010a) (74) | <p>Patient Education Program Parkinson (PEPP; developed by EduPARK): psychosocial intervention for patients and their caregivers (teaches knowledge and skills)</p> <p>Design: formative evaluation (baseline; one-week after PEPP; plus self-assessment of mood before and after each session)</p> <p>Sample size: 151 patients; 137 caregivers; in groups of 4-7 separately, but simultaneously</p> <p>Carer outcome: caregiver burden and need for help diminished significantly; no change in health state or depression; significant effect on mood after each session and across all sessions, 80% agreed PEPP was appropriate to them; 86% would recommend PEPP to others, 90% agreed that the exchange of experiences within the group was helpful, 75% reported improved understanding of PD; 20% found the exercises too difficult and 60% found the leader too directive</p> <p>Methodology notes: questionnaire data collected “at research location” in presence of researcher; mood data collected at sessions (possible social desirability bias); short follow up</p> |
| A'Campo et al (2010b) | <p>Patient Education Program Parkinson (PEPP; developed by EduPARK): psychosocial intervention for patients and their caregivers (teaches knowledge and skills)</p> |

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| (75) | <p>Design: RCT (baseline and one-week after PEPP; plus self-assessment of mood before and after each session)</p> <p>Sample size: 64 patients; 46 caregivers; in groups of 5-7 separately, but simultaneously</p> <p>Carer outcome: significant positive effect on psychosocial problems and need for help; significant effect on mood after each session and across all sessions; 90% agreed that the exchange of experiences within the group was helpful, more than half reported improved understanding of PD, more than 50% said they could deal better with PD-related problems now (patients and caregivers); no impact on depressive symptomatology (possible floor effect) or health-related QoL (possible lack of sensitivity in measure: EQ-5D)</p> <p>Methodology notes: no information on randomisation process; low drop out (three patients and two caregivers); unclear who collected data but mood data collected at sessions (possible social desirability bias); small sample size; MMSE scores differed at baseline by group; short follow up; control group offered PEPP at end of study</p> |
| Bucher et al (1999) (88) | <p>Prepared Family Caregiver Course (based on the COPE problem-solving model)</p> <p>Design: written evaluations and post-course follow up interviews at two months</p> <p>Sample size: written evaluations more than 2,000 participants (mixed); follow up interviews with first 36 caregivers</p> <p>Carer outcome: written evaluations reported high level of satisfaction and interest in using the information and problem-solving skills taught with 69% rating course as very helpful and 88% strongly recommending it to other family caregivers; follow up interviews</p> |

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| | <p>reported 18/36 used plans developed in the course and 24/36 used the book – most of those not using either reported patient remission or death; results suggest caregivers used the problem-solving information and strategies proactively</p> <p>Methodology notes: limited information on evaluation methods; experimental and control group studies planned</p> |
| Cashman et al (2007) (85) | <p>Educational program for the caregivers of persons diagnosed with a malignant glioma</p> <p>Design: before-after (multiple choice test-questionnaire and open-ended questions at baseline, immediately after course and four-six weeks later)</p> <p>Sample size: 24</p> <p>Carer outcome: statistically significant improvement in knowledge scores immediately post-course and 4-6 weeks later (but some decline at 4-6 weeks)</p> <p>Methodology notes: unclear who collected data but discussion describes a possible “desire to please the health care professionals caring for their loved one” as a limitation (therefore potential bias)</p> |
| Chiquelho et al (2011) (89) | <p>proFamilies (psycho-educational multi-family group intervention for cancer patients and their families)</p> <p>Design: quasi-experimental longitudinal study (based on the administration of scales to a sub-sample of 14 participant families and a control group of eight non-participant families at baseline and one-year later) and focus group interviews with participants one month</p> |

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| | <p>after programme</p> <p>Sample size: five groups of 4-6 families (20 participants max per group); 19 families and 57 people in total</p> <p>Carer outcome: results suggest the programme responds to needs, promotes adequate family cohesion and reduces perceived stress; but 56% abandonment rate before start with 17% subsequent intervention drop-out (usually due to lack of transport)</p> <p>Methodology notes: focus groups interviews led by the psychologists who co-ordinated the group (100% participation); 6/14 proFamily evaluation-participant families dropped out during evaluation</p> |
| <p>Collinge et al (2007) (86)</p> | <p>Brief instruction in massage and touch therapy to build caregiver efficacy</p> <p>Design: feasibility study using longitudinal within-subject repeated measures control and intervention phases design (self-report instruments five times, 30 days apart: two baseline testings at start and finish of 30 day control phase, then three one-monthly mail outs over a 90-day follow up) plus four pre-intervention and eight 2-hour follow up focus groups</p> <p>Sample size: 50 caregivers and 49 patients (seven workshops of 4-8 couples); focus groups pre-intervention involved 17 early enrolling couples and post-intervention involved 38 partners plus 35 patients</p> <p>Carer outcome: survey data showed perceived self-efficacy in massage more than doubled, focus groups reported increased confidence and valued the group experiences as much or more than the instruction</p> <p>Methodology notes: \$20 honoraria for survey return within one-week and \$50 per focus group; 97% survey return rate; only one subject</p> |

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| | lost to follow up (advanced cancer patient death); no information on who collected data |
| Grahn & Danielson (1996) (83) | <p>Learning to live with cancer: education and support programme for cancer patients and their significant others</p> <p>Design: open individual (one hour) and focus group interviews</p> <p>Sample size: 127 participants (250 invited) participating in eight programmes over a 4-year period; 94 interviews (37 significant others)</p> <p>Carer outcome: increased knowledge, understanding, confidence, and ability to use knowledge; anxiety reduced and easier to handle; discussion within carer-only groups was appreciated; value of being perceived as people who mattered in caring for patient; relationship strengthening</p> <p>Methodology notes: data collected by someone familiar with the programme but not teaching in it; 47 declined programme participation due to transport difficulties in evenings; 22 were unable to attend all sessions – final number 127 (54 significant others)</p> |
| Henriksson et al (2011) (80) | <p>Support Group Program during ongoing palliative care (includes information / educational element)</p> <p>Design: qualitative descriptive pilot study (telephone interviews two days to one week post-intervention)</p> <p>Sample size: 29/39 family members (six support groups, two per unit)</p> <p>Carer outcome: acceptable and useful intervention, topics of immediate interest, structure inviting (opportunity to establish relationships with other participants and the caring team)</p> |

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| | Methodology notes: researchers were not involved in program delivery |
| Hinckley & Packard (2001) (76) | <p>Opening Doors: family education seminars for adults with chronic aphasia and their families</p> <p>Design: participant and non-participant comparison group study using pre / post design between groups (baseline; 6 month follow up)</p> <p>Sample size: 8 and 13 (of 31 and 45) participant pairs (patients and caregivers) attending Opening Doors in 1996 and 1997 respectively who completed questionnaires (38% of those completing baseline); 15/46 non participant pairs (who had enquired about the seminar in either year but chose not to attend; 63% of those completing baseline)</p> <p>Carer outcome: participant pairs reported significant improvement in functional activity, knowledge and family relationships</p> <p>Methodology notes: non-randomised; non-participant group likely to be different to those who attended plus agreed to complete questionnaires; knowledge-ratings (rather than knowledge tests); participants paid a conference registration fee (may bias view of outcome)</p> |
| Hinckley et al (1995) (77) | <p>Opening Doors: family education programming for adults with chronic aphasia</p> <p>Design: programme evaluation (pre-programme questionnaires, immediate programme evaluation form collected at door and six-month postal follow up with telephone reminder to non-responders at 6 weeks)</p> <p>Sample size: unclear; data from participant pairs (patients and carers); Table 3 suggest 32 (most were carers); 42 carers and eight patients</p> |

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| | <p>completed a pre-programme questionnaire, 139 programme attendees over last 3 years (average 46 annually; some returners); average 50% response rate to overall programme evaluation annually (no number given); 21% (12) and 34% (22) responded to 6-month follow up in 1993 and 1994 respectively</p> <p>Carer outcome: participants (unclear if patients or carers, but most evaluation responders were carers) found it beneficial; most sought new resources and succeeded; positive impact on social behaviours, understanding of aphasia, and family communication patterns</p> <p>Methodology notes: low response rates to questionnaires; limited data on who responders were; authors acknowledge need for control group</p> |
| <p>Horowitz et al (1996) (84)</p> | <p>Psycho-educational support group for spouses of patients with brain tumours</p> <p>Design: unspecified but describes “verbal reports”</p> <p>Sample size: 20 spouses (average 10 per meeting)</p> <p>Carer outcome: verbal reports of help to facilitate home care, and reduced anxiety and depression; reluctance to terminate the group</p> <p>Methodology notes: initial 10 participants “selected” by team plus further members; no information on data collection methods or analysis; discussion suggests group leaders collected the data (“our support group...”)</p> |
| <p>Hudson et al</p> | <p>Caregiver Group Education Programme (CGEP; for family caregivers in home-based palliative care)</p> |

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| (2008) (67) | <p>Design: before-after study (described as “pilot” in 2009 paper below (68)) including session evaluation before and after each session, plus programme evaluation via self-report questionnaires (baseline; on programme completion and two weeks later) and qualitative programme evaluation via semi-structured interviews (two weeks after programme with at least one caregiver per programme) and facilitators’ journals</p> <p>Sample size: 74 caregivers over 16 education programmes (4-8 per programme); 44 complete datasets (three time points)</p> <p>Carer outcome: significant positive effect from baseline to programme completion on preparedness for caring role, caregiving competence, caregiving rewards, and having information needs met; improvements maintained at two week follow up; favourable programme feedback; programme had a positive impact on lives</p> <p>Methodology notes: qualitative data collected by independent researcher; 44/74 complete datasets (59%; no multivariate effects for incomplete participation); 96 refusals (reasons included: coping and supported (n=17), not interested (n=14), working (n=10), relative too unwell to leave (n=9)); no intervention fidelity checks; outcomes focused on caregivers’ perceptions rather than formal test of knowledge and skills; guidebook PI-developed</p> |
| Hudson et al (2009) (68) | <p>Caregiver Group Education Programme (CGEP; for family caregivers in home-based palliative care)</p> <p>Design: same design as Hudson et al (2008) pilot (and includes pilot data)</p> <p>Sample size: 156 caregivers over 32 education programmes including pilot (average 5 per programme); 96 complete datasets (three time</p> |

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| | <p>points)</p> <p>Carer outcome: significant positive effect on preparedness, competence, rewards, having information needs met; maintained at 2-week follow up</p> <p>Methodology notes: 96/156 complete datasets (62%; no multivariate effects for incomplete participation); 204 refusals (various reasons e.g. too busy working/caring (60; 29%), patient too unwell to leave (32; 16%), time/ location not suitable (25, 12%), coping/ supported (21; 10%), not interested (21; 10%); as for pilot, no intervention fidelity checks and outcomes focused on caregivers' perceptions rather than test of knowledge/ skills; guidebook PI-developed</p> |
| <p>Kwak et al (2007) (81)</p> | <p>Caregiving at Life's End (CGLE)</p> <p>Design: before-after study (trainers completed training rosters and caregivers completed pre- and/or post- surveys; pre-survey at end of first session)</p> <p>Sample size: 1,756 caregivers who completed at least one survey including 926 of whom completed both surveys (2,025 participated in CGLE)</p> <p>Carer outcome: significant improvement in comfort with caregiving, closure and caregiver gain; programme length made a difference for improvement in comfort with caregiving and closure, but not caregiver gain</p> <p>Methodology notes: some differences at baseline between three groups (those completing pre-survey only, post-survey only and both</p> |

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| | <p>surveys) in terms of types of intervention, amount of exposure to intervention and caregiving hours per week; pre-survey administered at end of first session (as trainers thought it would put participants off); trainers present when questionnaires completed; evaluation was optional to trainers; programme flexibly delivered in trainers' localities, thus there was variation in the amount of time caregivers received the programme; authors acknowledge need for control group</p> |
| <p>Lofvenmark et al (2012) (79)</p> | <p>Group-based multi-disciplinary educational programme to provide disease-related knowledge and forum for family members to interact</p> <p>Design: RCT</p> <p>Sample size: 128 family members (65 intervention, 63 controls)</p> <p>Carer outcome: intervention had no effects on anxiety, depression or QOL (previous publication on same programme (Lofvenmark et al 2011 (100)) found intervention group knowledge about CHF increased significantly)</p> <p>Methodology notes: block randomisation process; authors speculate that increased disease-related knowledge may only be beneficial for anxiety and depression if translated into enhanced sense of control and that interventions may need to target variables beyond disease-related knowledge; high number of patients did not permit study to invite family members to participate (possible selection bias)</p> |
| <p>Manne et al (2004) (87)</p> | <p>Psycho-educational group intervention for wives of men with prostate cancer</p> <p>Design: RCT using randomised block design with block sizes of 14 (questionnaires at baseline and one-month post intervention)</p> |

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| | <p>Sample size: 60 wives</p> <p>Carer outcome: intervention group participants perceived having a spouse with prostate cancer made a positive contribution to their lives, reported gains in the use of positive reappraisal coping and reductions in denial coping; no change in general or cancer-related distress</p> <p>Methodology notes: 68/120 agreed (four intervention and three controls dropped out); PI trained session leads; intervention fidelity checked; no information on randomisation process</p> |
| <p>Marsden et al (2010) (78)</p> | <p>CLASSiC (Community Living After Stroke for Survivors and Carers) – multi-disciplinary group programme in rural settings for patients and carers</p> <p>Design: pilot cross-over RCT (single-blinded for primary outcome measure only at t2; baseline (t1), one week after intervention group completed CLASSiC (t2), one week after control group completed CLASSiC (t3 – controls only), and five-weeks after control group completed CLASSiC (t4))</p> <p>Sample size: 25 patients and 17 carers (from 32 patients and 20 carers)</p> <p>Carer outcome: insufficient participants to reach statistical significance but between group trends favoured intervention group on most outcomes e.g. improved knowledge of stroke symptoms and risk factors, improved self-reported health-related QoL, and improved Six Minute Walk Test and Timed Up and Go, and less stress (Caregiver Strain Index)</p> <p>Methodology notes: some recruitment difficulties led to small sample size (one site unable to randomise - excluded from analyses); all</p> |

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| | <p>participants attended 4+ sessions and 88% attended six or seven; randomisation toss of a coin by a team member; programme conducted by “a number of the investigators”; blinded assessors for primary outcome measure only (t2); intention-to-treat analyses</p> |
| <p>Pasacrete et al (2000) (70)</p> | <p>Family Caregiver Cancer Education Program (FCCEP)</p> <p>Design: evaluation data from one of four contractors providing FCCEP using a pre- and post-test design (before and four months after)</p> <p>Sample size: analysis of complete data from 187 caregivers (384 at baseline and 195 at 4-month follow up); group sizes of 8-15 members</p> <p>Carer outcome: over time the perception of burden did not increase even when caregiving tasks increased in intensity, own health perception increased, and number of caregivers who said they were well informed and confident increased over time</p> <p>Methodology notes: authors acknowledge RCT needed, data (questionnaires) collected by local instructors, high missing data due to instructors not wanting to increase caregiver burden; 32% attrition rate among male caregivers; substantial number unable to attend due to caregiving role (bias)</p> |
| <p>Roberts et al (2002) (71)</p> | <p>Living with Cancer Education Programme (LWCEP; an education and support programme for cancer patients and their family and friends)</p> <p>Design: programme evaluation (baseline and post-programme questionnaires completed at first and last sessions)</p> <p>Sample size: 152 programmes involving 1460 participants over 6-year period</p> |

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| | <p>Carer outcome: high satisfaction with programme (all participants), significant improvement in coping abilities, knowledge, communication and relationships with significant others and health care professionals</p> <p>Methodology notes: questionnaires completed at first and last sessions (potential for bias, although participants were told facilitators would not see their responses and sealed envelopes were used); authors note potential for sample biased in favour of those who are already coping and lack of disease-specific data collected at baseline; unclear if findings relate to all participants or patients / families and friends</p> |
| Robinson et al (1998) (69) | <p>Family Caregiver Cancer Education Program (FCCEP)</p> <p>Design: participant evaluation (baseline and follow up survey 6-8 weeks after completion of course)</p> <p>Sample size: 1,020 caregivers attending 176 courses over a four-year period delivered by four contractors</p> <p>Carer outcome: caregivers felt less overwhelmed, better able to cope with the caregiver experience, improved ability to communicate with health care professionals and other family members, decreased stress levels, and more knowledgeable regarding all aspects of caring and available community resources and then used these resources</p> <p>Methodology notes: surveys sent out by the programme contractors; limited data presented</p> |
| Simons et al | <p>EduPark (early version of PEPP): an education programme for people with Parkinson's disease and their carers</p> |

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| (2006) (73) | <p>Design: formative evaluation (baseline at pre-programme session at hospital; follow up either at separate hospital session or at home; mood barometer at start and end of each sessions plus evaluation questionnaire at end of each session)</p> <p>Sample size: 36 participants (21 patients, 14 carers) across six groups (three for patients, three for carers)</p> <p>Carer outcome: favourably evaluated (most received helpful information, reported increased knowledge and understanding, reported exchange of experiences and ideas within group as helpful, felt better able to handle PD-related problems and most would recommend it to others); short-term positive effects on mood for all sessions except Session 1; no statistically significant effects on QoL or depression</p> <p>Methodology notes: high dropout (10/36 completed less than five sessions; remainder completed at least five of the eight); no information on who collected data; authors acknowledge need for control group, small sample size, and need for longer term outcomes</p> |
| Sutherland et al (2008) (72) | <p>Living with Cancer Education Programme (LWCEP)</p> <p>Design: evaluation of LWCEP (reported in Roberts et al, 2002, above (71)) using pre- and post-program questionnaires focusing on differences between patients' and family and friends' perceptions</p> <p>Sample size: 666 participants with cancer and 324 family and friends (from 1278 and 1088 participants who completed pre- and post-program questionnaires respectively)</p> <p>Carer outcome: 96% family / friends satisfied with programme; decrease in impact of cancer on lives, decrease in worry and stress, increase in perceptions of support, increase in knowledge and increase in perceived ability to communicate with health care professionals</p> |

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| | <p>more pronounced in family / friends than in patients</p> <p>Methodology notes: see Roberts et al (2002), above (71) (except final point); need for control group</p> |
| White et al (2008) (82) | <p>Learn Now; Live Well (LNLW): an educational programme for caregivers</p> <p>Design: combined summative and formative evaluation design; quantitative (questionnaires) and qualitative data (semi-structured interviews); three time points (immediately before (t1), immediately after (t2) and four-weeks after the education session (t3))</p> <p>Sample size: 205 caregivers attended LNLW; interviews with 5 carers from 24 randomly selected, and key informants from organizations and the inpatient setting</p> <p>Carer outcome: substantial reduction in care isolation and increase in care confidence and knowledge (some knowledge loss at t3, but remained higher than t1); strong support, reassurance and having a skilled facilitator were fundamental for the success of the programme; more flexible session times and a flip chart or summary manual for easy reference were suggested</p> <p>Methodology notes: no information on sampling for qualitative interviews, no information on who collected the data; some missing data so that only 44 cases included in one analysis on carer confidence in the inpatient setting; low response rate to qualitative interviews (5/24, 21%); authors acknowledge need for longer-term outcomes</p> |
| Resources (standalone) | |

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| <p>Cassileth et al (1982) (90)</p> | <p>Four audio-visual programmes about cancer and cancer treatment</p> <p>Design: evaluation of four new audio-visual programmes (self-report anxiety and knowledge questionnaires before and after watching one of four selected programmes; plus evaluation questionnaire after)</p> <p>Sample size: 240 patients (alone or with hospital roommates), families and friends; eligible patients approached consecutively until 60 people had evaluated each of the four films</p> <p>Carer outcome: knowledge scores increased; those who were least knowledgeable initially learned the most; significant decrease in anxiety scores; positive evaluation of technical qualities of the programmes on a 1-7 scale (i.e. clear, informative, important, worthwhile, visually pleasing, and easy to understand); 66% (of all respondents, not just carers) felt the number of facts about right and 69% (of all) felt the programme would make it easier to talk with doctors and nurses about illness and treatment)</p> <p>Methodology notes: participants chose one of four programmes, research assistant both showed the programmes and administered the questionnaires; assessed knowledge rather than perception of knowledge, but no follow up data to assess knowledge retention</p> |
| <p>Chung et al (2009) (91)</p> | <p>Informational stories for patients and caregivers with brain metastases</p> <p>Design: comparison of efficacy of story-based writing style to fact-based writing style for educational material using a self-administered 21 item (20 items used 5 point categorical scale for level of agreement with statements; one item on writing style format preference and why)</p> |

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| | <p>Sample size: 47; 26 patients and 21 caregivers</p> <p>Carer outcome: of all respondents (not just carers) 42% preferred facts, 7% stories and 51% both; for all respondents (not just carers) fact-based material was superior in providing factual information (e.g. discussion of treatment, side effects) and selected general characteristics (e.g. clarity of information) and a trend suggested story-based material superior in describing “how it feels to have brain metastases”, effects on spouse, and in being “sensitive to the frustrations” of the patient; overall carers scored the fact-based material lower than the patients, but there was no difference between carers and patients for the story-based resources (mean scores)</p> <p>Methodology notes: no information on who recruited sample or how, who delivered packs or how they were returned although sample characteristics section refers to the availability of summer-student researchers; slow recruitment (over 2.5 years)</p> |
| Collinge et al (2013) (93) | <p>Multi-media home-based instructional program for family caregivers in touch-based techniques to provide comfort to cancer patients</p> <p>Design: RCT (baseline; 4 weeks)</p> <p>Sample size: 95 patient-caregiver dyads (45 intervention, 50 attention control)</p> <p>Carer outcome: no differences between groups in stress and caregiver esteem; increased satisfaction with ability to help patient feel better and reduced concern about causing distress with touch for both groups; decreased symptomatology for both groups, but significantly greater for patients in intervention group for three symptoms including pain and nausea</p> <p>Methodology notes: block randomisation of dyads based on ethnicity to achieve equivalent ethnic diversity in treatment and control</p> |

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| | groups; authors acknowledge limitations due to heterogeneity of sample and lack of assurance of equivalence between groups; attention had an impact which should be controlled for in future studies |
| DuBenske et al (2014) (94) | <p>CHES (Comprehensive Health Enhancement Support System) eHealth System combined with Clinician Report</p> <p>Design: RCT (baseline; 6-months)</p> <p>Sample size: 246 caregivers (124 intervention, 122 control)</p> <p>Carer outcome: CHES group had significantly lower levels of caregiver burden and negative mood (small to medium effect size); no difference between groups for disruptiveness</p> <p>Methodology notes: block randomisation process;; authors acknowledge further research needed to illuminate specific mechanism for CHES's effect on burden and negative mood and highlight fact that 27% of CHES group did not access CHES; high attrition</p> |
| Kitamura et al (2011) (92) | <p>Combined story and fact-based educational booklet for patients with multiple brain metastases and their caregivers</p> <p>Design: evaluation of a combined story and fact-based educational booklet (developed following Chung et al, 2009, above (91)) regarding anxiety (before/after reading booklet) and satisfaction (after; two questionnaires)</p> <p>Sample size: 44 (22 patients and 22 caregivers)</p> <p>Carer outcome: all participants (not just carers) reported high satisfaction for both informational content and overall satisfaction toward</p> |

the booklet; carers' anxiety scores increased after reading the booklet (unchanged in patients) suggesting effectiveness in conveying serious prognostic implications; all participants (not just carers) endorsed the resource

Methodology notes: no information on who delivered by or where booklet read but post-booklet questionnaires were to be completed and returned within a week (suggesting home-completion); inclusion of end of life issues caused some distress so after first 20 recruits participants were warned of this content and given option of removal of these sections (last 4 pages) but none took up this option suggesting that the warning was enough; authors acknowledge lack of long-term follow up (to assess knowledge retention, repeated use of resource, and patient/carer use of resource with health care professionals), lack of measures of knowledge / knowledge gained (the focus was on satisfaction with the booklet), and small sample size

Abbreviations: RCT = randomised controlled trial; QoL = quality of life; PD = Parkinson's disease; CHF = chronic heart failure; CVA = stroke

Table 2: Summary of key elements of personnel-delivered interventions by delivery-mode type

| Delivery-mode type | Individual one-off | Individual series | Group series |
|------------------------------------|--------------------------------------|---|---|
| No. of papers | 10 papers | 24 papers | 23 papers |
| No. of interventions | 9 interventions | 18 interventions | 17 interventions |
| Type of contact | All face to face | 16 face to face: 9 with additional telephone contacts; 2 telephone only | All face to face |
| Disease groups | 8/9 cancer only 1: no data | 12/18 cancer only 5 chronic heart failure 1 Parkinson's disease | 10/17 cancer only 2 aphasia 1 chronic heart failure 1 Parkinson's disease 1 mixed cancer/ non cancer 2 no data |
| Target | 3 patients & carers 6 carers only | 9 patients & carers 9 carers only | 8 patients & carers 9 carers only |
| No of face-to-face contacts | n/a | Usually 2-3 contacts, weekly/fortnightly | Usually 2-3 contacts, weekly/fortnightly |
| Duration of each contact | Most 90 mins or less | 45 mins-2 hrs | Most 90 mins-2 hrs |
| Setting | Most clinical 2 home | 13/18 home setting | Most clinical None home |

| | | | |
|---|--|---|--|
| Delivered by | Most by research staff or nurses | Most by nurses | Most by multi-disciplinary teams (n=7); 6 health care professionals/ others intervention-trained; 3 other health care / allied health professionals; 1 unspecified |
| Use of additional resources | 9/9 used additional resources | 14/18 used additional resources | 14/17 used additional resources |
| Written only | All 9 used written | All 14 used written | 12 used written |
| Written & audio- visual / multimedia | 2/9 also used audio- visual/multimedia resources: 1 slides; 1 DVD | 5/14 also used audio- visual/multimedia resources: 2 audio tapes; 1 audio tape & video; 1 CD-ROM; 1 video | 5/12 also used audio- visual/multimedia resources: 3 video; 2 slides |
| Audio-visual / multimedia only | None | None | 2 used audio- visual/multimedia resources only: 1 videos; 1 unspecified |
| Other | None | Respite Money for non-drug interventions | Respite Free parking |
| Methodology design | Usually before-after | Usually RCTs | Usually before-after |