How can informal caregivers in cancer and palliative care be supported? An updated systematic literature review of interventions and their effectiveness

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Abstract

Introduction: Informal caregivers needs in cancer/advanced disease are largely unmet. The science of carer intervention evaluation is methodologically challenging, and the evidence historically weak.

Objective: This systematic review updates an earlier effectiveness review to determine both the effectiveness of subsequently published intervention studies, and the current state of science.

Method: The evidence was identified and appraised using a comprehensive search strategy. Articles were searched from 2001 to 2010 using the following electronic databases: Medline, PsychINFO and CINAHL. Inclusion criteria were studies reporting intervention data for informal adult caregivers of a patient with a diagnosis of cancer or receiving palliative care. The design and evidence rigour were assessed using the Jadad Rating Scale, and the Quality Rating Scale.

Results: 33 studies met inclusion criteria. From the original review, an encouraging increase was identified in the number of evaluations (from 8 to 33), in carer-specific interventions (from 6 to 17) and in the robustness of the study design (an increase from 2 to 12 studies with before/after measures, comparison groups and prospective data).

Conclusions: The evidence suggests a rapid increase in the number of robust intervention studies. However, the range of models remains narrow in relation to caregivers’ needs and preferences.

Keywords
Cancer, caregivers, carers, palliative, systematic review

Introduction

Studies have highlighted that informally caring for a relative or friend with cancer or advanced incurable disease can be associated with many problems, including sleeplessness, general deterioration in health, exhaustion\(^1,2\) and anxiety/depression.\(^3\) There have been consistent calls for well-conducted intervention studies to identify effective ways to support caregivers of patients with cancer or those receiving palliative care.\(^4,5\)

However, the challenge of improving outcomes for caregivers in cancer and palliative care (compared to, for example, informal care of the elderly, in mental health or disabled populations) is that only a relatively brief window of opportunity is available in which to learn new methods of coping, to put these methods into practice, and to achieve an improvement in outcome. Further, professionals must be careful to enhance (rather than dismantle) existing coping strategies during the limited period of advanced disease, and be mindful that while caregivers are helping the patient to prepare for dying, they are also trying to prepare themselves for the eventual death of their relative.\(^6\)

Further methodological challenges to efficacy studies are posed for those who attempt to undertake trials in populations with advancing disease. Even those who
succeed in conducting trials have concluded that it may not be possible to improve outcomes for informal carers in palliative care. Nevertheless, supportive and palliative care aim to improve outcomes for family members and other caregivers, and guidance, such as that of the National Institute for Health and Clinical Excellence (NICE), identifies the need to better support caregivers through delivery of evidence-based interventions.

The public health imperative to deliver effective interventions is great. During the last two weeks of life, both patients and carers identify anxiety in the nearest carer as one of their biggest problems, and the needs of the family may exceed those of the patient. Optimum home care for patients depends on adequate care for the caregivers to sustain them in their role. Despite a clear preference for home death, it is predicted that fewer than one in 10 will die at home by 2030. A meta-analysis of the available evidence demonstrated that achieving home death is associated with the availability of family support to the dying patient.

Systematic reviews of evidence allow clinicians to keep up-to-date with best practice, and are useful in drafting (and delivering) clinical practice guidelines and policy. A previous systematic review of carer outcomes under cancer and palliative care was conducted in 2001 as ‘it was not yet clear how to meet assessed need’. That review identified six interventions targeted at caregivers that had evaluated their outcomes, and concluded that ‘There was a lack of outcome evaluation designs, small sample sizes and a reliance on intervention descriptions and formative evaluations...The current evidence contributes more to understanding feasibility and acceptability than to effectiveness. Practitioners and evaluators must prioritize the further development of intervention studies’.

In order to appraise progress in methods, innovation in designing and delivering intervention, and the state of science and evidence over the ensuing nine years, this present study aimed to update the original review.

**Methods**

Studies were identified using a systematic search of electronic databases, with additional hand-searching of relevant journals and reference lists of published papers.

**Database search strategy**

Keywords used for the search were the union of ‘carer*’ and ‘caregiver*’ intersected with the union of ‘cancer’, ‘palliative’, ‘end of life’ and ‘terminal*’. These search terms were those of the original review, apart from the inclusion of the additional search term ‘end of life’.

**Inclusion criteria**

Studies evaluating any type of intervention that explicitly aimed to improve outcome(s) for current caregivers (i.e. unpaid informal providers of practical, physical or emotional care) published in peer-reviewed journals, and not included in the original review, were included. Studies were required to be one of the following designs: randomized controlled trial (RCT); prospective study; study with a concurrent mixed-methods design; qualitative post-intervention data; observational study with pre- and post-test measures.

The study population for inclusion was adult informal caregivers of adult patients with cancer or receiving palliative care. The final inclusion criterion was that papers were published in the English language. Case studies were excluded from the review, as were papers reporting models of intervention with no evaluation data. Bereavement interventions were also excluded.

**Study selection**

The titles and abstracts of all the identified papers generated from the search strategy were analysed and assessed against the eligibility criteria. Full versions of the papers considered for inclusion were retrieved in order to make a final decision. Any papers that were not clearly for inclusion or exclusion were reviewed by SL, HJ and EE and adjudicated by RH.

**Analysis**

Data were extracted using common forms previously reported for systematic reviewing. Variables included paper reference (including country and year), intervention model, palliative/cancer palliative or cancer population, intervention target population (i.e. solely caregivers or caregivers plus patients), study design, intended intervention outcome, sample size, findings, evidence grade (as applied in the previous review) and study quality score.

Data were organized by intervention type, and the evidence appraised according to the study quality. The quality of the studies was assessed using two quality assessment tools. These were the Jadad scoring checklist for randomized trials and the study design quality rating system of the Clinical Guidance Outcomes Group (the latter used in the original review) (see Figures 1 and 2).

The data were considered for suitability for meta-analysis (e.g. study quality, and heterogeneity of the intervention, aims, sample and outcome tools).
A total of 10,817 citations were identified by the search strategy in Medline, 810 in CINAHL and 1137 in PsychINFO. Following de-duplication, 33 were retained following scrutiny against the inclusion criteria. Hand-searching and the analysis of reference lists of reviews identified one further eligible study meeting the inclusion criteria. One article could not be found despite attempting to contact the author (a qualitative evaluation of music therapy).

At the end of this process, 33 studies were included in this review.

Origin of studies and populations

The reported data were collected in the following regions: USA \(n = 11\), Australia \(n = 7\), UK \(n = 6\), Canada \(n = 4\), Sweden \(n = 2\) and one each from Israel, Japan and South Africa. Concerning the research populations, the most interventions were in cancer palliative care \((n = 15)\), with the remaining equally conducted in palliative care \((n = 9)\) and
cancer care ($n = 9$). In terms of the target group for the intervention, 17 were targeted solely at carers and the remaining 16 for both patients and carers.

**Intervention models**

This review identified six intervention types. The retained studies are reported in Table 1.7,18–48

**One-to-one psychological models ($n = 8$).** Eight interventions were reported that were identified as one-to-one and psychological. Of these, two were evaluated using an experimental RCT design,7,18 one using an experimental design but no information on treatment allocation,19 three using single-group before/after quantitative designs20–22 and two using post-intervention qualitative methods.23,24

The RCT by Hudson et al.18 consisted of a psycho-educational coping intervention delivered to carers by palliative nurses and aimed to increase the perceived competence, rewards and preparedness and decrease carers’ distress. The second RCT,7 in which 271 carers received the intervention, involved weekly visits or telephone calls to the carer by a carer advisor and aimed to increase support for depressed carers. Despite multiple endpoints in both studies, the only significant treatment effect was in the Hudson study with respect to positive rewards of caring. Both studies were of high quality.

**Psychological interventions for patient/carer dyads ($n = 4$).** For this intervention model, four intervention studies emerged: three RCTs and one qualitative study.

Results from Northouse et al.,25 with 235 couples, revealed improved quality of life (QoL), less uncertainty, higher self-efficacy and better communication between patients and carers. Allen et al.26 indicated positive results too, with carers reporting reduced caregiving stress and moderate reduction of depression. However, Northouse et al.25 fail to show significant differences between the intervention and control group on uncertainty, hopelessness and coping. Evidence for the quality of the method was moderate in Allen et al.26 and Northouse et al.,27 while Northouse et al.25 was graded more highly.

**Palliative care/hospice interventions ($n = 6$).** Six interventions were reported that were models of hospice and palliative care delivery that evaluated outcomes for carers. These were evaluated using one RCT,28 one matched retrospective cohort,29 two before/after single-group designs,30,31 one post-intervention single-group,32 and one mixed-method cross-sectional survey with focus groups.33

The single high-evidence grade study28 found no effect on carer outcomes post-death.

**Information and training interventions ($n = 3$).** The fourth category of models, interventions that aimed to deliver training and information, consisted of three studies. The evaluation designs were one RCT,34 one before and after single-group design35 and one retrospective study.36 The trial findings34 found that the Question Prompt List significantly increased the number of questions that caregivers asked during medical consultations.

**Respite interventions ($n = 1$).** The fifth intervention model category was respite.

Only one study37 reported this model, and used a post-intervention structured (non-quantitative) interview design.

**Group interventions ($n = 10$).** The sixth category was for group interventions, of which there were nine papers. Of these, two were ‘pure’ RCT evaluation designs,37–40 two were observational quasi-experimental designs,39,40 three were before/after single-group designs,21,41,42 one was a single quantitative post-intervention43 and two were qualitative post-intervention.44,45

The first trial38 found significant improvements for caregiver QoL, patients’ symptoms and caregiver task burden. The trial that aimed to improve caregiver outcomes through a group training intervention for patients found no effect for caregivers.37

**Physical interventions.** The final category was of a single paper that reported a yoga intervention using a post-intervention survey.

**Discussion**

Our systematic review has identified a significant and encouraging growth in the number of intervention studies that aim to improve outcomes for informal caregivers in cancer and palliative care, and an improvement in the study designs used. Comparing the original systematic review (which reviewed the period 1966–August 2001) with the current review (which reviewed the ensuing 9 years from 2001 to July 2010), we find the following: an increase from 18 to 33 studies that have evaluated outcomes for carers; an increase from 6 to 17 studies that report evaluations of interventions targeted solely at the caregiver; and an increase from 2 to 12 study designs that incorporate before/after measures, prospective data collection and a comparison group.

There are a number of limitations in conducting systematic reviews, including the focus on the English language, the publication bias away from negative trials and publication in non-indexed journals. However, our search strategy attempted to minimize these biases.

In drawing conclusions from this body of evidence, the model of intervention with the largest number of
Table 1. Data extraction tables: evidence of effectiveness of interventions for informal carers in cancer and palliative care

<table>
<thead>
<tr>
<th>Authors Country</th>
<th>Evaluation Design</th>
<th>Intended outcome + Measures</th>
<th>Sample</th>
<th>Results</th>
<th>Jadad Score Evidence Grade</th>
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<tbody>
<tr>
<td><strong>One-to-one/psychological interventions</strong> (n = 8) studies</td>
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<tr>
<td>Cameron et al., 2004 Canada (^1)</td>
<td>Single group prospective study</td>
<td>To enhance the problem-solving abilities of carers, enhance confidence of carers in their role and decrease emotional distress</td>
<td>58 carers of patients dying of cancer at home</td>
<td>Small-scale project. 34 carers completed all aspects of the study. 68% of carers – female, 73.5% carers married to patient. The intervention resulted in improvements in emotional tension ((P = 0.03)), caring confidence ((P = 0.06)), and positive problem-solving orientation ((P = 0.06))</td>
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<td>Cameron et al., 2009 Australia (^2)</td>
<td>Single group repeated measures prospective study</td>
<td>To evaluate the effectiveness of the psycho-educational intervention for primary family carers of patients with advanced cancer to their preparedness, perceived competence, rewards and needs</td>
<td>156 family carers completed T1 questionnaire. 62% of participants completed all 3 time periods</td>
<td>Significant differences emerged between Time 1 and Time 2 on preparedness ((P &lt; 0.001)), rewards ((P &lt; 0.001)), perceived competence ((P &lt; 0.001)), and information needs met ((P &lt; 0.001))</td>
<td>1 III B</td>
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<tr>
<td>Hudson et al., 2005 Australia (^3)</td>
<td>RCT</td>
<td>The intervention would increase the competence, rewards, levels of preparedness and decrease anxiety</td>
<td>106 carers of a relative dying of cancer at home</td>
<td>No intervention effects were identified concerning preparedness to care, self-efficacy, competence and anxiety. However participants reported a significantly more positive carer experience than those who received standard care at both 5 weeks after intervention and 8 weeks following death of the patient</td>
<td>1 IA</td>
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<tr>
<td>Milberg et al., 2005 Sweden (^4)</td>
<td>Four tape recorded focus groups</td>
<td>To enhance the increased perception of support and knowledge</td>
<td>22 carers of a relative with advanced cancer</td>
<td>The qualitative analysis resulted in 6 main categories: reasons for support group participation, ‘group composition contributed to group cohesion’, ‘experience and sensitivity of group leader was a catalyst’, ‘meaningful</td>
<td>0 IIIC</td>
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(continued)
intervention in person and by telephone over a 12-week period

dialogue helped to solve everyday problems', 'sense of cohesion increased effectiveness of the group', and 'group sessions and post-session reflection increased perception of inner strength'.

The quantitative findings showed participants wanted a support group over a longer time period

Walsh and Schmidt, 2003 USA

A four-week telephone intervention with workbook (Tele-Care II) for carers of hospice patients

Walsh et al., 2007 UK

A brief support intervention involving 6 weekly visits or telephone calls to the carer by a carer advisor

Table 1. Continued

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<tr>
<td>Walsh and Schmidt, 2003 USA</td>
<td>Face-to-face pilot study with pre- and post-test assessment of the intervention</td>
<td>The intervention would decrease carers' feelings of depression, despair, and disorganization</td>
<td>14 carers of relatives diagnosed with cancer; 5 carers completed study before the patient died.</td>
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<tr>
<td>Walsh et al., 2007 UK</td>
<td>RCT</td>
<td>The intervention would increase support for distressed carers of patients with palliative care needs</td>
<td>271 carers of a relative with advanced cancer entered the project.</td>
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Mean scores in the intervention group were lower at all time points but these differences were not significant. No difference observed in secondary outcomes. Carers receiving the intervention reported qualitative benefit but study did not evidence significant reduction in psychological symptoms for carers with this intervention.
A brief cognitive-behavioural intervention that includes stimulus control, relaxation, cognitive therapy, and sleep hygiene elements.

A repeated measures experimental design (however intervention & control group allocation not described).

Ca C T o test the feasibility of The Caregiver Sleep Intervention (CASI) in improving the cancer carer's sleep quality, depressive symptoms and quality of life.

The CASI is a feasible behavioural intervention for cancer carers. Intervention caregivers showed more improvement in PSQI and CES-D scores than controls. The intervention appeared to improve sleep quality and depressive symptoms in the intervention group. Improvements in quality of life scores were similar across groups.

The project was well received by carers as the MCP workers offered information, useful contacts, financial advice, practical and emotional support. However some carers argued that the MCP workers offered 'old fashioned' social work rather than 'care management'.

Descriptors of the meaning of the music by carers led to 4 themes: 'music is a conduit', 'music gets inside us', 'live music makes a difference' and 'music is love'.

Northouse et al., 2007 USA

A family-based intervention for patients and their spouses consisting of three 90-minute home visits and two 30-minute home visits.

To examine whether a family-based intervention could improve appraisal variables, QoL, coping resources and symptom distress patients and their spouses during 3 phases of prostate cancer.

Medical Outcomes Study 12 item (MOS SF-12), the general Functional Assessment of Cancer

235 couples (112 intervention, 123 control group)

84% of couples were Caucasian. 65% of patients were newly diagnosed, 14% in the biochemical phase.

At 4 months spouses in the intervention group reported significantly better mental QoL (P < 0.05), better overall QoL (P < 0.01), less negative appraisal of caregiving (P < 0.01), less uncertainty about the illness (P < 0.01) and less hopelessness (P < 0.05).

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Table 1. Continued

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<thead>
<tr>
<th>Authors Country</th>
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<th>Ca = Palliative Cancer</th>
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<tr>
<td>Allen et al., 2008 USA 26</td>
<td>A family-based intervention consisting of 3 home visits</td>
<td>RCT</td>
<td>Pall Care C, P</td>
<td>To decrease caregiving stress and improve family communication between caregivers and their patients by targeting meaning-based coping</td>
<td>42 families entered the project. After 26% dropout: Control n = 14 dyads (patient with a life-limiting illness and caregiver) Intervention = 17 dyads</td>
<td>Higher self-efficacy at 4 and 12 months (P &lt; 0.05) and better communication with patients at all 3 assessments was also evident (P &lt; 0.01), (P &lt; 0.05), (P &lt; 0.01).</td>
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<td>Northouse et al., 2005 USA 27</td>
<td>Family-based intervention for carers and patients with recurrent breast cancer delivered</td>
<td>RCT</td>
<td>Ca C, P</td>
<td>The intervention group will report more favourable psychological outcomes Appraisal of Illness Scale, Appraisal of Caregiving Scale, Mishel Uncertainty in Illness Scale, Beck Hopelessness Scale, Brief COPE,</td>
<td>182 patient–family caregiver dyads; 134 dyads (74%) completed 3 and 6 month follow-up Intervention n = 69 dyads Control n = 65 dyads</td>
<td>The family intervention showed a significant decrease in negative appraisal of caregiving from baseline to 3 months (P = 0.004). This change was not evident at six months. No differences between the control and intervention group</td>
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<td>Christakis and Iwashyna, 2003 USA</td>
<td>A matched retrospective cohort study. Hospice use, $n = 30,383$; No hospice use, $n = 30,383$</td>
<td>Pall Care C</td>
<td>Spouses whose patients used hospice care would survive longer post bereavement</td>
<td>195,533 elderly couples</td>
<td>After adjustment for variables, an odds ratio (OR) of 0.92 (95% CI: 0.84–0.99) in favour of hospice use occurs for widowed wives. Similarly, an OR of 0.95 (95% CI: 0.84–1.06) in favour of hospice use occurs for widowed husbands. This is only significant for women and the risk of death is similar to that of other modifiable risk factors in women.</td>
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<td>Kirk and Collins, 2006 South Africa</td>
<td>A single group pre- and post-evaluation of a hospital palliative care team</td>
<td>Pall Care C, P</td>
<td>Improved QoL following the introduction of the hospital PCT FACT-G questionnaire</td>
<td>24 patients, 17 after 22.6% drop out</td>
<td>Statistically significant increase in FACT-Q percentage scores after introduction of HPCT ($P &lt; 0.001$). Physical and functional wellbeing scores were most improved; the least improvement was seen in social/family wellbeing.</td>
<td>1 III C</td>
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<td>Kusajima, 2009 Japan</td>
<td>A single group pre- and post-evaluation</td>
<td>Pall Ca C, P</td>
<td>Home palliative care would improve family physical health, anxiety and sleep. Family health status and perception of patient health status was collected by qualitative interview. Families were asked to rate anxiety regarding care at home, frequency of night-time awakenings for patient care, and physical status in addition to perceptions of patients' physical and psychological status.</td>
<td>55 family carers</td>
<td>Reduced family anxiety about care at home ($p = 0.002$), however frequency of night-time awakenings for patient care increased ($p &lt; 0.001$) and physical health deteriorated ($p = 0.01$)</td>
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<td>Grande et al., 2004 UK</td>
<td>RCT</td>
<td>Pall Care C, P</td>
<td>HAH would increase quality of care for patient and so provide positive bereavement outcome for carers</td>
<td>96 bereaved carers</td>
<td>Treatment $n = 78$ Control $n = 18$</td>
<td>There was no evidence that HAH had an impact on bereavement outcome. However perceptions of inadequate terminal support</td>
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<td>McLaughlin et al., 2007 UK</td>
<td>A single-group retrospective study using a postal questionnaire</td>
<td>To explore the bereaved caregivers’ experience of the Hospice at Home service delivered in one region of the UK.</td>
<td>128 bereaved carers returned the questionnaire – 41% response rate</td>
<td>The bereaved caregivers were thankful for the Hospice at Home service. Areas highlighted for improvement included the need for practical support, increased awareness of the service and bereavement support.</td>
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<td>O’Connor, 2009 Australia</td>
<td>Survey and focus group</td>
<td>Satisfaction with home care Focus group of bereaved and current carers, survey of carers receiving care in previous 5 years</td>
<td>Survey: 300 carers (41.7% response rate) Focus group: 7 bereaved, 3 current carers</td>
<td>High satisfaction with home care (86.8%) Lack of continuity. Carers valued patience and understanding from staff but have poor knowledge and need to share their feelings.</td>
<td>0 III C</td>
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<tr>
<td>Clayton et al., 2007 Australia</td>
<td>RCT</td>
<td>Provision of a QPL will influence patients’/caregivers’ questions and discussion topics during PC consultations Coding of taped consultations; one question from the CISQ; the SSAI; a specially designed questionnaire on information needs; satisfaction Likert scales</td>
<td>174 patients Treatment n = 92, control n = 82</td>
<td>QPL carers asked 2.11 times more questions than controls (p = 0.0005) specifically with respect to lifestyle and quality of life (p = 0.05), and end-of-life issues (p = 0.04). The total number of issues raised by caregivers was significantly increased (p = 0.08)</td>
<td>3 I A</td>
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<td>Hendrix et al., 2009 USA</td>
<td>Pre- and post follow-up study</td>
<td>Confidence/self-efficacy in home care and symptom management Caregiver Demographic Questionnaire, Cancer Caregiver</td>
<td>20 carers of cancer patients</td>
<td>Increased self-efficacy at post intervention (p = 0.001) and at 1 week follow-up (p = 0.01).</td>
<td>0 III C</td>
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### Table 1. Continued

| Authors                      | Country | Intervention                                                                 | Evaluation Design | Intended outcome + Measures                                                                                       | Sample               | Results                                                                                     | Jadad Score | Evidence Grade |
|------------------------------|---------|------------------------------------------------------------------------------|-------------------|------------------------------------------------------------------------------------------------------------------|----------------------|-----------------------------------------------------------------------------------------------|-------------|----------------|----------------|
| Dobrof et al., 2006          | USA     | A single-group, retrospective assessment of a support program                 | Pall Care C       | Caregivers will benefit from social work interventions that focus both on emotional impact and multiple resource issues. Specifically designed instrument measuring caregiver characteristics, social work interventions and the result of these interventions. | 169 caregivers       | There was a significant positive correlation between the number of contacts and the number of positive results of social work interventions reported ($p = 0.0001$). This suggests that when caregivers are engaged in services, caregivers' abilities to cope and to acquire necessary resources are enhanced. | 0 III C     |                |
| Respite n = 1                | Barrett et al., 2009 | Australia | Structured post-intervention interviews                                  | Pall Care C, P     | Respite care would improve carer outcomes. A carer evaluation form evaluated the impact and perceptions of carers of the service. | 12 carers            | Carers showed satisfaction with care and the opportunity for rest this gave. Carers perceived respite care providers to be competent. | 0 III C     |                |
| Group interventions n = 10   | McMillan et al., 2006 | USA     | A coping-skills training programme for carers - with four components (COPE) | RCT                | Intervention would improve carer quality of life, carer burden, carer burden due to tasks and carer mastery. Caregiver Quality of Life Index, The Memorial Symptom Assessment Scale, the Caregiver Demands Scale, the Brief COPE Scale and the General Caregiver Mastery Scale | 329 patient–carer dyads | At the 30-day follow-up, the coping skills intervention led to significantly greater improvement in caregiver QoL ($p = 0.03$), burden of patient symptoms ($p < 0.001$), and caregiving task burden ($p = 0.038$). None of the groups showed significant change in overall caregiving mastery, caregiver mastery specific to caregiving tasks, problem-focused or emotion-focused coping. | 5 I B       |                |

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<tr>
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<tr>
<td>Parsons and Anderson, 2009 Canada</td>
<td>Ethnographic qualitative study</td>
<td>Pall Ca C, P</td>
<td>Sharing and support Ethnography and qualitative interviews with patients to determine the meaning of Friday afternoon tea</td>
<td>8 qualitative family interviews</td>
<td>Time to interact with staff, feeling supported through the gesture of tea, sense of community and positive distraction, feel cared for</td>
<td>0 III C</td>
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<tr>
<td>Cohen and Kuten, 2006 Israel</td>
<td>Quasi-experimental observational study i.e. participants selected group</td>
<td>Ca C</td>
<td>The CB intervention would reduce psychological distress + increase psychological adjustment for carers Brief Symptom Inventory + PAIS, the Mini-Sleep Questionnaire + the Multidimensional Scale of Perceived Social Support</td>
<td>104 carers (before drop out 143) Control n = 52 Intervention n = 52 (drop out 27%)</td>
<td>Carers in the intervention group scored significantly lower than the control group on the BSI and PAIS instruments, and reported fewer sleep difficulties and higher perceived support in the follow-up measures. 30.8% of intervention carers but only 3.9% of the control carers had statistically significant improvements in their psychological distress. The intervention lasted for 4 months after intervention ended</td>
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<td>Witkowski and Carlson, 2004 Sweden</td>
<td>A small-scale single-group prospective study – with a phenomenographic method</td>
<td>Pall Ca C, P</td>
<td>Carer support provided – information, education and opportunity to share experiences with other carers Pilot study with 20 ranked most important topics for group program. Questionnaire for carers and intervention staff to complete</td>
<td>39 carers (48 before dropout) All subjects answered five open-ended questions, and 12 completed semi-structured interviews</td>
<td>The intervention highlighted the value of the group programme for carers with qualitative evidence.</td>
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<tr>
<td>Harding et al., 2004 UK</td>
<td>A prospective, quasi-experimental observational outcome study – involving qualitative and quantitative methods</td>
<td>Pall Ca C</td>
<td>To reduce anxiety, and increase psychological support and information-giving and enhance short-term coping Palliative Outcome Scale, Eastern Cooperative Oncology Group Performance Scale, Zarit Burden Inventory, Coping Responses Inventory, General Health Questionnaire-12, State Anxiety Scale Shortened Version</td>
<td>73 carers of a relative with palliative care needs Control n = 37 Intervention = 36 At baseline, post-intervention, and follow-up, the intervention condition consisted of 36, 24, and 15 carers,</td>
<td>There was a contradiction between qualitative and quantitative data may be result of pre-post measure evaluation methods. Attrition disallowed global measures from showing potential significant benefits, the qualitative data demonstrates that the primary aims were met</td>
<td>I II A</td>
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(continued)
### Table 1. Continued

<table>
<thead>
<tr>
<th>Authors</th>
<th>Country</th>
<th>Intervention</th>
<th>Evaluation Design</th>
<th>Intended outcome + Measures</th>
<th>Sample</th>
<th>Results</th>
<th>Jadad Score Evidence Grade</th>
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</thead>
<tbody>
<tr>
<td>Kwak et al., 2007 USA</td>
<td>Pre-post intervention single group</td>
<td>Pall Care C</td>
<td>Evaluating when the program can improve comfort with caregiving, sense of relationship closure, and improve caregiver gain. Comfort with Care giving Scale, Caregiver Closure Scale and the Caregiver Satisfaction Scale</td>
<td>2025 Carers of a relative during last years of life. Intervention n = 926 completed pre- and post-training questionnaires</td>
<td>The length of training significantly increased the level of caregiver comfort and closure experiences. Those who received an average of 9.28 hours of training compared to those who had an average of 5.26 hours had higher levels of comfort and closure.</td>
<td>I II B</td>
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<tr>
<td>Arnaert, 2010 Canada</td>
<td>Qualitative interviews post-intervention</td>
<td>Ca C</td>
<td>Educate relatives of cancer patients how to communicate with the medical system, inform them about nutrition and other complementary therapies, provide suggestions on how to manage stress through relaxation and yoga, inform them about support group therapy and lectures on alternative healing. Qualitative interviews.</td>
<td>8 carers</td>
<td>Benefits for carers included emotional openness, shared experiences, mutual support and a sense of community</td>
<td>0 III C</td>
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<td>Hudson et al., 2008 Australia</td>
<td>Single-group repeated measures pre- and post-study</td>
<td>Pall Ca C</td>
<td>To develop, deliver and evaluate a group education programme aimed to prepare cancer carers for their role in supporting a relative/friend receiving home-based palliative care Demographic questionnaire, caregiver competence scale, preparedness for caregiving scale, family inventory of need, rewards for caregiving scale, social support questionnaire, brief assessment scale for caregivers, life orientation test, session evaluation, programme evaluation, semi-structured interviews</td>
<td>74 people (56 females, 18 males) completed Time 1 questionnaires 44 people completed all three time periods. 25% male, 75% female</td>
<td>Qualitative results: favourable feedback with the majority of carers reporting that the programme had a positive impact on their lives. The intervention had a positive effect on the carers’ preparedness ($P &lt; 0.001$), competence ($P &lt; 0.01$), rewards ($P &lt; 0.05$) and having met needs from T1 to T2, which was maintained at T3</td>
<td>I III B</td>
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<tr>
<td>Authors Country</td>
<td>Intervention</td>
<td>Evaluation Design</td>
<td>Carers = C</td>
<td>Patients = P</td>
<td>Intended outcome + Measures</td>
<td>Sample</td>
<td>Results</td>
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<tr>
<td>Hudson et al., 2009 Australia</td>
<td>Do family meetings reduce care needs of family carers?</td>
<td>Single group repeated measures pre- and post-study</td>
<td>Ca</td>
<td>C</td>
<td>To explore the utility and benefits of using recently developed multidisciplinary clinical guidelines in 19 family meetings. Family Inventory of needs (FIN), pre-meeting questionnaires to assess the carer’s concerns; rate their confidence. Short evaluation form after the meeting.</td>
<td>20 informal family carers of people with advanced cancer (76% women, 80% living with the patient, 59% spouse). 2 patients with advanced cancer and 18 health professionals attended the meetings.</td>
<td>Following the family meeting, between T1 and T2, carers were less worried (P = 0.001), the concerns arose less often (P = 0.004) and the problem interfered less with their lives (P = 0.002). The meeting had a positive effect on having their needs met from T1 to T3 (P &lt; 0.001).</td>
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<tr>
<td>Clark et al., 2006 USA</td>
<td>An 8-session structured multi-disciplinary intervention for cancer patients designed to improve carer’s burden and QoL</td>
<td>RCT</td>
<td>Ca</td>
<td>P</td>
<td>Evaluate how a patient-focused QoL intervention for cancer patients impacts the carer’s QoL and burden. Linear Analog-self-assessment (LASA), Burden Interview.</td>
<td>Patients (n = 103): 66 male, 37 female, 17% had primary head and neck cancer, 15% lung cancer, 12% primary brain tumours. Carers (n = 83): 75% female, 86% spouse.</td>
<td>Although the intervention improved the cancer patients’ overall QoL, no overall between group differences in the carers’ burden and QoL emerged.</td>
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<td>Physical intervention n = 1</td>
<td>McDonald et al., 2006 UK</td>
<td>A single-group post-treatment pilot evaluation</td>
<td>Pall Care C, P</td>
<td></td>
<td>Whether yoga sessions in the form of exercise, visualization and relaxation would be beneficial. Specially designed, simple survey of patient views using Likert scales and yes/no responses. Qualitative feedback. Carers not formally included in the study.</td>
<td>5 patients. The number of carers was not specified.</td>
<td>More than 90% of patients reported improved wellbeing and around 70% wanted more sessions. Following the success of the pilot scheme the classes were extended to the monthly support meeting for carers of day care patients. Carers participating reported they experienced a marked reduction in their stress levels; making them feel relaxed and giving them a general feeling of wellbeing.</td>
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(quasi)experimental evaluation data is the group intervention. This is the most commonly evaluated model of intervention, and has the largest number of (quasi)experimental designs with 4 out of 10 studies. Of these four, two reported some statistically significant quantitative benefit for the intervention group over the control. The next largest numbers of studies were one-to-one psychological interventions (with three out of eight studies using (quasi) experimental methods, and two of these finding a positive effect for the intervention) and psychological interventions for patient/carer dyads (with three out of four using (quasi)experimental methods, and all three finding some positive effect).

In terms of outcomes, it is encouraging that the studies focus on a wide range of endpoints. This is to be encouraged, as specificity of aims, intervention mechanisms and outcomes may be preferable over a ‘scattergun’ approach that aims to improve too many outcomes within a fixed period of intervention. Further, it is essential that some consensus is achieved in the selection of outcome measures to allow future meta-analysis.

The timing of interventions and outcome measurement also requires consideration – as palliative care is often introduced late in the disease trajectory consideration should be given to delivery outside of specialist palliative care services. In terms of measuring outcomes, it may be that follow-up post-intervention measurement may miss the benefits that carers experience whilst in receipt of targeted care, and therefore it may be advantageous and appropriate that measurement focuses on the ‘before–during’ period rather than the ‘before–after’.

In terms of the populations in which studies were conducted, it is notable that almost none were from low- and middle-income countries where the burden of terminal illness is highest. Further, the needs of children and families in paediatric palliative care merit specific study. With respect to analysis, the studies commonly reported the persisting challenge of attrition on palliative care populations. In order to fully utilize the data points available, longitudinal data analysis methods, such as multi-level models, should be advocated.

In conclusion, there has been an impressive increase in the number of targeted interventions for informal caregivers in cancer and palliative care. However, this activity needs to continue to focus on mechanisms of intervention, tightly focused aims and outcomes, robust designs and a plurality of models and target populations/settings.

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**Conflict of interest statement**

None declared.

**References**