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Abstract

The demand for family caregivers steadily increases as the number of people receiving hospice and palliative care rises. Family caregivers play a significant role in supporting their loved ones in end-of-life care. However, there is limited evidence about the effectiveness of the interventions for supporting family caregivers. This article synthesizes behavioral and educational interventions that support family caregivers in end-of-life care. A systematic review was conducted and searched interventional studies published between 2004 and 2014 in PubMed, CINAHL, Embase, and The Cochrane Library electronic databases. Fourteen studies were identified and analyzed: 4 educational studies, 6 cognitive behavioral therapy studies, and 4 psychoeducational studies. All educational and behavioral interventions had developed structures and treatment manuals and improved family caregivers' outcomes. The cognitive behavioral therapy resulted in more positive outcomes than the other 2 interventions. More rigorous randomized controlled trials are needed to replicate current effective interventions with larger and diverse sample. Future studies need to develop tools for assessing family caregivers' needs, create consistent and specific tools to effectively measure family caregivers' outcomes, incorporate a cost-effectiveness analysis, and find the most efficient intervention format and method.

Keywords

hospice care, palliative care, end-of-life care, family caregiver, cognitive behavioral therapy, cognitive psychotherapy, behavior therapy, education

Introduction

The goal of hospice or palliative care is to provide medical care, symptom management, emotional and spiritual support, and improve the quality of life (QOL) for terminally ill patients and their families.¹ According to the National Hospice and Palliative Care Organization, approximately 44.6% of all deaths in the United States were under the care of a hospice program in 2011.² In 2013, an estimated number of 1.5 to 1.6 million Americans received hospice services and 66.6% of them received hospice service at their place of residence (41.7% home, 17.9% nursing home, and 7.0% residential facility).³ Family caregivers play an important role in taking care of and supporting their loved ones in hospice care.

Family caregivers, or often called informal caregivers, are unpaid caregivers such as family members, partners, and relatives who take care of their loved ones. The demand for family caregivers steadily increases as the number of people with chronic disease or terminal illness rises. According to national statistics, approximately 43.5 million American adults served as family caregivers in 2014.⁴ However, caregiving may also

bring negative impact on caregivers' health due to physical demands, emotional distress, and expected loss of their loved one. Many studies have demonstrated that caregiving to patients with terminal illness resulted in more physical burden, higher levels of depression and anxiety, and increased mortality on caregivers.⁵⁻⁸

In 2003, Harding and Higginson conducted one of the earliest systematic reviews and comprised of 22 studies published between 1966 and 2001 for cancer and palliative caregivers.⁹ Harding and Higginson summarized the interventions that supported family caregivers in cancer and palliative care including home care, respite care, social networks and activities, one-to-one interventions (education and problem-

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solving training), and group work.⁹ The lack of outcome evaluation, the use of untested measures, and a small sample size design made it difficult to conclude the effectiveness of these interventions for caregivers.⁹ In 2010, Hudson et al reviewed the literature of psychosocial interventions published between 2000 and 2009 for family caregivers of palliative care patients.¹⁰ Fourteen studies were identified, and the interventions included psychosocial support, psychoeducation, coping training in patient care and symptom management, sleep promotion, and family meetings.¹⁰ Hudson et al concluded that the types of intervention and the rigor of the study designs have slightly increased over the last decade.¹⁰ Candy et al conducted a meta-analysis and synthesized 11 randomized controlled trials (RCTs) that had interventions to support informal caregivers of patients in the terminal phase of a disease from 1872 to 2010.¹¹ Only 7 of the studies had interventions that provided direct supports to the caregiving role such as emotional support and coping skills training.¹¹ Although there is an increasing number of studies focused on enhancing caregivers' knowledge and coping skills, the effectiveness of these interventions on family caregivers for end-of-life patients is still difficult to assess because of the paucity in clinical trials and lack of evidence. Hence, this article aims to synthesize current behavioral and educational interventions that support family caregivers of patients receiving end-of-life care.

Methods

Search Strategies

Phase I clinical trials are used to test the feasibility and acceptability of interventions.¹² Phase II pilot studies are designed to test the impact of interventions under ideal circumstances and the appropriateness of the interventions.¹² In phase III, researchers conduct randomized clinical trial based on phase II pilot study.¹² Phase III studies test the efficacy of the interventions with a large group.¹² The objective of this review is to synthesize current research evidence on behavioral and educational interventions to support family caregivers of patients receiving end-of-life care. Both phase II and phase III interventional studies relevant to this topic were included in this review.

Our review included studies that specifically designed educational and behavioral interventions for family caregivers of patients with terminal illness or who received end-of-life care (including palliative care and hospice care). The literature published in the past 10 years, between 2004 and 2014, was searched in electronic databases including PubMed, CINAHL, Embase, and The Cochrane Library. A combination of the following search terms was employed to identify studies: end of life, palliative, hospice, family, family caregiver, cognitive behavioral therapy, cognitive therapy, cognitive psychotherapy, behavior therapy, and education. An experienced librarian assisted with selecting most relevant search terms and electronic databases.

Inclusion and Exclusion Criteria

Studies were included if they were phase II or phase III clinical trials and published in English with behavioral or educational interventions for supporting family caregivers in end-of-life care. After search, all studies were screened by reading abstracts and full texts and excluded if they were not peer-reviewed articles (magazine, dissertation, conference abstract, note, editorial, or books), not relevant to behavioral or educational interventions, not phase II or phase III interventional studies (theory or framework development paper, policy document, study protocol, review, feasibility study, evaluation study, description study, case report, expert opinion, and letter), not caregiver focused, and not family caregivers of adult patients with terminal-illness or at the end-of-life stage.

An initial search generated 2649 articles, and 648 articles were published in English and focused on humans in the last 10 years. After eliminating 30 duplicated articles, 618 articles were screened by reading their abstracts or full text and applied the criteria. Six hundred and six articles were further excluded as they were not peer-reviewed articles ($n = 113$), not relevant to behavioral or educational interventions ($n = 114$), not phase II or phase III interventional studies ($n = 263$), not caregiver focused ($n = 86$), not caregivers of adults ($n = 17$), and not family caregivers of patients with advanced/terminal illness or at the end-of-life stage ($n = 13$). In addition to the search of these databases, 2 articles met the criteria were identified when consulting the articles' reference lists. Finally, 14 articles were included in this review.

Data Extraction and Management

Data were extracted from each article to synthesize the results including authors, published year and country, journal, study aim, study design and setting, sample size and other characteristics, intervention, conceptual framework, measures, outcomes, and limitations. Each article was scored for the level of evidence using the Oxford Centre for Evidence-based Medicine framework to evaluate the strength of the findings.¹³ This framework consists of 10 levels, and lower scores indicate higher strength of evidence (1a: meta-analysis; 1b: individual RCT; 1c: non-RCT; 2a: systematic reviews of cohort studies; 2b: individual cohort study; 2c: outcomes research; 3a: systematic review of case-control studies; 3b: individual case-control study; 4: case series; and 5: expert opinion without explicit critical appraisal).¹³

Results

Published Journal, Study Countries, and Settings

Fourteen articles were published in 7 journals by 11 different first authors. The types of journals are end-of-life care (*Journal of Palliative Medicine*,¹⁴⁻¹⁷ *Journal of Palliative Care*,¹⁸ *International Journal of Palliative Nursing*,¹⁹ and *Journal of Social Work in End-of-Life & Palliative Care*²⁰), symptom

management (*Journal of Pain and Symptom*²¹⁻²⁴), and cancer care (*Psycho-Oncology*^{25,26} and *Cancer*²⁷).

The included studies were conducted primarily in the western countries: the United States,^{14,15,17,20,22,27} Australia,^{16,19,23,24,26} United Kingdom,²¹ Canada,¹⁸ and Germany.²⁵ Although some studies included participants from more than 1 type of settings, the majority were participants at home (patients received home-based hospice or palliative services),^{15,17,18,21-24,26} followed by hospital (including outpatient and inpatient),^{14,16,19,25} and nursing home or community.^{15,19,20,27}

Study Design

All studies included were interventional studies modeling phase II or phase III trials to test the efficacy or effectiveness of the interventions. Seven studies were RCTs,^{14,15,22,23,25-27} 3 were comparative trials,^{18,20,21} and 4 were quasiexperimental trials.^{16,17,19,24} According to the Oxford Centre for Evidence-based Medicine framework,¹³ the studies were graded as level 1b: RCT and 1c: non-RCT, which indicates high level of evidence strength.

Sample Size and Characteristics

Eight articles included family caregivers of patients with advanced cancer,^{14,16,18,22-24,26,27} 5 articles included family caregivers of patients receiving palliative or hospice care,^{15,17,19,11,25} in which 2 of them had more than 80% of caregivers of patients with advanced cancer.^{21,25} One article included the family caregivers of patients with advanced dementia.²⁰ Regarding the sample size, 3 studies had sample sizes ranging from 10 to 50 participants,¹⁶⁻¹⁸ 2 had sample sizes ranging from 50 to 100 participants,^{21,22} 5 included more than 100 participants,^{15,20,23-25} 2 included more than 200 participants,^{19,26} 1 included more than 300 participants,²⁷ and 1 included more than 400 participants.¹⁴ Only 5 studies provided either effect size calculation or sample size estimation based on prior research.^{14,18,23,25,26}

In all, 3 articles included both patients and their family caregivers,^{14,22,27} while 11 articles included only family caregivers and focused on the effects of interventions on family caregivers. The mean age of family caregivers ranged from 55 to 61, approximately 70% of the caregivers were female in 10 articles, about 60% to 80% of the caregivers were caucasian in 7 articles, and 60% to 70% of the caregivers were spouses/partners in 6 articles.

Types of Interventions, Conceptual Framework, and Outcomes

The types of interventions in this review were education, cognitive behavioral therapy, and psychoeducation.

- (1) *Education (4 studies)*. Educational interventions aim to provide family caregivers education to enhance caregivers' care knowledge and skills. Harding et al

designed 6 weekly sessions (90 minutes each week) of multiprofessional teaching (welfare benefits advice, occupational and physical therapy, clinical nurse specialist, and aromatherapy) in a group format for palliative caregivers.²¹ The family caregivers received help from professionals as well as support from their peers. Due to a high attrition rate and the short-term duration of the intervention, it was difficult to evaluate the effectiveness of intervention on the family caregivers' psychological health.²¹ However, the family caregivers reported increased support and knowledge in their qualitative interviews.²¹ White et al developed 6 sessions of educational modules delivered over the course of 3 weeks including pain, physical side of caring, communication, medicine, nutrition and exercise, and symptom control for family caregivers of patients with a life-threatening illness.¹⁹ The family caregivers showed increased knowledge and confidence at the fourth week of follow-up.¹⁹ Reinhardt et al provided caregivers of patients with advanced dementia 1-time educational conversation about end-of-life care with a palliative care team (an average of 47 minutes) and 3 psychosocial support telephone calls.²⁰ The topics included resuscitation, hospitalization, artificial nutrition and hydration, and pain and symptom management. The family caregivers had higher satisfaction with care at the sixth month of follow-up.²⁰ These 3 articles did not address any specific concept framework guiding their interventions.

Lindstrom and Melnyk developed an education and skill-building intervention following a conceptual framework that combined self-regulation theory and role theory.¹⁷ The intervention provided hospice caregivers with information and caregiving skills for their new caregiving role. The program consisted of 2 educational compact disc sessions, 48 minutes in total.¹⁷ The caregivers reported increased preparedness, more helpful beliefs, and more confidence about their ability after intervention.¹⁷

In these studies, the researchers primarily measured the outcomes of the family caregiver's health, knowledge, coping skills, self-efficacy, and satisfaction. The dose of interventions ranged from 47 minutes (single meeting) to 9 hours (6 weekly sessions). The results showed that educational interventions can positively affect caregivers' knowledge,^{19,21} self-efficacy and preparedness,^{17,19} and satisfaction with care²⁰ but not their general health, psychological health, and coping skills^{17,20,21} (see details in Table 1).

- (2) *Cognitive behavioral therapy (6 studies)*. The goal of cognitive behavioral therapy is to change people's behaviors by altering their thoughts and beliefs.^{28,29} In these studies, the family caregivers were guided to examine their relationship between thoughts and behaviors following the cognitive behavioral approach. The caregivers also received problem-solving/coping

Table 1. Characteristics of Included Studies: Educational Interventions for Family Caregivers.

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/treatment dosage	Measures for CG/data collection	CG outcomes/study limitations
Harding et al ²¹ / 2004/United Kingdom/ <i>Journal of Pain and Symptom Management</i>	<ul style="list-style-type: none"> Patients received home-based palliative care (86% cancer) N = 73 CGs (intervention: comparison = 37:36) CG: mean age 59, 69% female, 80% caucasian, 8% African American, 7% Asian, 63% spouse, and 11% adult children 	<ul style="list-style-type: none"> To evaluate a short-term group intervention for CGs of patients attending a home palliative care service 	<ul style="list-style-type: none"> Comparative study Intervention: the intervention combined multiprofessional teaching with facilitated peer exchange and support that aimed to promote self-care Dosage: 6 weekly sessions, 90 minutes per week Comparison: patients and CGs received standard home-based palliative care in these 2 participating services including 24-hour home access to specialist nursing, advice, and support 	<ul style="list-style-type: none"> Assessments: at baseline, 8 weeks (56% complete), and 20 weeks (36% complete) Psychological health (burden, anxiety, and general health): the Zarit Burden Inventory (ZBI), the General Health Questionnaire-12 (GHQ-12), the State Anxiety Scale (SAI) Shortened Version Coping skills: the Coping Responses Inventory (CRI) Postintervention qualitative interviews (satisfaction and acceptance) were analyzed using a content analysis 	<ul style="list-style-type: none"> ↑Support and knowledge (qualitative data) No significant effects on CGs' psychological health (anxiety and burden) Limitations: Small sample size Short-term intervention High attrition rate Selection bias: English language requirement
White et al ¹⁹ / 2008/ Australia/ <i>International Journal of Palliative Nursing</i>	<ul style="list-style-type: none"> Life-threatening illness Inpatient and community settings N = 205 CGs CG: mean age 56, 86% female 	<ul style="list-style-type: none"> To evaluate the effectiveness of a structured educational program on enhancing the knowledge and support of CG living with a life-threatening illness 	<ul style="list-style-type: none"> Evaluation study, quasiexperimental design Intervention: all CGs received educational modules. The topics included pain, the physical side of caring, communication, knowing medicine, nutrition and exercise, and symptom control Dosage: 6 modules were delivered over 3 weekly sessions 	<ul style="list-style-type: none"> Assessments: pre- and postintervention and at the fourth week of follow-up Measured outcomes: knowledge, confidence, and general feedback were measured by using questionnaires and qualitative interviews. All the tools were tested in a pilot phase 	<ul style="list-style-type: none"> ↑Knowledge and confidence after intervention at the fourth week of follow-up Limitations: Short posteducation follow-up One-group design Attendance rate Eligibility criteria did not specify where in the illness trajectory of the patient the CGs sought help Lack of details about intervention delivery and data collection (session duration, interventionist, and data collector)

(continued)

Table 1. (continued)

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/treatment dosage	Measures for CG/data collection	CG outcomes/study limitations
Lindstrom and Melnyk ^{17/} 2013/United States/Journal of Palliative Medicine	<ul style="list-style-type: none"> Patients received hospice care Home-based hospice care N = 18 CGs CG: mean age 59, 72% female, 56% spouse, 22% adult children, 78% caucasian, and 11% African American 	<ul style="list-style-type: none"> To test the feasibility and preliminary effects of the education and skill building intervention for hospice CGs 	<ul style="list-style-type: none"> Feasibility study, quasiexperiment Intervention: an education and skill-building program. The program consisted of 2 sessions on a professionally recorded CD to address the end-of-life topics and patient care issues Dosage: 2 sessions, 48 minutes in total 	<ul style="list-style-type: none"> Assessments: pre- and postintervention (66% complete) Psychological health (depression and anxiety): the Center for Epidemiological Studies Depression (CES-D) and the State-Trait Anxiety Inventory The Caregiver Activity Restriction Scale Preparedness: the Family Preparedness Scale Beliefs/confidence. The adapted Family Beliefs Scale for Caregivers of Hospice patients-Qualitative evaluation: participants' open-ended comments on program feasibility were analyzed through content analysis 	<ul style="list-style-type: none"> ↑Preparedness ↑Helpful beliefs, and confidence Decreased anxiety levels but not significant. No changes in depressive symptoms Limitations: Small sample size One-group design Selection bias: English language requirement
Reinhardt et al ^{20/} 2014/ United States/Journal of Social Work in End- of-Life & Palliative Care	<ul style="list-style-type: none"> Advanced dementia Nursing home N = 110 family members (intervention: comparison = 47:40) CG: mean age 59, 80% female, 60% >college, 40% African American, 30% caucasian, and 20% Hispanic 	<ul style="list-style-type: none"> To assess the effect of information and support provided to family members 	<ul style="list-style-type: none"> Randomized comparative study Intervention group: a palliative care team conducted structured educational conversations with family members to discuss about resuscitation, hospitalization, artificial nutrition and hydration, and pain and symptom management. Psychosocial support was also provided via telephone at three 2-month intervals. Dosage: the range of the meetings is 20-75 minutes, and the average is 47 minutes. Each of these 3 telephone calls lasted an average of 10 minutes. Comparison group: the residents received their usual care and their family members received social contact via telephone. These calls averaged 11 minutes at baseline and 9 minutes for each of 3 follow-up calls 	<ul style="list-style-type: none"> Assessments: at baseline, the third- and sixth month of follow-up via telephone The perception of resident's symptom control: the Symptom Management at the End-of-Life in Dementia Scale Satisfaction with care: a 4-point scale ranging from strongly agree to strongly disagree CG's well-being: the Patient Health Questionnaire (PHQ-9) used to assess CG's depressive symptoms CG's life satisfaction: the Satisfaction with Life Scale 	<ul style="list-style-type: none"> ↑Satisfaction with care in both groups at the third month but only the intervention group maintained the level at the sixth month No significant changes in the perception of resident's symptom control, CGs' life satisfaction and CG's well-being for both groups Limitations: Generalizability

Abbreviations: CG, caregiver; EOL, end of life; QOL, quality of life; RCT, randomized controlled trial; I, intervention group; C, control group.

trainings from professionals to resolve their current caregiving and life challenges. There is a therapeutic relationship between trainers and caregivers.

Both McMillan et al and Meyers et al conducted 3 sessions of coping trainings for the family caregivers of patients with advanced cancer.^{14,27} The trainings adopted the family Creativity, Optimism, Planning, and Expert information (COPE) model and used a standardized guide book "The Home Care Guide for Cancer."^{30,31} McMillan et al reported improved QOL and psychological health (burden of cancer symptoms) for the family caregivers at the second week of follow-up but not coping skills.²⁷ Meyers et al found no decline in the family caregivers' QOL and no significant improvements in the scores of their coping skills at the sixth month of follow-up.¹⁴ One of the potential limitations of these 2 studies was that patients' death and disease progression at the end-of-life stage caused high attrition.^{14,27}

Keefe et al included patients and their partners to receive 3 sessions (45-60 minutes each) of nurse-led pain management trainings.²² The caregivers showed increased self-efficacy in pain management after intervention.²² Fegg et al designed 6 sessions (22 hours in total) of group existential behavioral therapy to teach the palliative caregivers mindfulness, self-care, and stress management.²⁵ At the 12th month of follow-up, the caregivers reported significant long-term improvements in psychological health and QOL.²⁵

Demiris et al conducted a randomized, comparative, and noninferiority trial. The hospice caregivers received 3 sessions (45 minutes each) of problem-solving therapy training delivered either via face-to-face meeting or videophone.¹⁵ The family caregivers in both groups showed increased psychological health, QOL, and problem-solving skills after the intervention.¹⁵ The delivery of problem-solving training via videophone was not inferior to face-to-face meeting.¹⁵

Duggleby et al conducted a pilot, quasiexperimental study to test a psychosocial supportive hope-focused intervention.¹⁸ Hope theory guided the intervention to encourage the family caregivers to live in the moment, being positive, and write their own story to enhance their QOL.¹⁸ The program consisted of a hope video and a hope activity over 2 weeks and the caregivers had increased scores in their QOL.¹⁸

The cognitive behavioral therapy interventions mainly assessed the improvements in family caregivers' psychological health, coping skills, and QOL. The interventions usually consisted of 3 to 6 sessions and delivered over 1 week to 1 month. These interventions significantly improved the family caregivers' psychological health (anxiety, burden, strain, and mood), coping skill, self-efficacy, and QOL (see details in Table 2).

- (3) *Psychoeducation (4 studies)*. An educational intervention focuses on providing knowledge but not necessarily facilitating behavioral change; while a psychoeducational intervention provides not only education but also counseling and supportive interventions. Hudson conducted a series of psychoeducational studies for the

family caregivers of patients with advanced cancer at home-based or hospital-based palliative care.^{16,23,24,26}

In these studies, Hudson not only taught caregivers caregiving roles and skills, self-care strategies, positive thinking, available resources, and services but also assisted them with identifying issues and planning goals. Hudson adopted Lazarus and Folkman transactional model of stress and coping.^{32,33}

One-to-one intervention. In 2005, Hudson et al conducted a nurse-delivered psychoeducational program for the family caregivers of patient with advanced cancer receiving home-based palliative care.²³ The program also consisted of 2 home visits supplemented by a follow-up phone call.²³ The program had positive effects on the family caregivers' competence, anxiety, and rewards.²³ In 2013, Hudson et al designed a 3-arm RCT to compare the effect of psychoeducational intervention plus 1 home visit versus 2 home visits for the family caregivers of home-based palliative care patients.²⁶ The family caregivers in 2-visit group showed significant improvements in levels of preparedness and competence.²⁶ However, there were no significant improvements in psychological health and unmet needs.²⁶ The authors commented that higher refusal and attrition rates and a short-term follow-up may have affected the outcomes.²⁶

Group session. In 2009, Hudson et al developed 3 weekly group psychoeducational sessions (1.5 hours each time) for family caregivers of patients with cancer receiving home-based palliative care.²⁴ The intervention showed significant positive effects on family caregivers' preparedness, competence, rewards, and less unmet informational needs.²⁴ In 2012, Hudson et al conducted a pilot, quasiexperimental study to test the effectiveness of a group, single-session (1.5 hours) psychoeducational program on family caregivers of hospitalized palliative care patients.¹⁶ The program improved the family caregivers' level of preparedness but not competence, unmet needs, or psychological distress.¹⁶ The limitations included a small sample size ($n = 15$), selection bias, and therapeutic dosage.¹⁶

The psychoeducational interventions assessed the impacts of interventions on the family caregivers' health, anxiety, self-efficacy, competence, and needs. The outcomes stated that one-to-one intervention or group session had significant increased general health, competence, preparedness, rewards, social support as well as lower unmet needs, and anxiety for family caregivers of patients receiving home-based or hospital-based palliative care (see details in Table 3).

Discussion

Study Countries, Study Settings, Sample, and Characteristics

Family caregivers in end of life are invisible in research and lack of sufficient interventions to support them. As the paucity in body of literature, this review synthesized the effectiveness

Table 2. Characteristics of Included Studies: Cognitive Behavioral Therapy for Family Caregivers.

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/treatment dosage	Measures for CG/data collection	CG outcomes/study limitations
Keefe et al ²² /2005/ United States/ <i>Journal of Pain and Symptom Management</i>	<ul style="list-style-type: none"> Advanced cancer (met hospice eligibility) Outpatient or home-based hospice care N = 78 patient-partner dyads (I:C = 41:37) Partner: mean age 58, 62% female, 79% caucasian, and 19.7% African American 	<ul style="list-style-type: none"> To test the efficacy of a partner-guided cancer pain management protocol for patients who are at the EOL 	<ul style="list-style-type: none"> Feasibility study, RCT Intervention: a nurse-led pain management training. Patients and their partners received 3 sessions for training in pain management and coping strategies Dosage: the 3 sessions were structured to last for 45-60 minutes and delivered over 1-2 weeks Control: patients received routine care provided through their medical outpatient or hospice program 	<ul style="list-style-type: none"> Assessments: pre- and postmeasurements (about 1 week after completing intervention) Self-Efficacy in Pain Management: the Chronic Pain Self-Efficacy Scale Psychological health (caregiver strain, partners' mood): the Caregiver Strain Index and the Profile of Mood States-B 	<ul style="list-style-type: none"> ↑ Self-efficacy ↑ Psychological health (strain; an increased trend but not statistical significance) Limitation: Small sample size
Duggleby et al ¹⁸ / 2006/Canada/ <i>Journal of Palliative Care</i>	<ul style="list-style-type: none"> Advanced cancer Home-based palliative care (rural area) N = 10 CGs CG: mean age 60, 60% female, 70% spouse, 30% adult children, and 100% caucasian 	<ul style="list-style-type: none"> To evaluate the Living with Hope Program for feasibility, acceptability, and effectiveness on increasing hope and quality of life for CG 	<ul style="list-style-type: none"> Pilot, quasiexperiment Intervention: a psychosocial supportive hope-focused intervention consisted of a hope video and a hope activity to teach CG living in the moment, having a positive approach, and writing their own story Dosage: after watching the hope video, the CGs write their thoughts and challenges and what gave them hope over the next 2 weeks 	<ul style="list-style-type: none"> Assessments: at baseline, 1-week postintervention, and 2-week postintervention (80% complete) QOL: the Quality of Life in Life Threatening Illness-Family Caregiver (QOLLTI-F) with established reliability and validity Hope: the Herth Hope Index (HHI) Qualitative open-ended evaluation questions 	<ul style="list-style-type: none"> ↑ QOL ↑ Hope ↑ Easy to use Limitations: Small sample size One-group design Missing data (due to high attrition rate) Selection bias: homogeneous sample, English language requirement

(continued)

Table 2. (continued)

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/treatment dosage	Measures for CG/data collection	CG outcomes/study limitations
McMillan et al ²⁷ / 2006/United States/Cancer	<ul style="list-style-type: none"> Advanced cancer Community-based hospice N = 329 patient CG dyads (3 armed: 111:109:109) CG: mean age 60, >80% female 	<ul style="list-style-type: none"> To assessed the impact of a coping skills training on hospice CGs' QOL, burden, mastery, and coping 	<ul style="list-style-type: none"> Three-armed RCT Intervention group 1: a nurse-led coping skills intervention. Patients and CGs receive standard care plus 3 visits to learn coping skills followed by a family COPE model (creativity, optimism, planning, and expert information; n = 111) Intervention group 2: standard hospice care pulse 3 supportive visits. The research nurses discussed with CGs about their feelings and fears to provide emotional supports (n = 109) Control: only standard hospice care (n = 109) Dosage: 3 sessions 	<ul style="list-style-type: none"> Assessments: at baseline, 1 week after intervention (50% complete), and 2 weeks after intervention (31% complete) QOL: the Caregiver Quality of Life Index-Cancer (CQOL-C) Psychological health (Burden of cancer symptoms): assessed with the Memorial Symptom Assessment Scale (MSAS) General CG mastery: assessed by a 6-item scale including caregivers' reports of their feelings of control and confidence in caregiving. Burden and mastery specific to caregiving tasks: CGs completed the Caregiver Demands Scale (CDS) 	<ul style="list-style-type: none"> At the second week of follow-up, the coping skill group showed: <ul style="list-style-type: none"> ↑QOL ↑Psychological health (burden of cancer symptoms) None of the groups showed significant changes in overall CG mastery Limitations: <ul style="list-style-type: none"> High attrition rate Selection bias: English language requirement, limited enrollment of ethnic minorities
Meyers et al ¹⁴ /2011/ United States/ <i>Journal of Palliative Medicine</i>	<ul style="list-style-type: none"> Advanced cancer Hospital (multi-institution) N = 476 patient CG dyads (1:C = 348:128) CG: mean age 61, 31% female, 70% spouse, 85% caucasian, and 66% at least college education 	<ul style="list-style-type: none"> To examine the effects of a problem-solving intervention on QOL for patients with advanced cancer and their CGs 	<ul style="list-style-type: none"> RCT (multi-institution; a 3:1 weighted randomization scheme; intention-to-treat) Intervention: 3-session intervention over one month. A health educator facilitated problem-solving training using a family COPE model (creativity, optimism, planning, and expert information) and a standardized guide (The Home Care Guide for Cancer) Control: usual care (did not mention the content) Dosage: 3 sessions over 1 month 	<ul style="list-style-type: none"> Assessments: at baseline, 30, 60, 90, 120, and 180 days (28% complete) QOL: the City of Hope Quality of Life Instrument. Problem-solving skills: the Social Problem Solving Inventory-Revised 	<ul style="list-style-type: none"> Showed no decline in QOL at 6-month follow-up (a moderately statistically significant impact) No significant improvements in coping skills for both groups Limitations: <ul style="list-style-type: none"> Turnover in trainers High attrition rate Selection bias: limited enrollment of ethnic minorities, English language requirement

(continued)

Table 2. (continued)

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/treatment dosage	Measures for CG/data collection	CG outcomes/study limitations
Demiris et al ¹⁵ / 2012/United States/Journal of Palliative Medicine	<ul style="list-style-type: none"> • Patients received hospice care • At home or nursing home (multisite, rural + urban) • N = 126 hospice CGs (face-to-face:video:telephone = 77:49) • CG: mean age 60, 87% caucasian, and 70% at least college education 	<ul style="list-style-type: none"> • To compare the effectiveness of a problem-solving therapy intervention delivered face-to-face and via video:telephone to hospice CGs 	<ul style="list-style-type: none"> • A randomized comparative, noninferiority trial • Intervention: 3 session problem-solving trainings were delivered via face-to-face or video:telephone. The interventionists guided CGs to solve their problems • Dosage: 3 session, 45 minutes each 	<ul style="list-style-type: none"> • Assessments: pre-post measurements (90% complete; a period of 20 days after hospice admission) • QOL: the Caregiver Quality of Life Index-Revised (CQLI-R) has validated with hospice CGs • Psychological health (Anxiety): the State-Trait Anxiety Inventory (STAI) • Problem-solving skills: the Problem-Solving Inventory (PSI) assesses problem-solving appraisal, or an individual's perceptions of their problem-solving behavior and attitudes • Assessments at baseline, pre- and posttreatment, and the 3rd-month and 12th month of follow-up (93% complete) • Psychological health: the Brief Symptom Inventory (subscales somatization, anxiety, and depression). And the Positive and Negative Affect Scale (PANAS) • QOL: the Satisfaction with Life Scale (SWLS), the WHO Quality of Life-BREF (WHOQOL-BREF) and a numeric rating scale for QOL (QOL-NRS, range 0-10) 	<ul style="list-style-type: none"> • Both groups: • ↑QOL • ↑Psychological health (Anxiety) • ↑Problem-solving skills • The delivery of problem-solving training via video:telephone was not inferior to face-to-face delivery • Limitations: Without a control group • Selection bias: the lack of racial diversity
Fegg et al ²⁵ /2013/ Germany/Psychology Oncology	<ul style="list-style-type: none"> • Patients received palliative care (82% cancer) • Inpatient (palliative care and oncology) • N = 133 CGs (I:C = 69:64) • CG: mean age 55, 70% female, 62% partners, and 42% with university degree 	<ul style="list-style-type: none"> • To test the effectiveness of existential behavioral therapy on CGs' mental stress and QOL 	<ul style="list-style-type: none"> • RCT • Intervention: a group existential behavioral therapy taught CG mindfulness, self-care and stress management • Dosage: 6 sessions, 22 hours in total • Control: usual care 	<ul style="list-style-type: none"> • Assessments at baseline, pre- and posttreatment, and the 3rd-month and 12th month of follow-up (93% complete) • Psychological health: the Brief Symptom Inventory (subscales somatization, anxiety, and depression). And the Positive and Negative Affect Scale (PANAS) • QOL: the Satisfaction with Life Scale (SWLS), the WHO Quality of Life-BREF (WHOQOL-BREF) and a numeric rating scale for QOL (QOL-NRS, range 0-10) 	<ul style="list-style-type: none"> • At the 12th month of follow-up • ↑Psychological health (depression, less negative affect) • ↑QOL • Limitations: Heterogeneous sample

Abbreviations: CG, caregiver; EOL, end of life; QOL, quality of life; RCT, randomized controlled trial; I, intervention group; C, control group.

Table 3. Characteristics of Included Studies: Psychoeducational Interventions for Family Caregivers.

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/ treatment dosage	Measures for CG data collection	CG outcomes/study limitations
Hudson et al ^{23/} 2005/ Australia/ <i>Journal of Pain and Symptom Management</i>	<ul style="list-style-type: none"> Advanced cancer Home palliative care N = 106 CGs (I:C = 54:52) CG: mean age 60, 65% female, and 67% spouse/partner 	<ul style="list-style-type: none"> To test the effectiveness of a psychoeducational intervention to enhance the support and guidance offered to CGs 	<ul style="list-style-type: none"> RCT Intervention: a nurse-delivered psychoeducational intervention. The intervention consisted of 2 home visits supplemented by a follow-up phone call between the 2 visits. The nurse provided the CGs education about caregiving roles and skills, available services, and self-care strategies Control: received standard care services from the community (home-based) palliative care service including access to 24-hour phone advice, emergency visits from nurses, and prescheduled home visits from health professionals 	<ul style="list-style-type: none"> Assessments: at baseline (upon commencement of home-based palliative care), the fifth week of follow-up, and the eighth week following patient death (25% completed all 3 assessments. There was insufficient power to detect differences based on a simultaneous comparison of data obtained at all 3 assessment times) Preparedness to care: the Preparedness for Caregiving Scale Competence: the Caregiver Competence Scale Rewards: the Revised The Rewards of Caregiving Scale Anxiety: the Hospital Anxiety and Depression Scale (HADS) Self-efficacy: the self-efficacy instrument has 2 subscales: caregiver self-efficacy and problem-solving self-efficacy 	<ul style="list-style-type: none"> Compare the data from baseline and the fifth week of follow-up: no significant effects or trends found with self-efficacy, competence, and anxiety Compare the data from baseline and the eighth week following patients' death: Competence and lower anxiety were found in both groups Rewards were reported in the intervention group Limitations: High attrition rate Insufficient power Selection bias: English language requirement, highly functioning CGs
Hudson et al ^{24/} 2009/ Australia/ <i>Journal of Pain and Symptom Management</i>	<ul style="list-style-type: none"> Advanced cancer Home-based palliative care N = 156 CGs (I:C = 54:52) CG: mean age 59, 70% female, 59% spouse, and 26% adult children 	<ul style="list-style-type: none"> To examine the effectiveness of a group education program on CGs 	<ul style="list-style-type: none"> Quasiexperiment Intervention: a group psychoeducational program consisted of 3 consecutive weekly sessions and conducted at 6 home-based palliative care services. The education topics included caregiving roles and skills in palliative care, available supports and services, self-care strategies, and strategies for caring dying patients Dosage: 3 sessions, 1.5 hours each 	<ul style="list-style-type: none"> Assessments: at baseline, postintervention, and 2 weeks after the final intervention (62% completed all assessments) Competence: the Carer Competence Scale Preparedness: the Preparedness for Caregiving Scale Rewards: the Rewards of Caregiving Scale Information needs: the Family Inventory of Need 	<ul style="list-style-type: none"> Levels of preparedness, competence, rewards, and less unmet information needs Social supports and knowledge (qualitative data) Limitations: One-group design High refusal rate Selection bias: English language requirement A cost-benefit analysis was not undertaken

(continued)

Table 3. (continued)

Author/year/ country/journal	Patient diagnosis/setting/ sample	Study aims	Study design/intervention/ treatment dosage	Measures for CG data collection	CG outcomes/study limitations
Hudson et al ^{16/} 2012/ Australia/ <i>Journal of Palliative Medicine</i>	<ul style="list-style-type: none"> Advanced cancer Hospital palliative care units N = 15 CGs CG: mean age 61, 80% female, 60% spouse, 20% adult children, and 80% at least high school education 	<ul style="list-style-type: none"> To develop and test effectiveness of a psychoeducational group education program on CGs of hospitalized palliative care patients 	<ul style="list-style-type: none"> Pilot, quasiexperiment Intervention: a group psychoeducational program. The single-session consisted of 5 topics: introduction of palliative care, caregiving roles and skills, available supports and services, self-care strategies, and preparing for the future Dosage: 1 session, 1.5 hours 	<ul style="list-style-type: none"> Assessments were conducted at pre- and postintervention. They are all validated self-reported questionnaires The Family Inventory of Needs Psychological health: the General Health Questionnaire Preparedness: the Preparedness for Caregiving Scale Competence: the Caregiver Competence Scale Assessments were conducted at baseline (within 2 weeks of referral to palliative care), the first-week postintervention (92% complete), and the eighth-week postpatient death to assess residual intervention effect (54% complete) Psychological well-being: the General Health Questionnaire (GHQ) with established reliability and validity Preparedness: the preparedness for caregiving scale Competence: the Caregiver Competence Scale Rewards: the Rewards of Caregiving Scale 	<ul style="list-style-type: none"> ↑ Levels of preparedness No significant effect on competence, importance of information, unmet needs, or psychological distress Limitations: Small sample size One-group design Selection bias: one-quarter of those eligible participated, English language requirement ↑ Levels of preparedness and competence in the 2-visit group ↑ Psychological health in both intervention groups, but not significant No significant reduction in unmet needs Limitations: High refusal rate High attrition rate Short-term follow-up
Hudson et al ^{26/} 2013/ Australia/ <i>Psycho- Oncology</i>	<ul style="list-style-type: none"> Advanced cancer Home-based palliative care N = 298 CGs (1 visit:2 visit:control = 148:57:93) CG: mean age 59 and 70% female 	<ul style="list-style-type: none"> To prepare CGs for the role of supporting a patient with advanced cancer receiving home-based palliative care 	<ul style="list-style-type: none"> Three-armed RCT Intervention: the psychoeducational intervention was delivered over 4 weeks for group 1 and group 2. The research nurses assessed CG's needs, developed care plan, and provided CGs palliative care education and bereavement preparation After received psychoeducation, group 1 received one home visit and 3 phone calls After received psychoeducation, group 2 received 2 home visits and 2 phone calls Control: usual care in these home-based palliative care services included initial assessment, scheduled home visits and access to a health care professional after hours for advice. Specific caregiver support strategies varied within services and were not always systematic or comprehensive Dosage: 4 weeks 	<ul style="list-style-type: none"> Assessments were conducted at baseline (within 2 weeks of referral to palliative care), the first-week postintervention (92% complete), and the eighth-week postpatient death to assess residual intervention effect (54% complete) Psychological well-being: the General Health Questionnaire (GHQ) with established reliability and validity Preparedness: the preparedness for caregiving scale Competence: the Caregiver Competence Scale Rewards: the Rewards of Caregiving Scale 	

Abbreviations: CG, caregiver; EOL, end of life; QOL, quality of life; RCT, randomized controlled trial; I, intervention group; C, control group.

of international studies that designed specific interventions to support family caregivers in end-of-life care, which will advance the current evidence and improve future interventional study design that may be translatable in multiple settings.

The national statistics reported that 66.6% of the people received hospice service at their place of residence (including home, nursing home, and residential facility), and 26.4% of people received hospice service in an in-patient setting.³ The study settings in this review were at home-based hospice or palliative care, hospital, nursing home, and community, which increased the generalizability of the results to caregivers at different settings.

The majority of the studies recruited caregivers of patients with advanced cancer receiving end-of-life care. Patients with cancer used to be the largest population who received end-of-life care. Recently, however, patients with cancer constituted only 36.5% of patients enrolled in hospice service while the other 63.5% had a noncancer diagnosis (dementia, heart disease, lung disease, and so on) in 2013.³ Future studies should focus on family caregivers of patients with a noncancer diagnosis. National hospice and palliative care statistics revealed that 83.1% of the patients were 65 years of age or older (38.2% were older than 85 years old) and 80.9% of patients were caucasian.³ Most of the hospice caregivers in this review were female caucasian with a mean age of 60 years old, which is 10 years older than the average of American family caregivers. Since the majority of hospice caregivers are older adults, effective interventions to support those caregivers are paramount. The homogeneous sample in this review was a potential limitation but it reflected the reality, which is that hospice service is rarely utilized by minorities. More exploratory studies are needed to explore the psychosocial, cultural, and spiritual aspects of end-of-life care for minorities and develop culturally appropriate strategies that cater toward minorities' needs.

Research Designs and Interventions

The systematic review of studies published over the last decade with a focus on supporting family caregivers of patients in the end-of-life care indicates that the attention on family caregivers, the quality of evidence, and the types of intervention have significantly increased and improved. In the review article for cancer and palliative caregivers by Harding and Higginson, only 9 (40%) of them studied interventions specifically designed for family caregivers, 2 (9%) were RCT, and 13 (60%) focused on improving caregivers' knowledge, coping skills, and stress management.⁹ In Hudson review article of psychosocial interventional studies, 5 (36%) of them were RCT and most of the studies aimed to improve caregivers' knowledge and coping skills.¹⁰ Seven (64%) of the studies provided caregivers direct support in caregiving and coping training in Candy meta-analysis.¹¹ Our review included 14 studies with educational and behavioral interventions published between 2004 and 2014, specifically for family caregivers of patients in end-of-life care. Seven (50%) articles were published between 2011 and 2014. Seven (50%) studies were RCTs and

others (50%) were comparative trials and quasiexperimental studies. Nine (65%) studies included more than 100 participants. The types of intervention used to support caregivers included education, cognitive behavioral therapy, and psychoeducation. All of them effectively improved the family caregivers' outcomes. Although the amount of high-quality clinical trials targeted to improve family caregiver's knowledge, behaviors, and coping skills have increased, the quantity is still limited. An RCT studies the effects of an intervention between the intervention and the controlled group over a period of time, which can minimize the time effect and the testing effect to strengthen the quality of findings. More rigorous RCTs are needed to expand the body of literature.

The 3 types of interventions in this review enhanced the family caregivers' outcomes, regardless of the format such as single meeting, multiple sessions, one-to-one intervention, or group intervention. The educational studies created the structured modules to improve the caregivers' knowledge, self-efficacy, and satisfaction. Both of the cognitive behavioral therapy and psychoeducation had professional educators to deliver structured treatment manuals following theoretical frameworks. The psychoeducational intervention provided the caregivers knowledge, available resources, and positive thinking to adapt to their caregivers' role. The outcomes showed improved general health, anxiety, competence, preparedness, rewards, social support, and met needs. The cognitive behavioral therapy focused on changing the family caregivers' thoughts and attitudes and improving caregivers coping skills to face challenges associated with caregiving. Hence, the cognitive behavioral therapy brought more positive outcomes than the other 2 interventions. The caregivers reported increased psychological health, coping skill, self-efficacy, and QOL. However, none of the studies evaluated the cost of intervention delivery and the effectiveness. Cognitive behavioral therapy requires experienced and trained interventionists, so it is important to evaluate the cost-effectiveness of the intervention and delivery method. Future studies should include a cost-effectiveness analysis and find the most efficient intervention format and method as well as delivery tool such as a telehealth application. As more and more patients prefer to receive end-of-life care at their place of residence, home telehealth is a valuable means to deliver interventions for patients and families. We need ongoing studies to test and identify the most cost-effectiveness home telehealth.

Measures

The measures for family caregivers in this review were reliable and validated instruments. For example, Hudson et al has developed a series of instruments for measuring the effects of psychoeducation on hospice caregivers' preparedness, competence, and rewards. More studies are needed to test these validated and reliable instruments for hospice and palliative care caregivers. In this review, most of the studies assessed the family caregivers' burden, anxiety, and depression by using various instruments, which made it difficult to compare their

effects on the family caregivers' psychological health across the studies. The majority of the instruments used to measure the family caregivers' burden, anxiety, depression, general health, QOL, and coping skills were not designed originally to assess hospice and palliative family caregivers. In addition, none of the studies assessed the effects of the interventions on the family caregivers' physical health. As the goal of educational and behavioral intervention is to improve family caregivers' overall health, QOL, and caregiving and coping skills, future studies should develop consistent, reliable, and valid instruments to measure psychological health, physical health, QOL, caregiving, and coping ability for the family caregivers in end-of-life care.

Moderators

The majority of the studies reported there were no baseline differences in the family caregivers' characteristics (age, gender, race, education, marital status, etc) and measures among groups. However, some factors such as the family caregivers' baseline functions and health literacy are potential moderators that could affect the family caregivers' ability to receive the interventions and show positive outcomes. Reinhardt et al discussed that the participants enrolled in their study had relatively lower depression and higher life satisfaction scores than general family caregivers, which was one of the potential factors that affect the ability to improve the family caregivers' life satisfaction.²⁰ Hudson et al also stated that the recruitment of a highly functioning cohort of family caregivers in their study made it difficult to produce the significant intervention effect on the participants' self-efficacy and competence.²³

Every family caregiver has a different background, needs, and levels of function and health literacy, so the ability to detect the strength of the interventions will be influenced by these factors. However, none of the studies in this review discussed and identified how individuals' health literacy might affect the caregivers' ability to learn these intensive materials and accept educational interventions in a short-period of time. Future studies should create simple tools or short questionnaires to evaluate the family caregivers' health literacy. In addition, future studies need to design different levels of educational and behavioral interventions that target each family caregiver's needs and functions. Prior to each study, family caregivers should be assessed to gauge their needs and function, so the intervention can be administered accordingly.

Limitations

The most common limitations identified across studies were high attrition rate, short-term intervention or follow-up, selection bias, small sample size, and non-RCT design. As recruitment and retention are difficult in end-of-life care studies, most studies designed a shorter intervention or follow-up. Four studies only assessed the pre- and postinterventions, 10 had a follow-up (ranging from 2 weeks to 12 months), and 3 had an attrition rate about 70%. Six studies reported a high attrition

rate due to the patients' death or disease progress, and it was difficult to measure the effectiveness and suitability of the interventions. Approximately 34.5% of hospice patients either died or discharged within 7 days of admission,³ and many caregivers left the studies after the patients' death. Future studies need to define an appropriate duration of a study so they are less burdensome intervention for the family caregivers. The study could encourage the bereaved caregivers to stay and learn the long-term impact of interventions on their health and bereavement and assist the family caregivers to transition from caregiving to grieving.

The majority of the studies stated that homogenous sample (caucasian and English-speaking caregivers for patients with advanced cancer) might affect the results and limit the generalizability of the findings. The majority of the studies recruited participants who spoke fluent English, which might exclude many family caregivers who need educational interventions are ethnic minorities, or do not identify English as their language choice. Future studies should include caregivers across race, gender, role, language, and disease to meet the needs for diverse family caregivers.

Seven studies were RCTs and only 4 of these studies reported an effect size (small to medium effect) that showed the sample size had adequate power to detect the differences between groups. Another 7 non-RCT studies (quasiexperimental or comparative studies) were single-group designs or lacked a controlled group. The researchers did not provide effect size estimations. Five studies in this review noted that small sample size was a limitation to detect significant outcomes. Future studies should include larger samples to enhance the statistical power.

Directions for Future Research

This review demonstrated that current educational and behavioral interventions for family caregivers in end-of-life care have developed structured and effective treatment manuals. All of the interventions achieved positive outcomes, regardless of format (single meeting, multiple sessions, one-to-one intervention, or group intervention). However, few outcomes failed to show significant improvements, which might be caused by the potential moderator effects such as the family caregivers' baseline function and healthy literacy. Future studies need to develop tools to assess family caregivers' needs, function, healthy literacy, and provide different levels of interventions that can target individuals' needs.

High refusal to participate and attrition rates are the common issues in the end-of-life research because of the patients' death or disease progress. Hence, there is a need for cost-effectiveness analysis to find the most efficient intervention method, frequency, period, and delivery tool and channels. More studies are needed to test the effectiveness of telehealth and technology application at home settings as intervention delivery tools for making the interventions more accessible to more family caregivers.

Although this review included the 14 most recent, high-quality interventional targeted to improve family caregivers' outcomes, most of these studies were pilot trials with small and homogenous samples. More RCTs are needed to replicate current effective interventions in larger samples. In addition, there is a need to develop consistent and specific tools to effectively measure family caregivers' outcomes (psychological and physical health, QOL, caregiving, and coping ability) in the context of end-of-life care. Furthermore, future studies need to incorporate effect size calculations to assess the impact of the intervention in efficacy trials.

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