

# Family Caregiver Strain and Burden

## A systematic review of evidence-based interventions when caring for patients with cancer

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**BACKGROUND:** Caregivers of patients with cancer experience high levels of caregiver-related strain and burden (CGSB). Cancer caregiving is complex and can change dramatically depending on the cancer trajectory. Often, this experience leads to poor health outcomes for the caregiver.

**OBJECTIVES:** This review appraises the evidence on CGSB published from 2007 to October 2017.

**METHODS:** 128 interventional studies found in PubMed® and CINAHL® were appraised and categorized based on the Oncology Nursing Society's Putting Evidence Into Practice schema.

**FINDINGS:** Psychoeducation, supportive care/support interventions, and cognitive behavioral interventions are recommended to decrease CGSB. Caregiver skill training, couples therapy, decision support, mindfulness-based stress reduction, multicomponent interventions, and palliative care are likely to be effective. The evidence is not established for 13 interventions. Despite the proliferation of studies focusing on CGSB, studies with stronger designs and larger samples are needed.

### KEYWORDS

family caregiver; caregiver strain and burden; evidence-based practice

**APPROXIMATELY 15.5 MILLION AMERICANS ARE LIVING WITH A HISTORY** of cancer, and an estimated 1.76 million new cases were expected in 2019 (American Cancer Society, 2019). In recent years, increased attention has been given to family caregivers. Often, caregiving involves significant amounts of time and energy, and requires the performance of tasks that may be physically, emotionally, socially, or financially demanding. Although caregivers report many positive aspects of providing care, the complex care is a stressor and leads to negative consequences that are referred to as caregiver strain and burden (National Alliance for Caregiving [NAC], 2016).

Caregiver strain and burden, terms used interchangeably in this article, is multidimensional in nature and encompasses difficulties in assuming and functioning in the caregiver role; caregiving is also associated with alterations in caregivers' emotional and physical health that can occur when care demands exceed resources (Oncology Nursing Society, 2017). Increased caregiving can negatively affect the patient and the caregiver. Forty-two percent of family caregivers perform skilled medical or nursing tasks for their loved ones, often with insufficient assistance or training from healthcare professionals (Mollica, Litzelman, Rowland, & Kent, 2017).

The NAC (2016), in collaboration with the National Cancer Institute and the Cancer Support Community, estimated the number of caregivers of patients with cancer at 3 million. The estimate was based on a nationally representative sample of adults; however, the authors cautioned that the actual percentage of cancer caregivers is likely higher because cancer may be a secondary condition for many older family members who require support. The cancer caregivers in the NAC (2016) report experienced episodic and intense caregiving, which was associated with high burden where they spent an average of 32.9 hours per week caring for their loved ones.

Caregivers of patients with cancer have a unique role compared to caregivers of patients with other chronic illnesses (Kim & Schulz, 2008). Their role and level of involvement can change quickly and dramatically depending on the nature of cancer. They are expected to respond to and monitor multiple disease symptoms and treatment modalities, in addition to the uncertainty that persists across the disease trajectory (Kent et al., 2016).

Although there have been novel methods to provide caregiver support, including specialized education, psycho-spiritual interventions, and support groups, there is a continued need to appraise the effectiveness of those methods. The Oncology Nursing Society (ONS) Putting Evidence Into Practice (PEP) resource provides a comprehensive overview of the current available research and summarizes those studies that look at the effectiveness of interventions specific to the topic of caregiver strain and burden (Johnson, 2014). In this article, the PEP review by Honea et al. (2008) is updated, as is the evidence on interventions to reduce caregiver strain and burden.

**Methods**

A systematic review of the literature was performed in PubMed® and CINAHL® databases to identify effective interventions for caregiver strain and burden. Some studies were identified outside of these two databases via email alerts (journal eTOC and online ahead-of-print articles) and the reference lists of relevant articles. Research studies, systematic reviews, guidelines, and meta-analyses published in English from January 2007 to October 2017 were included in this review. Abstracts, proceedings, letters to the editor, grey literature, descriptive studies, and case reports were excluded. Research that did not report on interventions for caregiver strain or burden or did not include patients with cancer were excluded. The search strategy, search terms, databases, and inclusion/exclusion criteria are found at [www.ons.org/node/1011?ref=CO](http://www.ons.org/node/1011?ref=CO). The literature search is detailed in Figure 1.

The process for PEP evidence retrieval, synthesis, and classification follows the decision rules for summative evaluation of a body of evidence method, which is a rigorous method that

**“Nurses should routinely assess for caregiver needs by observation and informal screening.”**

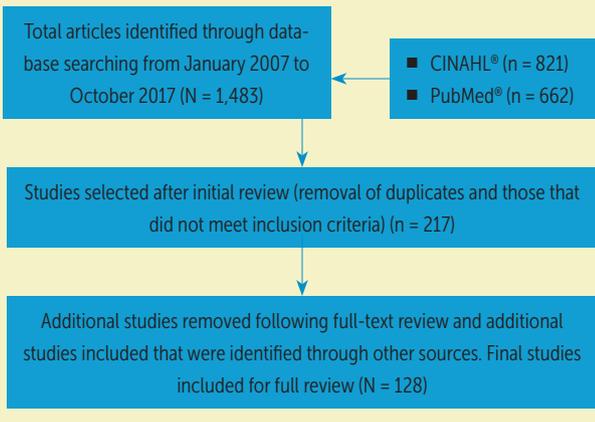
was developed by experts at ONS, and has been described elsewhere in detail (Johnson, 2014; Mitchell & Friese, n.d.). Briefly, the process involves identifying relevant studies by an expert medical librarian, critically appraising studies that meet inclusion criteria by pairs of expert PEP team members, evaluating the collective body of evidence using ONS’s decision rules and weight-of-evidence, and classifying it into one of six categories. These categories include recommended for practice, likely to be effective, benefits balanced with harm, effectiveness not established, effectiveness unlikely, and not recommended for practice. The decision rules and classification schema can be accessed at [www.ons.org/explore-resources/pep/decision-rules-summative-evaluation-body-evidence](http://www.ons.org/explore-resources/pep/decision-rules-summative-evaluation-body-evidence). Despite the rigorous method, it is possible that other studies not retrieved via PubMed or CINAHL were missed because only these two databases were used during evidence retrieval.

**Results**

For this review, 128 published studies were reviewed, including 22 systematic reviews or meta-analyses. The number of studies included in these systematic reviews or meta analyses varied widely and ranged from 6 to 50 studies (Kaltenbaugh et al., 2015; Kavalieratos et al., 2016; Waldron, Janke, Bechtel, Ramirez, & Cohen, 2013). Overall, 23 distinctively different interventions have been studied in relation to caregiver strain. Although all of the reviews involved caregivers, not all of them exclusively involved caregivers of patients with cancer; several reviews involved patient-caregiver dyads rather than focusing on caregivers alone.

The majority of systematic reviews and meta-analyses were conducted on psychoeducation interventions (n = 13), followed by supportive care interventions (n = 4), multicomponent therapy (n = 3), and cognitive behavioral therapy (CBT) (n = 3). The interventions are provided in the following sections, which are organized based on the level of evidence for effectiveness schema categories described by Mitchell and Friese (n.d.). Tables 1 and 2 detail the interventions classified as recommended for practice and likely to be effective, respectively.

**FIGURE 1.**  
PRISMA DIAGRAM OF SEARCH STRATEGY



PRISMA—Preferred Reporting Items for Systematic Reviews and Meta-Analyses

## Recommended for Practice

**PSYCHOEDUCATION INTERVENTIONS:** Psychoeducation interventions are those with a focus on providing education in combination with other activities, such as counseling or support, that are delivered in a variety of methods to the caregiver or the patient-caregiver dyad as well as individually or in a group setting (ONS, 2017).

More than 45 articles, including 13 systematic reviews, were published that evaluated psychoeducation interventions since the last PEP review (Honea et al., 2008). Nine systematic reviews recommended psychoeducation interventions for practice (Applebaum & Breitbart, 2013; Caress, Chalmers, & Luker, 2009; Chi, Demiris, Lewis, Walker, & Langer, 2016; Hopkinson, Brown, Okamoto, & Addington-Hall, 2012; Li & Loke, 2014; Northouse et al., 2010; Regan et al., 2012; Waldron et al., 2013; Zheng et al., 2016). Improvements were reported in a variety of caregiver outcomes, including burden, self-efficacy, preparedness, psychological health, and coping. In addition, four of these reviews provide additional insight into the specific delivery method or components of the psycho-educational intervention that were most effective (Hopkinson et al., 2012; Li & Loke, 2014; Regan et al., 2012; Zheng et al., 2016). For example, Hopkinson et al. (2012) reported on the value of supporting patient-caregiver dyads versus caregivers alone, with one finding that outcomes are superior when support is delivered to a dyad. Northouse et al. (2010) reported on 29 RCTs with 3,495 participants who had face-to-face and group interventions that were superior to a variety of mixed methods. On the other hand, findings from Waldron et al. (2013) confirmed that targeting certain components (i.e., problem solving and coping skill) produced larger effect sizes, which supported previous research (Caress et al., 2009).

Four of the 13 reviews had neutral or conflicting results (Chambers, Pinnock, Lepore, Hughes, & O'Connell, 2011; Griffin et al., 2013; Harding, List, Epiphaniou, & Jones, 2012; Langford, Lee, & Miaskowski, 2012). Examination of these four reviews suggests that their results may be explained by the nature and quality of the studies they included in the review. The reviewed studies included not only caregivers and patient-caregiver dyads, but patient-only studies as well. In these reviews, caregiver-specific studies and good quality studies were, at times, lacking. In addition, the reviews involved studies with small sample sizes, which were further challenged by high attrition rates. Therefore, outcomes reported did not include increases in quality-of-life (QOL) scores and, at times, reported combinations of both positive and neutral findings.

Twenty-nine individual studies demonstrate that these interventions are effective in improving multiple caregiver outcomes or document improvements in very specific aspects of caregiver strain and burden. Multiple systematic reviews, large and small randomized controlled trials (RCTs), and numerous smaller studies with minor design limitations show improvement in

self-efficacy (Applebaum & Breitbart, 2013; Dockham et al., 2016; Holm et al., 2015; Hudson et al., 2008; Jones et al., 2013; Lee, Yiin, & Chao, 2016; Leow, Chan, & Chan, 2015; Li, Xu, Zhou, & Loke, 2015; Luker et al., 2015; Mokuau, Braun, Wong, Higuchi, & Gotay, 2008; Northouse, Katapodi, Schafenacker, & Weiss, 2012; Northouse et al., 2010; Regan et al., 2012; Titler et al., 2017; Tsianakas et al., 2015). Mood, specifically depression, anxiety, and distress, also improved (Badger et al., 2011; Chambers et al., 2011; DuBenske et al., 2014; Hopkinson et al., 2012; Hudson & Aranda, 2014; Lapid et al., 2015; Laudenslager et al., 2015; Lewis et al., 2008; Li et al., 2015; Li & Loke, 2014; Shum, 2014). Improvements were also noted in caregiver well-being, overall QOL, reduced burden, positive effect on coping, and caregiver knowledge and preparedness (Applebaum & Breitbart, 2013; Bahrami & Farzi, 2014; Budin et al., 2008; Dockham et al., 2016; DuBenske et al., 2014; Heinrichs et al., 2012; Hopkinson et al., 2012; Hudson et al., 2012; Lee et al., 2016; Li et al., 2015; Mokuau et al., 2008; Northouse et al., 2010, 2013; Regan et al., 2012; Shum, 2014). Titler et al. (2017) reported on the feasibility and overall cost of FOCUS, a multicomponent psycho-educational intervention administered to patient-caregiver dyads to improve family involvement, optimistic attitude, and coping effectiveness and reduce uncertainty.

There are several small non-experimental reports and four RCTs that demonstrate mixed findings in which caregiver stress decreased and anxiety remained unchanged or there was no change in caregiver outcomes (Mosher et al., 2016; Nejad, Aghdam, Hassankhani, & Sanaat, 2016; Sherwood et al., 2012; Steel et al., 2016). Three of these were looking at different methods of delivery (i.e., web based, telephone, or face to face), which may contribute to the mixed results (Mosher et al., 2016; Nejad, 2016; Steel et al., 2016). Similar findings of no impact or insignificant change for caregivers were reported in a few smaller nonexperimental studies (Farquhar et al., 2014; Northouse et al., 2014).

**SUPPORTIVE CARE INTERVENTIONS:** Supportive care interventions are those that provide emotional support to caregivers, with the goal to build rapport with them and/or provide a safe space to discuss feelings and learn problem-solving techniques. Supportive care interventions can be informal or structured and can be delivered in person, over the phone, or online and may include direct counseling, active listening, or physical presence (ONS, n.d.). Three systematic reviews reported positive effects on a variety of outcomes, including caregiver burden and mastery, mood and self-efficacy, and perceived support and knowledge (Glasdam et al., 2010; Kaltenbaugh et al., 2015; Slev et al., 2016). A meta-analysis, in which 8 of the 11 studies reviewed focused on caregivers of patients with terminal illness, showed that support interventions reduced psychological distress (Candy, Jones, Drake, Leurent, & King, 2011). Two large RCTs demonstrated sustainable improvement in mood (Chih et al., 2013) and decreased number of patient hospitalizations and emergency department visits (Shaw et al., 2016). One study of a nonexperimental

**TABLE 1.**  
RECOMMENDED FOR PRACTICE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Cognitive behavioral intervention or approach</b>			
Bevans et al., 2010	Individualized problem-solving educational intervention with dyads; repeated-measures design with 8 patient-spouse dyads	No changes over time; qualitative themes include opportunity to talk and satisfied with sessions	<ul style="list-style-type: none"> <li>■ Small sample</li> <li>■ Aimed at feasibility</li> </ul>
Bevans et al., 2014	Individualized, problem-solving educational intervention with dyads; repeated-measures design with patient-caregiver dyads (55 patients and 71 caregivers)	Improvement in self-efficacy and distress	<ul style="list-style-type: none"> <li>■ No randomization</li> <li>■ Limited racial and ethnic diversity</li> </ul>
Boele et al., 2013	Psychoeducation and CBT; RCT with 56 dyads	Feelings of mastery in intervention group increased over time, whereas mastery declined in the control group.	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ No attention control</li> <li>■ No blinding</li> </ul>
Campbell et al., 2007	Telephonic cognitive behavioral intervention; RCT with 30 patient-spouse dyads	No differences in caregiver strain or self-efficacy; some patient symptom improvements were noted.	<ul style="list-style-type: none"> <li>■ Significant withdrawal from scheduling difficulties</li> <li>■ Small sample</li> <li>■ No attentional control</li> </ul>
Chambers et al., 2014	Psychoeducational interventions; RCT with 132 caregivers	Cancer-specific distress decreased for caregivers, and positive adjustment increased ( $p < 0.001$ ). ES for nurse session was 0.19, and ES for CBT was 0.2.	<ul style="list-style-type: none"> <li>■ Measurement not well described</li> <li>■ No blinding</li> </ul>
Chi et al., 2016	Behavioral and educational interventions; systematic review of 14 studies with 1,773 caregivers	CBT had the strongest evidence of significant improvement in self-efficacy, quality of life, and psychological health.	<ul style="list-style-type: none"> <li>■ High attrition</li> <li>■ Heterogeneous studies included</li> </ul>
Langford et al., 2012	Interventions for sleep disturbances; meta-analysis of 13 studies from a total of 49 studies (2 with caregivers)	CBT had at least a moderate effect for sleep improvement, but no separate analysis was conducted for caregivers.	<ul style="list-style-type: none"> <li>■ Low-quality studies</li> </ul>
Manne et al., 2011	Intimacy-enhancing psychological intervention; pre-/post-test design with 71 men and their partners	No significant treatment effects for general distress, cancer-specific distress, and relationship intimacy. Survivors with high levels of concerns at baseline significantly reduced those concerns after the intervention.	<ul style="list-style-type: none"> <li>■ High drop-out rate</li> <li>■ Well-educated, mainly Caucasian sample</li> </ul>
Meyers et al., 2011	Cognitive-behavioral educational intervention; RCT with 441 dyads	No changes in problem-solving skills. Quality of life declined in both groups, but declined less in the treatment group ( $p < 0.02$ ).	<ul style="list-style-type: none"> <li>■ 25% withdrawal rate</li> <li>■ No attention control</li> <li>■ Small control group</li> <li>■ Compares only predicted results, not actual</li> </ul>
Northouse et al., 2010	Various psychoeducational and skills training interventions; systematic review and meta-analysis of 29 RCTs with 3,495 participants	Coping and self-efficacy significantly improved by face-to-face and group methods aimed at improving caregiver coping. Caregiving burden and effect of caregiving was positively influenced with small effect sizes.	<ul style="list-style-type: none"> <li>■ Effects seen were statistically significant, but positive effect sizes were small</li> </ul>
Onyechi et al., 2016	Rational-emotive hospice care therapy; RCT with 52 caregivers	Distress declined for both caregivers and patients in the intervention group ( $p = 0.00$ ).	<ul style="list-style-type: none"> <li>■ Small sample size</li> </ul>
O'Toole et al., 2017	CBT approach; systematic review and meta-analysis of 36 studies with 3,820 patients	Small but significant effect was noted for CBT, but not significant with removal of RCTs.	<ul style="list-style-type: none"> <li>■ Not clear that all were truly CBT; included relaxation and mindfulness</li> </ul>

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**TABLE 1. (CONTINUED)**

RECOMMENDED FOR PRACTICE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Psychoeducation interventions</b>			
Appelbaum & Breitbart, 2013	Multiple interventions; systematic review of 49 studies	Psychoeducation knowledge and care ability improved, with positive effects noted on caregiver burden.	<ul style="list-style-type: none"> <li>■ No effect size information</li> </ul>
Badger et al., 2011	Telephone counseling versus health information/education; RCT of 70 dyads	Depression, fatigue, social support, and social and spiritual well-being improved more with health education. Both groups showed symptom/problem decline over time.	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Quality of life was high at baseline.</li> <li>■ Multiple repeated measures with same tool</li> </ul>
Badr et al., 2015	Psychosocial phone-delivered intervention; RCT of 39 dyads	Intervention was rated as relevant, convenient, and helpful. Retention was good, with 88% completing assignments.	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Methods not well described</li> </ul>
Bahrami & Farzi, 2014	Supportive educational program; RCT with 64 caregivers of patients with breast cancer	Burden lower in intervention group after the intervention ( $p < 0.001$ ); burden increased in the control group	<ul style="list-style-type: none"> <li>■ Sample size.</li> <li>■ Instruments not well known</li> <li>■ No attention control</li> <li>■ Usual care control not described</li> </ul>
Budin et al., 2008	Psychoeducational videos versus telephone counseling or combination versus control; RCT with 126 patient-partner dyads	Combined telephone and psychoeducational intervention had highest well-being (group plus time effect, $p = 0.004$ )	<ul style="list-style-type: none"> <li>■ No attentional control</li> <li>■ No actual mean data results reported</li> <li>■ Varied timeframes of intervention and lack of blinding would affect results.</li> </ul>
Caress et al., 2009	Interventions to support family caregivers who provide physical care; systematic review of 19 studies	Interventions with problem solving suggested some benefit.	<ul style="list-style-type: none"> <li>■ "Semi" systematic review</li> </ul>
Chambers et al., 2011	Psychosocial and cognitive interventions; systematic review with 21 of 263 couples	Patient-caregiver dyad psychoeducation improved quality of life. Inconsistent effects were noted on caregiver physical quality, uncertainty, and distress.	<ul style="list-style-type: none"> <li>■ Small study samples</li> <li>■ High study attrition rates</li> </ul>
Chi et al., 2016	Educational and behavioral interventions; systematic review of 14 studies (8 focused on cancer)	4 studies for psychoeducation, improved preparedness, psychological health	<ul style="list-style-type: none"> <li>■ High heterogeneity</li> <li>■ High attrition rates</li> </ul>
Demiris et al., 2011	Videophone used for delivering psychoeducation problem solving; quasi-experimental design with 42 caregivers	Video phone use feasible; lower anxiety after intervention ( $p < 0.04$ )	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Design</li> </ul>
Demiris et al., 2012	Psychoeducational counseling delivered via videophone versus face to face after hospice admission; randomized noninferiority design with 126 hospice caregivers	Anxiety was reduced in both study groups ( $p < 0.0001$ ); video phone delivery was not inferior.	<ul style="list-style-type: none"> <li>■ No blinding</li> <li>■ More than 10% lost to follow-up</li> </ul>
Dockham et al., 2016	Psychoeducational program; quasiexperimental design with 34 dyads	Dyad quality of life and self-efficacy were improved.	<ul style="list-style-type: none"> <li>■ Design</li> <li>■ Sample size</li> </ul>
Dubenske et al., 2014	Home-based e-health system; RCT with 246 patients and partners	Significant improvement in burden and negative mood at 6 months	<ul style="list-style-type: none"> <li>■ No blinding</li> <li>■ Doctor consent needed for participation</li> <li>■ System not universally available</li> </ul>
Farquhar et al., 2014	Symptom management for breathlessness; RCT with 39 caregivers	No impact on caregivers	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Highly specific to dyspnea management</li> </ul>
Griffin et al., 2013	Family and caregiver interventions; systematic review of 27 studies with 3,354 patients	Family focus did not appear to reduce caregiver burden. Skill training aimed at the family had a positive effect.	<ul style="list-style-type: none"> <li>■ Only 2 studies were good quality.</li> <li>■ Lack of data in some studies</li> </ul>
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**TABLE 1. (CONTINUED)**

RECOMMENDED FOR PRACTICE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Psychoeducation interventions (continued)</b>			
Harding et al., 2012	Interventions to support caregivers; systematic review of 33 studies	No clear conclusions; overall findings equivocal	<ul style="list-style-type: none"> <li>Not all in cancer</li> <li>Varied intervention types and modes of delivery</li> </ul>
Heinrichs et al., 2012	Couples-based skills training; RCT with 72 dyads	Short-term positive effect on fear of disease progression and avoidance behavior (coping and communication)	<ul style="list-style-type: none"> <li>Key baseline sample differences</li> <li>No attentional controls</li> <li>High attrition</li> </ul>
Holm et al., 2016	Psychoeducation group intervention; RCT with 194 caregivers	Intervention group increased in preparedness and competency compared to controls. No other changes	<ul style="list-style-type: none"> <li>Uncertain fidelity across sites</li> <li>No attention control</li> </ul>
Hopkinson et al., 2012	Psychosocial interventions; systematic review of 27 studies	Dyad-focused interventions may improve coping, anxiety, depression, and emotional support; likely better results with dyad than intervention with single member.	<ul style="list-style-type: none"> <li>High attrition rates in studies</li> </ul>
Hudson & Aranda, 2014	2 versions of psychoeducation interventions versus usual care as part of palliative care; RCT with 298 caregivers	No significant effect of group over time; those in the intervention groups had less increase in distress.	<ul style="list-style-type: none"> <li>Subject withdrawal</li> </ul>
Hudson et al., 2008	Psychoeducation group program; quasiexperimental study with 44 family caregivers	Decrease in variables over time ( $p < 0.001$ ); caregiver burden increased across 2 post-program time points.	<ul style="list-style-type: none"> <li>Incomplete data (only 59% completed study measures)</li> <li>Small sample</li> </ul>
Hudson et al., 2012	Inpatient group psychoeducational intervention; quasiexperimental study with 107 caregivers	Improvement in met needs ( $p = 0.028$ ) and preparedness ( $ES = 0.34, p < 0.001$ )	<ul style="list-style-type: none"> <li>Design</li> </ul>
Hudson et al., 2013	Psychoeducation counseling, planning, and bereavement; RCT with 161 in a home-based palliative care program	Caregivers with intervention had higher preparedness and competence ( $p = 0.04, ES = 0.29$ ). No difference in psychological distress	<ul style="list-style-type: none"> <li>High attrition (42%)</li> <li>Intervention noted to be labor intensive</li> </ul>
Jones et al., 2013	Group-delivered educational intervention; prospective mixed-method design with 54 male partners	Improved self-efficacy ( $p < 0.001$ ) and increase in skills ( $p < 0.001$ )	<ul style="list-style-type: none"> <li>Study design</li> <li>Outcomes were from the patient, not caregivers</li> </ul>
Langford et al., 2012	Multiple interventions for sleep disturbance of caregivers; meta-analysis of 2 studies with caregivers among 47 total studies	No substantial effects of educational type interventions	<ul style="list-style-type: none"> <li>Few caregiver studies</li> <li>No analysis of heterogeneity</li> </ul>
Lapid et al., 2016	Structured, in-person, group interprofessional intervention; quasiexperimental design with 131 patients and caregivers	Improved spiritual well-being and vigor subscale of the Profile of Mood States ( $p < 0.05$ )	<ul style="list-style-type: none"> <li>Limited subscale improvements</li> <li>No attention control</li> <li>No blinding</li> <li>No demographic info provided</li> </ul>
Laudenslager et al., 2015	Psychosocial intervention; RCT with 122 caregivers	Caregivers in the intervention group had lower stress ( $p = 0.039$ ), a decline in depression ( $p = 0.016$ ), and a decline in anxiety ( $p = 0.009$ ) compared to the control group.	<ul style="list-style-type: none"> <li>Risk of bias</li> </ul>
Lee et al., 2016	Integrated caregiver support; RCT with 81 caregivers	Caregiver burden scores were lower with intervention ( $p < 0.001$ ) and higher with self-efficacy ( $p < 0.001$ ).	<ul style="list-style-type: none"> <li>Usual care not well defined</li> <li>No attention control</li> </ul>
Leow et al., 2015	Psychoeducational intervention; RCT with 56 caregivers	The intervention group showed improvement ( $p < 0.05$ ) in all outcomes.	<ul style="list-style-type: none"> <li>Sample size</li> <li>High dropouts related to death</li> </ul>

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**TABLE 1. (CONTINUED)**

RECOMMENDED FOR PRACTICE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Psychoeducation interventions (continued)</b>			
Lewis et al., 2008	Educational counseling; pre-/post-test design with 20 spouses of women with breast cancer	Depressed mood and anxiety improved significantly ( $p \leq 0.0001$ ). Spousal skills significantly improved.	<ul style="list-style-type: none"> <li>■ 23% dropouts</li> <li>■ Small sample</li> </ul>
Li et al., 2015	Couples-based education and group sharing; quasiexperimental design with 117 couples	Increased self-efficacy, positive emotions, and anxiety ( $p < 0.05$ )	<ul style="list-style-type: none"> <li>■ Design</li> </ul>
Li & Loke, 2014	Couples-based interventions in cancer; systematic review of 17 studies	Interventions were skills training combined with psychoeducation and counseling. All studies found improvement with the intervention.	<ul style="list-style-type: none"> <li>■ High heterogeneity; cohort studies included and not differentiated from RCTs</li> </ul>
Luker et al., 2015	Intervention to support family caregivers; mixed-methods design with 31 caregivers	The booklet was acceptable and beneficial to caregivers.	<ul style="list-style-type: none"> <li>■ Sample size</li> </ul>
Mahendran et al., 2017	Psychoeducational support group; prospective, nonrandomized, with 91 caregivers	No significant differences between groups postintervention	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Baseline group differences</li> </ul>
Mokuau et al., 2008	Psychoeducational intervention incorporating cultural values; RCT with 12 caregivers	With intervention, patients and family members reported significant increases in self-efficacy and coping.	<ul style="list-style-type: none"> <li>■ No complete attentional control</li> <li>■ Small sample</li> </ul>
Mosher et al., 2016	Telephone symptom management, CBT approach, communication skills by social worker versus education and support; RCT with 106 dyads	No significant difference between groups	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ Education and support not described; unclear if sufficiently different</li> </ul>
Nejad et al., 2016	Patient-caregiver education intervention; RCT with 60 dyads	Both groups had significant reduction in caregiver strain index results ( $p < 0.001$ ). No difference between groups	<ul style="list-style-type: none"> <li>■ Sample size</li> </ul>
Northouse et al., 2010	Various psychoeducational and skills training supportive interventions delivered to caregivers; systematic review and meta-analysis of 29 RCTs involving 3,495 participants	Coping and self-efficacy significantly improved by face-to-face and group methods aimed at improving caregiver coping. Caregiving burden and positive effect of caregiving was positively influenced with small ES.	<ul style="list-style-type: none"> <li>■ Effects seen were statistically significant, but positive effect sizes were small</li> </ul>
Northouse et al., 2013	Brief and extensive psychoeducation; RCT with 484 dyads	Intervention associated with improved coping, self-efficacy, quality of life, and health behaviors at 3 months ( $p < 0.05$ ). No sign of effect by 6 months	<ul style="list-style-type: none"> <li>■ No attentional control</li> </ul>
Northouse et al., 2014	Web-based psychoeducational intervention; quasiexperimental design with 38 dyads	Decreased emotional distress and other emotional symptoms, improved quality of life ( $p < 0.05$ ). Changes from baseline were not significant for caregivers.	<ul style="list-style-type: none"> <li>■ Well-educated and high-income sample</li> </ul>
Regan et al., 2012	Psychosocial interventions, couples-based; systematic review of 23 studies	Improved social adjustment (6 studies), improved partner relationship (9 studies), self-efficacy improvement (2 studies), improved partner communication (2 studies); no difference if in person or telephonic	<ul style="list-style-type: none"> <li>■ Homogeneous sample</li> </ul>
Sherwood et al., 2012	Education and problem-solving intervention; RCT with 225 dyads	No difference in caregiver depression, burden between groups; caregivers involved in intervening for patient symptoms had lower depression levels.	<ul style="list-style-type: none"> <li>■ Homogeneous sample</li> </ul>

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**TABLE 1. (CONTINUED)**

RECOMMENDED FOR PRACTICE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Psychoeducation interventions (continued)</b>			
Shum et al., 2014	Telephone psychoeducational intervention; RCT with 135 caregivers	Depression and anxiety declined more in the intervention group; caregiver burden declined more in the intervention group ( $p < 0.001$ ).	<ul style="list-style-type: none"> <li>Repeated measures (testing effect)</li> <li>Low baseline depression and anxiety (possible floor effects)</li> </ul>
Steel et al., 2016	Web-based psychoeducation and support system; RCT with 188 participants	At 6 months, caregiver stress for intervention group was reduced ( $ES = 0.748$ ); caregiver depression ( $ES = 0.372$ ) showed no statistical difference.	<ul style="list-style-type: none"> <li>No statistical analysis</li> </ul>
Tsianakas et al., 2015	DVD, booklet, and group consultation prior to beginning chemotherapy; RCT with 47 caregivers	Intervention group had improved caregiver knowledge of chemotherapy	<ul style="list-style-type: none"> <li>Sample size</li> <li>Design</li> </ul>
Waldron et al., 2013	Psychosocial and educational interventions; systematic review with 6 RCTs	Studies with interventions to improve caregiver ability to communicate and education on coping had most impact; small effect sizes	<ul style="list-style-type: none"> <li>High study attrition rates</li> <li>Small number of studies</li> </ul>
Zheng et al., 2016	Telehealth interventions; systematic review of 9 studies in hospice, 1 in cancer	Studies used videophones for communication and 2 studies used phones for counseling. Overall, 66.7% showed positive effects on caregiver anxiety.	<ul style="list-style-type: none"> <li>Mostly high risk of bias studies</li> <li>Low sample sizes</li> </ul>
<b>Supportive care/support intervention</b>			
Candy et al., 2011	Support interventions; meta-analysis of 11 studies	Support interventions reduced caregiver psychological distress ( $SMD = 0.15$ , $p = 0.02$ ).	<ul style="list-style-type: none"> <li>Mostly high risk of bias studies</li> <li>High heterogeneity</li> </ul>
Chih et al., 2013	Online symptom reporting and supportive management; RCT with 235 dyads	The intervention group had more positive mood at 6 and 12 months ( $p < 0.009$ ).	<ul style="list-style-type: none"> <li>Well-educated sample</li> <li>No blinding</li> </ul>
Glasdam et al., 2010	Varied support interventions; systematic review of 32 studies	Studies that showed a positive effect focused on caregiver burden and mastery of skills.	<ul style="list-style-type: none"> <li>Variable study quality</li> </ul>
Kaltenbaugh et al., 2015	Web-based support interventions; systematic review of 6 studies	Moderate to high effect sizes ( $d = 0.436-0.88$ ) on mood and self-efficacy	<ul style="list-style-type: none"> <li>No information on ethnicity</li> </ul>
McCorkle et al., 2007	Standardized nursing intervention; RCT with 107 patient-spouse pairs	Intervention group had higher sex distress scores and no effect on depression.	<ul style="list-style-type: none"> <li>Sample size</li> </ul>
Shaw et al., 2016	Structured telephone intervention; RCT with 128 dyads	No difference in caregiver quality-of-life scores; reported fewer hospitalizations and emergency department visits	<ul style="list-style-type: none"> <li>No blinding</li> </ul>
Slev et al., 2016	Various e-health interventions; systematic review of 10 studies	Evidence found for positive effects on perceived support and knowledge	<ul style="list-style-type: none"> <li>Few studies with caregiver outcomes</li> </ul>
CBT—cognitive behavioral therapy; ES—effect size; RCT—randomized controlled trials; SMD—standardized mean difference			

nature demonstrated mixed findings with actual worsening of sex distress scores and no effect on depression among spouses of patients with prostate cancer (McCorkle, Siefert, Dowd, Robinson, & Pickett, 2007).

**COGNITIVE BEHAVIORAL INTERVENTIONS:** Cognitive behavioral interventions are those that draw on the principles of

cognitive behavioral therapy (CBT). The interventions are aimed at helping the caregiver identify negative thoughts, beliefs, and behaviors so that they can be altered in a positive way. Such interventions can be delivered individually or in a group format and through a variety of methods, such as in person, over the phone, or other methods (ONS, 2017).

A systematic review with meta-analysis of 29 RCTs and 3,495 participants showed significant positive effects of face-to-face interventions on self-efficacy and coping (Northouse et al., 2010). Although improvement was documented across multiple caregiver outcomes, universally, the effect size was not large. A systematic review, including six CBT studies (N = 1,152), supported previous conclusions with positive effects on caregiver self-efficacy, QOL, and psychological health (Chi et al., 2016). The individual studies included in this review varied in types of cancer, disease stage, and in method of delivery, either to a patient-caregiver dyad or to an individual caregiver. Six of 10 studies were delivered to dyads (Bevans et al., 2010, 2014; Campbell et al., 2007; Manne et al., 2011; Meyers et al., 2011; Onyechi et al., 2016). In addition to strain and burden, the RCTs showed improved mastery, decreased distress, and positive adjustment, as well as positive impact on the QOL of the caregivers (Boele et al., 2013; Chambers et al., 2014; Meyers et al., 2011; Onyechi et al., 2016). Two smaller nonexperimental studies showed videophone to be a feasible method of delivery as well as a way to decrease anxiety (Demiris, Oliver, Wittenberg-Lyles, & Washington, 2011; Demiris et al., 2012). Two smaller individual studies with particularly small sample sizes failed to demonstrate a difference (Bevans et al., 2010; Campbell et al., 2007; Manne et al., 2011).

### Likely to Be Effective

**CAREGIVER TRAINING AND SKILL DEVELOPMENT:** Caregiver training and skill development interventions are those that offer education and training to increase caregiver knowledge and assist with the development of the skills needed to assume the caregiver role (ONS, 2017). Eight studies were published looking at caregiver training and skill development. Although only one smaller study showed a decrease in caregiver burden (Belgacem et al., 2013), seven individual studies showed a positive effect on several specific outcomes, including improving self-efficacy (Belgacem et al., 2013; Hendrix, Abernethy, Sloane, Misuraca, & Moore, 2009; Hendrix et al., 2016; Hendrix, Landerman, & Abernethy, 2013; Porter et al., 2011) and reducing caregiver anxiety (Belgacem et al., 2013; Hendrix et al., 2009, 2013, 2016; Loerzel, Crosby, Reising, & Sole, 2014; Porter et al., 2011) and fatigue (Frambes et al., 2017). One study (Frambes et al., 2017) also described a positive effect on depression of friends of patients with breast cancer who were taught to deliver the intervention as well as perhaps a gender difference in the impact of the intervention on physical functions, with women showing better physical functioning than men. A systematic review of 27 studies (Griffin et al., 2013) looking at family-focused interventions, indicated that a family focus did not improve burden, although when looking at specific interventions, it was suggested that skill training aimed at the family did have a positive effect. The conflicting results may be a result of the quality of studies as well as the types of interventions. It is

possible that those delivered to the family versus the caregiver or the patient-caregiver dyad have different effects.

**COUPLES THERAPY:** Couples therapy, a counseling intervention, is delivered to the dyad by a professional psychologist. The focus is on improving interpersonal processes to enhance the quality and intimacy of the relationship (ONS, 2017). Two studies showed that couples therapy improved marital function and/or relationship quality and intimacy, but did not improve mood or caregiver burden (McLean, Walton, Rodin, Esplen, & Jones, 2013; Porter et al., 2011). Another study (Barth, Delfino, & Kunzler, 2013) reported a significant decrease in anxiety and distress for those caregivers who were highly distressed at baseline.

**DECISION SUPPORT/DECISION AID:** Decision support/decision aid interventions are designed to alleviate decision conflict and facilitate patient decision making to improve patient outcomes and reduce caregiver strain. A variety of techniques are applied, including videos, workbooks, decision-making tools, and/or counseling (ONS, 2017). Facilitating discussions between patients and caregivers about patient decision-making preferences improves some caregiver outcomes. A multisite RCT showed improvement in decision conflict, uncertainty, and depression (Yun et al., 2011). Another multisite RCT involving 46 dyads of patients with gastrointestinal cancer and their caregivers, who are designated as surrogates, did not show improvement in surrogate confidence in shared decision making and showed an increase in caregiver burden. However, it did significantly decrease surrogate stress and increase surrogate satisfaction in their level of involvement in the patient decision-making process (Sulmasy et al., 2017).

**MINDFULNESS-BASED STRESS REDUCTION:** Mindfulness-based stress reduction (MBSR) is a structured intervention led by a trained professional to improve mindfulness, or awareness of the present moment, using meditative practices, body awareness, and yoga. Two individual studies suggest that MBSR therapy is likely to be effective in improving mood (Birnie, Garland, & Carlson, 2010; Fegg et al., 2013), and one study (van den Hurk, Schellekens, Molema, Speckens, & van der Drift, 2015) demonstrated improved caregiver burden.

**MULTICOMPONENT INTERVENTIONS:** Multicomponent interventions are combination therapies. They include a combination of educational, supportive, psycho-therapeutic, and respite therapies (ONS, 2017). One systematic review focused on caregivers of patients with cancer that document several positive outcomes from multicomponent interventions. Northouse et al. (2010) reviewed 29 RCTs with 3,495 participants and demonstrated significant increases in coping and self-efficacy with face-to-face and group methods and an improvement in caregiver burden and the positive effects of caring. Caress et al. (2009) conducted a narrative review of 19 studies (N = 3,289) and concluded no clear efficacy of multicomponent interventions for

**TABLE 2.**  
 LIKELY TO BE EFFECTIVE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Caregiver training and skill development</b>			
Belgacem et al., 2013	Caregiver educational program; RCT with 67 dyads	Intervention group caregivers had improvement in quality of life. Burden was lower than controls ( $p < 0.05$ ) 3 months later.	<ul style="list-style-type: none"> <li>■ No blinding</li> <li>■ Data collection</li> <li>■ Intervention potentially too rigorous</li> </ul>
Frambes et al., 2017	Caregivers trained in reflexology and performed on patient; RCT with 180 caregivers	Caregivers in the intervention group had improvements in fatigue at weeks 5 ( $p = 0.02$ ) and 11 ( $p = 0.05$ ).	<ul style="list-style-type: none"> <li>■ Risk of bias (sample characteristics)</li> <li>■ Key sample group differences that could influence results</li> <li>■ Intervention expensive, impractical</li> <li>■ Participant withdrawals 10% or greater</li> </ul>
Griffin et al., 2013	Psychosocial/psychoeducation intervention provided to family; systematic review of 27 studies with 3,354 patients	Family focus did not appear to reduce caregiver burden. Some suggestion that skill training aimed at the family had a positive effect	<ul style="list-style-type: none"> <li>■ Only 2 studies were good quality</li> <li>■ Lack of data in some studies</li> </ul>
Hendrix et al., 2009	Caregiver training in managing patient symptoms; pre-/post-test design with 16 caregivers	Caregiver self-efficacy was higher after training and at 1 week.	<ul style="list-style-type: none"> <li>■ No caregiver burden/strain measure</li> </ul>
Hendrix et al., 2013	Caregiver training in managing patient symptoms; RCT with 120 dyads (patients with hematologic malignancies)	Increased self-efficacy following training and better symptom management and caregiver anxiety in group by time ( $p = 0.008$ ) to 3 weeks. No significant effect on caregiver quality of life or longer-term outcomes	<ul style="list-style-type: none"> <li>■ No blinding</li> <li>■ 4 weeks post-hospital discharge only</li> </ul>
Hendrix et al., 2016	Caregiver training in symptom management as well as caregiver stress management versus usual care given information on resources; RCT with 76 caregivers	Significant difference between intervention and control for self-efficacy	<ul style="list-style-type: none"> <li>■ Sample size</li> <li>■ No blinding</li> </ul>
Loerzel et al., 2014	Training in tracheotomy care; quasiexperimental design with 11 caregivers	Anxiety scores declined after the intervention ( $p = 0.008$ ).	<ul style="list-style-type: none"> <li>■ Sample size</li> </ul>
Porter et al., 2011	Caregiver training in symptom management and coping skills training compared to education and support; RCT with 233 dyads	Intervention associated with main effect for anxiety ( $p = 0.02$ ) and self-efficacy ( $p = 0.01$ ); both groups had decline in anxiety	<ul style="list-style-type: none"> <li>■ No pure control group</li> </ul>
<b>Couples therapy</b>			
Barth et al., 2013	Patients and partners referred for psycho-oncology therapy; naturalistic design with 43 patients and 27 partners	Significant decline in anxiety and distress among highly distressed partners ( $d = 0.42$ , $p < 0.02$ ), but no difference in those not highly distressed at baseline	<ul style="list-style-type: none"> <li>■ Distress measure not stated</li> <li>■ No evaluation of treatment specifics or fidelity</li> </ul>
McLean et al., 2013	Emotion-focused couples therapy; RCT with 42 dyads	Improvement in marital functions with treatment; no difference between groups in caregiver burden, hopelessness, or depression	<ul style="list-style-type: none"> <li>■ No attention control</li> <li>■ No blinding</li> <li>■ Small sample</li> </ul>
Porter et al., 2011	Training and therapy in skills to disclose and communicate acceptance and understanding; RCT of 132 dyads	Improved relationship quality and intimacy ( $p < 0.02$ ); no effect on mood	<ul style="list-style-type: none"> <li>■ No blinding</li> <li>■ Attrition rate</li> </ul>
<b>Decision support/decision aids</b>			
Sulmasy et al., 2017	Nurse-facilitated discussion intervention between patients and their caregivers (surrogates) about the role patients would prefer their surrogates play when they are unable to make decisions; RCT with 137 dyads	Surrogate stress declined significantly from baseline to follow-up in the treatment group. At follow-up, treatment group stress score was 20% lower than that of control. Caregiver burden increased from baseline to follow-up in treatment group.	<ul style="list-style-type: none"> <li>■ Risk of bias (no blinding)</li> <li>■ Key sample group differences that could influence results</li> <li>■ Questionable protocol fidelity</li> <li>■ Participant withdrawals of 10% or greater</li> </ul>

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**TABLE 2. (CONTINUED)**

LIKELY TO BE EFFECTIVE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Decision support/decision aids (continued)</b>			
Yun et al., 2011	Decision aid to discuss death with family members; RCT with 119 dyads	Decisional conflict, uncertainty, and value improved in treatment group. Depression scores significantly improved with treatment.	<ul style="list-style-type: none"> <li>At post-test only, 27% of sample remained (underpowered)</li> </ul>
<b>Mindfulness-based stress reduction</b>			
Birnie et al., 2010	MBSR intervention; pre-/post-test design with 21 couples	Post program, patients and partners had reduction in mood disturbance, muscle tension, fatigue, and upper respiratory symptoms ( $p < 0.05$ )	<ul style="list-style-type: none"> <li>Small sample</li> <li>No control/comparison</li> </ul>
Fegg et al., 2013	Existential behavioral intervention; RCT with 133 caregivers	Immediate post effects medium to large on anxiety ( $p = 0.006$ ) and quality of life measures; at 3 months, no significant effect; at 12 months, medium effects on depression ( $p = 0.04$ ) and overall quality of life	<ul style="list-style-type: none"> <li>No blinding</li> <li>No attention control</li> <li>Group versus intervention impact</li> </ul>
van den Hurk et al., 2015	MBSR intervention; quasiexperimental design with 19 patients and 16 caregivers	Caregiver burden decreased postintervention and at 3 months ( $p < 0.01$ ).	<ul style="list-style-type: none"> <li>Sample size</li> </ul>
<b>Multicomponent interventions</b>			
Caress et al., 2009	Review of various types of interventions; narrative review of 19 studies with 3,286 caregivers	High variability among studies in cancer stage and phase of care; no clear efficacy of intervention types	<ul style="list-style-type: none"> <li>Variability among studies</li> </ul>
Groh et al., 2013	Multicomponent proactive care services; quasiexperimental design with 60 patients and 52 caregivers	Patient and caregiver burden improved ( $p < 0.001$ ); 30% reduction in proportion of caregivers with clinically relevant anxiety scores ( $p < 0.001$ )	<ul style="list-style-type: none"> <li>No control group</li> <li>No blinding</li> <li>Burden questionnaire with an unknown validity measure</li> </ul>
Hutchinson et al., 2011	Community-based counseling service; pre-/post-test design with 681 patients and 520 caregivers	Both patients and caregivers showed decreased distress after completion of sessions ( $p < 0.001$ ); 86% had 5 sessions; caregivers had more baseline distress than patients ( $p < 0.001$ )	<ul style="list-style-type: none"> <li>Distress thermometer only measure</li> <li>No blinding (data collection by support line staff)</li> </ul>
Lim et al., 2016	Home hospice services compared to palliative care as outpatient; cross-sectional with 258 participants	With home hospice, better caregiver overall quality of life scores ( $p = 0.008$ ) and scores regarding financial worry/burden ( $p = 0.004$ )	<ul style="list-style-type: none"> <li>Limited to Chinese caregivers</li> </ul>
Mattila et al., 2009	Nursing interventions; systematic review of 22 quantitative, 4 qualitative, and 5 mixed method studies	Interventions involving education, counseling, and use of both individual and group activities can assist a variety of caregivers.	<ul style="list-style-type: none"> <li>Majority included patients with cancer, but other patient types included</li> <li>Most studies were aimed at single family members rather than the wider context.</li> </ul>
Northouse et al., 2010	Various psychoeducational and skills training supportive interventions delivered to caregivers; systematic review and meta-analysis of 29 RCTs involving 3,495 participants	Coping and self-efficacy significantly improved by face-to-face and group methods aimed at improving caregiver coping; burden and positive effect of caregiving positively influenced with small effect sizes	<ul style="list-style-type: none"> <li>Effects seen were statistically significant, but positive effect sizes were small</li> </ul>
Titler et al., 2017	FOCUS, a psychoeducational intervention delivered to dyads; pre-/post-intervention study with 36 dyads	Significant positive effects on dyad quality of life, emotional well-being, functional well-being, and emotional distress; significant effect on benefits of illness and self-efficacy; FOCUS was feasible; high satisfaction among caregivers about helpfulness of intervention, length of sessions, and number of sessions	<ul style="list-style-type: none"> <li>Small sample (less than 100)</li> <li>Risk of bias (no control group)</li> <li>Risk of bias (sample characteristics)</li> <li>Intervention expensive, impractical</li> <li>Administered by trained social worker/family therapist</li> <li>Results reported as a dyad, not caregiver</li> </ul>

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**TABLE 2. (CONTINUED)**

LIKELY TO BE EFFECTIVE: CAREGIVER STRAIN AND BURDEN

STUDY	INTERVENTION DESIGN AND SAMPLE	SIGNIFICANT FINDINGS	STUDY LIMITATIONS
<b>Palliative care</b>			
Dionne-Odom et al., 2015	Early versus delayed palliative care; RCT with 122 caregivers	Early group showed decline in depression ( $d = -0.32, p = 0.02$ ); no other differences; among caregivers of those who died, depression and stress burden were greater ( $p < 0.02$ ). Both groups showed decline in all measures.	<ul style="list-style-type: none"> <li>32% did not complete all measures; by measure 3, only 79 caregivers remained across both groups.</li> </ul>
El-Jawahri et al., 2017	Early integrated palliative care; RCT with 275 caregivers	At 12 weeks, the intervention group has significantly lower total psychological distress (anxiety and mood) assessed by HADS total score ( $p = 0.029$ ). At 24 months, no significant differences between the two groups for any of the outcomes. Using terminal decline model, caregivers in the intervention group had significantly lower HADS total scores (and lower scores on the depression and anxiety subscales) (95% CI [4.11, 9.58]).	<ul style="list-style-type: none"> <li>Risk of bias (no blinding)</li> <li>Unintended interventions or applicable interventions not described that would influence results</li> <li>Intervention expensive, impractical, or training needs</li> <li>Questionable protocol fidelity</li> </ul>
Gomes et al., 2013	In-home palliative care service; systematic review and meta-analysis of 23 studies with more than 30,000 participants	No impact on caregivers seen	<ul style="list-style-type: none"> <li>High heterogeneity (some across various countries)</li> </ul>
Kavalieratos et al., 2016	Palliative care interventions; systematic review and meta-analysis of 30 studies with 2,479 caregivers	Insufficient evidence to determine caregiver outcomes	<ul style="list-style-type: none"> <li>High heterogeneity</li> <li>Differences in palliative care interventions</li> </ul>
McDonald et al., 2017	Early palliative care referral versus usual care; RCT with 182 participants	Caregiver satisfaction was greater in the palliative care group, but no difference in quality of life or other measures; no correlation between palliative care visits and outcomes	<ul style="list-style-type: none"> <li>Complex intervention, but no information about other interventions</li> </ul>
O'Hara et al., 2010	Palliative care versus usual care; RCT with 198 participants	No improvement in caregiver burden demonstrated	<ul style="list-style-type: none"> <li>High drop-out rate</li> </ul>
Sun et al., 2015	Palliative assessment and care plan compared to usual care; prospective non-random design with 354 dyads	Caregivers in study group had improved social well-being ( $p < 0.001$ ) distress ( $p < 0.001$ ), and reported less burden or life disruption ( $p < 0.001$ )	<ul style="list-style-type: none"> <li>Usual care was not described.</li> </ul>

CI—confidence interval; HADS—Hospital Anxiety and Depression Scale; MBSR—mindfulness-based stress reduction; RCT—randomized controlled trials

caregivers. In addition, a few individual studies support a positive effect with decreased caregiver burden and anxiety (Groh, Vyhnalek, Feddersen, Führer, & Borasio, 2013) and decreased distress (Hutchison et al., 2011).

**PALLIATIVE CARE:** Palliative care is the provision of service with an approach aimed at improving QOL of patients and families through prevention and relief of suffering from physical, psychosocial, and spiritual distress. This type of intervention refers to ongoing patient management by healthcare providers who have expertise in this approach (ONS, 2017).

Two systematic reviews (Gomes, Calanzani, Curiale, McCrone, & Higginson, 2013; Kavalieratos et al., 2016), one large prospective non-randomized two-group study (Sun et al., 2015), and four large RCTs ( $N > 100$ ) (Dionne-Odom et al., 2015; El-Jawahri et al.,

2017; McDonald et al., 2017; O'Hara et al., 2010) have examined the impact of adding palliative care services on caregiver burden. Overall, the systematic reviews were inconclusive regarding the impact of palliative care, most likely related to high heterogeneity among the studies reviewed as well as the diversity in the palliative care interventions. However, one review (Gomes et al., 2013) cited two studies (Hudson, 2005; McMillan, 2007) that showed specific positive effects on appreciation of the benefits of caring. Three large RCTs specifically focused on patients with cancer and their caregivers reporting an improvement in caregiver satisfaction (McDonald et al., 2017) and improvement and/or stabilization of caregiver psychological distress (Dionne-Odom et al., 2015; El-Jawahri et al., 2017). Finally, although one large study by Sun et al. (2015) reported an improvement of social well-being,

distress, and burden, another RCT by O'Hara et al. (2010) did not find an improvement in burden, possibly related to the high dropout rate of caregivers in the study.

### Effectiveness Not Established

A variety of other interventions have been studied, and many demonstrate mixed results. In most cases, the majority of the 19 studies published since 2007 have small samples and/or produced inconclusive findings due to study design limitations. Thirteen of these studies involved complementary or alternative interventions, including art (Walsh, Radcliffe, Castillo, Kumar, & Broschard, 2007), music (Lai, Li, & Lee, 2012), massage/aromatherapy (Cronfalk, Ternstedt, & Strang, 2010; Lopez et al., 2017; Pinar & Afsar, 2015), meditation (Dharmawardene, Givens, Wachholtz, Makowski, & Tjia, 2016), yoga (Martin & Keats, 2014; Milbury et al., 2015), exercise (Barber, 2013), expressive writing, emotional disclosure, journaling (Duggleby et al., 2013; Harvey-Knowles, Sanders, Ko, Manusov, & Yi, 2017), and spiritual interventions (Mosher et al., 2018; Sankhe, Dalal, Agarwal, & Sarve, 2017).

Fraught with similar design limitations and/or small sample sizes, a few of the interventions that focused on healthcare providers produced insufficient evidence for effectiveness in improving caregiver outcomes. These interventions include adding palliative care advisor services to affect caregivers' outcomes (Walsh, Jones, et al., 2007) and additional training of healthcare providers to improve their communication skills (Lienard et al., 2008) or their palliative care knowledge and skills (Maeda et al., 2016; Mitchell et al., 2013). Similarly, other interventions that involved provision of orientation and information (Otani et al., 2014) or performing structured assessment (McMillan, Small, & Haley, 2011) did not produce sufficient evidence to support the effectiveness of these interventions. Of note,

### IMPLICATIONS FOR PRACTICE

- Assess caregiver strain and burden routinely and comprehensively and consider its impact on the caregiver, the patient, and the family.
- Counsel caregivers regarding specific interventions that are recommended for caregiver strain, such as reframing negative thoughts, problem solving, and coping.
- Collaborate with the interprofessional team and facilitate referrals of caregivers to services and resources that would help them mitigate the impact of caregiver strain and burden.

the majority of these studies involved interventions at advanced phases of palliative care and/or hospice.

### Benefits Balanced With Harms, Effectiveness Unlikely, and Not Recommended for Practice

Three weight of evidence categories are used to categorize studies that have sufficient evidence to suggest that one should avoid recommendation of the intervention or, in certain cases, recommend against the use of the intervention: benefits balanced with harms, effectiveness unlikely, and not recommended for practice (Mitchell & Friese, n.d.). To date, there are no intervention studies large enough in size or number to indicate that a particular type of intervention must be used with caution or is harmful or ineffective in decreasing caregiver distress.

### Discussion

Interventions designed to improve various outcomes in caregivers of patients with cancer have grown markedly since the last PEP publication (Honea et al., 2008). The proliferation of studies may reflect the rise in concern for caregivers. The Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregiver Act of 2017 (42nd U.S.C. 3030, public law 115-119) became law in January 2018, requiring the U.S. Secretary of Health and Human Services to develop, maintain, and update a strategy to recognize and support family caregivers (AARP, 2019). Caregiving has

**TABLE 3.**  
INSTRUMENTS TO ASSESS CAREGIVER OUTCOMES IN CLINICAL SETTINGS

OUTCOME	TOTAL INSTRUMENTS	NAME OF INSTRUMENT, ITEM TOTAL, AND SOURCE*
Caregiver burden	26	<ul style="list-style-type: none"> <li>■ Brief Assessment Scale for Caregivers (BASC): 14 items (Glajchen et al., 2005)</li> <li>■ Caregiving Consequences Inventory (CCI): 16 items (Sanjo et al., 2009)</li> </ul>
Caregiver needs	14	<ul style="list-style-type: none"> <li>■ Family Inventory of Needs: 20 items (Kristjanson et al. 1995)</li> <li>■ Palliative Care–Needs Assessment (PC-NAT): 18 items (Waller et al., 2008)</li> </ul>
Caregiver quality of life	9	<ul style="list-style-type: none"> <li>■ Caregiver Quality of Life Index: 4 items (McMillan &amp; Mahon, 1994)</li> <li>■ Family Pain Questionnaire (FPQ): 13 items (Ferrell et al., 1993)</li> <li>■ Quality of Life in Life-Threatening Illness–Family Carer Version (QoLLTI-F): 16 items (Cohen et al., 2006)</li> </ul>
Caregiver satisfaction with care	5	<ul style="list-style-type: none"> <li>■ Caregiver Evaluation of Quality of End-of-Life Care (CEQUEL): 13 items (Higgins &amp; Prigerson, 2013)</li> <li>■ FAMCARE: 20 items (Kristjanson, 1993)</li> </ul>
Other aspects of caregiving	5	<ul style="list-style-type: none"> <li>■ None with 20 items or less</li> </ul>

\*Self-report instruments; less than 20 items; with reliability and validity; adult patients with cancer  
**Note.** Based on information from Tanco et al., 2017.

also been acknowledged on the state level through the introduction and the enactment of the Caregiver Advise, Record, Enable (CARE) Act (AARP, 2014). The goal of the CARE Act is to improve the preparedness of caregivers and requires that hospitals work closely with family caregivers when admitting and discharging patient.

Caregivers of patients with cancer take on a wide range of complex roles and tasks. As a result, their burden is often multifaceted (Bevans & Sternberg, 2012; Kim & Schulz, 2008). Therefore, interventions to alleviate their burden should also be multifaceted and respond to the complex nature of their needs (Bevans & Sternberg, 2012; Kent et al., 2016). The interventions reviewed in the published studies mirror the complex nature of caregiving and how it affects caregivers of patients with cancer. Several interventions have been shown to be effective. The review revealed that such interventions are moving slowly, but more increasingly, to the clinical community where they can be readily accessed and beneficial to caregivers and patients. The fact that a number of

these interventions are effective is not enough to ensure that they are used. Several components interact to facilitate, or hinder, the uptake of these interventions by the recipients (caregivers) and providers (i.e., nurses and members of the healthcare team). Administrators who make decisions, and entities that advocate and help to institute interventions as routine practices, all play a role in ensuring that caregivers receive interventions that target their strain and burden (Ratcliff, Vinson, Milbury, & Badr, 2019). A number of the caregiving interventions are complex and require funding, training, and/or interprofessional team effort, which may or may not be available in resource-challenged settings.

Nurses can begin, first and foremost, by acknowledging that caregivers are an integral part of the healthcare team and that the demands of caring can be significant. They should routinely assess for caregiver needs by direct observation and informal screening. This can be as simple as directly asking the caregiver how they are doing or using an available assessment tool.

Tanco et al. (2016) identified 59 instruments to assess outcomes of caregivers of patients with cancer. The majority of these instruments are based on self-report and are for caregivers of adult patients with cancer. Of the 59 instruments, 13 were identified by Tanco et al. (2016) as valid, reliable, and appropriate for use by clinicians because they had less than 20 items. Although the number of items (less than 20) is a pragmatic way to evaluate the usability and appropriateness of these tools in busy clinical settings, it may not be the best parameter. Overall, the instruments fell into five categories that assessed caregiver needs, burden, QOL, satisfactions with care, and other. Table 3 summarizes examples of the instruments to assess these categories and highlights the ones that were recommended for use by clinicians because they had 20 items or less.

### Implications for Practice

Hospital, clinic, and advanced practice nurses are well positioned to provide quality care for patients with cancer, which includes caring for the caregiver. Nurses have an opportunity to promote caregivers' health and well-being and to influence the quality of care that patients receive at home.

Nurses can assess for caregiver needs by direct observation and informal screening. This can be as simple as directly asking the caregiver how they are doing or using an available assessment tool. Caregivers can be observed or asked directly about their level of distress and whether they need support. Nursing interventions that have been recommended for practice include psychoeducation, CBT, and supportive interventions. Figure 2 serves as a quick reference for the current status of evidence related to interventions. The ONS website offers a plethora of written resources and educational videos for practicing nurses about assessment of caregiver strain and burden and interventions that nurses can offer; these resources can be accessed at [www.ons.org/pep/caregiver-strain-and-burden](http://www.ons.org/pep/caregiver-strain-and-burden).

**FIGURE 2.**  
CAREGIVER STRAIN AND BURDEN  
INTERVENTIONS AND STATUS OF EVIDENCE

**RECOMMENDED FOR PRACTICE**

- Psychoeducation interventions
- Supportive interventions
- Cognitive behavioral interventions/approach

**LIKELY TO BE EFFECTIVE**

- Caregiver training and skill development
- Couples therapy
- Decision support/decision aids
- Mindfulness-based stress reduction
- Multicomponent interventions
- Palliative care

**EFFECTIVENESS NOT ESTABLISHED**

- Art making/art therapy
- Provider communication skill training
- Family focused grief therapy
- Massage/aromatherapy massage
- Palliative care advisor services
- Music/music therapy
- Structured assessment
- Healthcare provider interventions
- Expressive writing, emotional disclosure, journaling
- Yoga
- Exercise
- Meditation
- Orientation and information provision
- Spiritual intervention

By providing information on the caregiver role and disease-specific education and counseling, nurses have an opportunity to increase caregiver competence and confidence. Content may include specifics of the caregiver role—for instance, organizing care and communication with the healthcare team—or specific tasks, such as medication administration or symptom management. Instruction on problem solving and positive coping has been shown to have positive outcomes. Nurses are also in a key position to actively listen and help caregivers identify faulty beliefs or concepts that they may have about the illness and/or caring, and work toward reframing of those thoughts and beliefs in a more positive manner. Nurses can collaborate with social workers and patient navigators so that they aware of what support resources are available to caregivers and are able to access the information easily and encourage caregivers to take advantage of the support that is available to them.

Nurses can offer additional interventions that seem likely to be effective, such as caregiver training and skill development. Nurses are encouraged to use the relationships developed with caregivers to suggest couples therapy to promote communication, decision support, and decision assistance to help with advanced care planning and MBSR courses for stress management. Multicomponent interventions that include combinations of educational, supportive, psychotherapeutic, and respite care have also been shown as likely to be effective. Finally, nurses who are open and flexible can provide a variety of strategies as needs emerge and resources permit. These could include information, education, emotional support, and referrals for additional support when needed to reduce caregiver strain and burden.

## Conclusion

Several interventions are recommended for practice to reduce caregiver strain and burden. These interventions fall into the categories of psychoeducational, supportive, and CBT interventions. However, because these interventions are often bundled and can be delivered in various ways (e.g., face-to-face or virtually, to caregivers alone, to patient-caregiver dyads), it is challenging to evaluate which component has the most or least impact, and to discern whether the mode of delivery attenuated or enhanced the efficacy of these interventions. Therefore, whether the results are related more to a specific component of the intervention under investigation or perhaps the method of how it was delivered must be considered. Additional research is needed to determine evidence-based components of an intervention, the optimal frequency and intensity of administering it, tailoring it to a changing nature of a caregiver's needs, and assessments throughout the intervention to determine its effectiveness.

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