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Care for the cancer caregiver: A systematic review

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Abstract

Objective—Informal caregivers (ICs) are relatives, friends, and partners who have a significant relationship with and provide assistance (i.e., physical, emotional) to a patient with a life-threatening, incurable illness. The multidimensional burden that results from providing care to a patient with cancer is well documented, and as a result, a growing number of psychosocial interventions have been developed specifically to address this burden. The purpose of the present study was to characterize the state of the science of psychosocial interventions for informal cancer caregivers.

Method—A comprehensive systematic review of interventions for cancer caregivers was conducted via an electronic literature search of publications between 1980 and January 13, 2011. A final sample of 49 interventions was reviewed in detail.

Results—The interventions, which varied in terms of modality and patient population, fell into the following eight categories: psychoeducation, problem-solving/skills building interventions, supportive therapy, family/couples therapy, cognitive-behavioral therapy, interpersonal therapy, complementary and alternative medicine interventions, and existential therapy. Benefits and disadvantages of each of the categories are discussed, with special attention given to studies that produced null findings.

Significance of results—Beyond specific techniques, structured, goal-oriented, and time-limited interventions that are integrative appear to be the most feasible and offer the greatest benefits for ICs of cancer patients. Future studies are needed to examine the specific benefits and challenges of delivering interventions in alternative modalities (Internet, Skype) so that the needs of a greater number of ICs may be addressed.

Keywords

Cancer caregivers; Caregiver burden; Psychosocial interventions

INTRODUCTION

There is growing recognition that comprehensive care for cancer patients involves attending to the psychosocial needs of their informal caregivers, as well as the various needs of the patients themselves (Breitbart & Alici, 2009). Informal caregivers (ICs) are defined as any relatives, friends, or partners who have a significant relationship with and provide assistance

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(i.e., physical, emotional) to a patient with a life-threatening, incurable illness (Hudson & Payne, 2009). In 2009, 65,700,000 people in the United States served as ICs for medically ill relatives, including 4,600,000 cancer patients (National Alliance for Caregiving, 2009). This number may be a reflection of the rising costs of healthcare, which have placed the responsibility of caring for the chronically medically ill – including cancer patients – on family caregivers (Pasacreta & McCorckle, 2000). As the number of ICs will likely continue to rise in the future, special attention should be paid to the unique burden of ICs, not only for the benefit of the caregiver but also for that of the patient.

CAREGIVER BURDEN

Providing care to a patient with cancer has been described as a full-time job (Rabow et al., 2004). When family/friends become caregivers, they take on the responsibilities of the patient and the household, in addition to their own, which often leads to caregiver burden (e.g., Vess et al., 1985; Northouse, 1989; Siegel et al., 1991; Schott-Baer, 1993; Kissane et al., 1994; Boyle et al., 2000; Kuijter et al., 2002). Given et al. (2001a, p. 5) describe such burden as a “multidimensional biopsychosocial reaction resulting from an imbalance of care demands relative to caregivers’ personal time, social roles, physical and emotional states, financial resources, and formal care resources given the other multiple roles they fulfill” (as cited in Given et al., 2001b). ICs are often unprepared to take on all of the aspects that this new role entails (Hinds, 1985; Morse & Fife, 1998; Northouse et al., 2000; Carlson et al., 2001; Given et al., 2001b; Nijboer et al., 2001; Bishop et al., 2007) and often have a wide range of unmet needs (Northouse, 1984; Hileman et al., 1992; Laizner et al., 1993; Covinsky et al., 1994; Kissane et al., 1994; Hodgkinson et al., 2007; Kim & Given, 2008). Not only do ICs face the physical and emotional demands associated with caregiving, but, also, the patients for whom they provide care may no longer be able to provide them with the emotional support that they once did (Francis et al., 2010). Therefore, ICs are not only often unprepared to provide instrumental support (i.e., the “doing” of caregiving), but they also often may be in great need of emotional support themselves.

Perhaps not surprisingly, then, ICs experience a range of psychological complications (Ell et al., 1988; Johnson, 1988; Pederson & Valanis, 1988; Northouse, 1989; Oberst, 1989; Sales, 1991; Kissane et al., 1994; Toseland et al., 1995; 1999; Weitzner et al., 1999; Emanuel et al., 2000; Manne, 2007; Murray et al., 2010), including fear, hopelessness, and mood disturbances (Dumont et al., 2006; Oldham et al., 2006). Studies have reported rates of anxiety and depression among family caregivers that are comparable to (Given et al., 1993, 2006; Kornblith et al., 1994; Baider et al., 1996; Cliff & MacDonagh, 2000; Kris et al., 2006; Rivera, 2009) and even surpass (Baider et al., 1988, 1989; Ey et al., 1998; Cliff & Macdonagh, 2000; Gallagher et al., 2002; Braun et al., 2007; McLean et al., 2011) those of the patients for whom they provide care. For example, rates of depression between 12 and 59% (Grunfeld et al., 2004; Hauser & Kramer, 2004) and anxiety between 30 and 50% (Grunfeld et al., 2004) have been reported in samples of family caregivers, in comparison to rates of depression between 10 and 25% (Pirl, 2004) and rates of anxiety between 19 and 34% (Traeger et al., 2012) in patient samples.

In addition to mental health issues, ICs also experience a range of physical health complications as a result of their role (e.g., Burton et al., 1997; Given & Given, 1992; Given et al., 2004). These include sleep difficulties (Carter, 2003; Cho et al., 2006; Hearson & Clement, 2007), fatigue (Jensen & Given, 1991; Teel & Press, 1999), cardiovascular disease (Lee et al., 2003; von Kanel et al., 2008), poor immune functioning (Kiecolt-Glaser et al., 1987; Rohleder et al., 2009), and increased mortality (Schulz & Beach, 1999; Christakis & Allison, 2006). Studies have also reported an increase in alcohol and tobacco use, lack of exercise, and decreased health service utilization among family caregivers (e.g., Riess-Sherwood et al., 2002; Sherwood et al., 2008).

Additionally, caring for a patient with cancer places a large financial and temporal demand on those providing care (e.g., Hauser & Kramer, 2004; Grov et al., 2006). Data from a national survey of caregivers showed that, on average, cancer caregivers provide care for 8.3 hours each day for 13.7 months (Yabroff & Kim, 2009), and that this care includes providing emotional, instrumental, tangible, and medical support. Moreover, the annual economic value of caregiving in the United States was recently estimated at \$375 billion (National Alliance for Caregiving, 2009). Therefore, the burden experienced by ICs is multifaceted and includes the potential for significant psychological, physical, temporal, and financial demands.

STUDY PURPOSE

This recognition of the importance and needs of ICs has been met by the development of an increasing variety of psychosocial interventions designed specifically to address these needs. Such interventions range from psychoeducation to cognitive behavioral therapy to supportive psychotherapy delivered to individuals, couples, and groups, in person, over the phone, and via the Internet. Recent meta-analyses (Northouse et al., 2010) and systematic reviews (Harding & Higginson, 2003; McMillan, 2005; Hudson et al., 2010) have highlighted the potential for various interventions (i.e., psychoeducational, skill building, supportive) to ameliorate the burden experienced by ICs. These studies have also highlighted the great variation in study design and stage of development of current interventions targeted to ICs of cancer patients. Such variations may serve as potential limitations, such that many pilot studies and quasi-experimental designs without reported effect sizes cannot be evaluated via meta-analyses. Additionally, as was noted by Harding and Higginson (2003), rarely are null findings reported. However, such studies serve as sources of rich descriptive information regarding intervention feasibility and elements of interventions that are potentially efficacious. Caregiver intervention research is a relatively new area of study, and therefore attention should be paid to studies that are not yet presented as randomized clinical trials. Indeed, in their systematic review of interventions for caregivers of cancer patients using home or palliative care services, Harding and Higginson (2003) acknowledge that their review is limited by the ability to implement a randomized controlled trial (RCT) in the palliative care population, and that additional thought should be given to studies of interventions at earlier stages of development, a conclusion echoed by Hudson et al. (2010).

The purpose of the present study was to characterize the state of the science of psychosocial interventions for informal cancer caregivers. This comprehensive systematic review was

inclusive of RCTs, as well as interventions not yet at the RCT level (i.e., pilot studies). Additionally, by including ICs of patients across the entire cancer trajectory we sought to expand upon the recent review of Hudson et al. (2010), which was limited to interventions delivered to ICs of patients receiving palliative care. The current review was also inclusive of interventions conducted with ICs of patients across all cancer diagnoses and in varying relationships (i.e., spouse, child, parent) to the patient.

METHOD

A medical librarian conducted a literature search in the following databases: PubMed, Embase, Cumulative Index to Nursing and Allied Health Literature (CI-NAHL®), PsycINFO® via the Ovid platform, and the Cochrane Library via the Wiley platform. Although limits were not placed on language or publication type, only publications from 1980 to the present were selected. Controlled vocabulary (Medical Subject Headings [MeSH], Emtree, CINAHL Subject Headings, and PsycINFO Subject Headings) as well as keywords were used. PubMed was last searched on January 13, 2011. The PubMed search strategy and terminology were modified for other databases.

Three broad categories of concepts were searched, and the results were combined using the Boolean operator *and*. The broad categories included: 1) non-professional caregivers of people with illness/disease; 2) the psychosocial impact of the IC role; and 3) interventions or coping mechanisms that ease negative impacts of this role. Each of these broad categories had multiple terms that were combined using the Boolean operator *or*.

Search terms for the caregiver category included *caregiver(s)* combined in various ways *with spouse, family, informal, or partner*. Terms for the psychosocial category included *caregivers/psychology, burden, strain, irritability, concentration, vulnerable, demand, mental health, psychosocial, anxiety, depression, depressed, confidence, bereavement, grief, unmet need, psychological, or sleep*. Terms for the intervention category included *adjustment, psychological adaptation, intervention, resilience, resilient, treatment, therapy, psychotherapy, uplift, hope, support, effect, existential, spiritual, spirituality, religious, religion, emotional, meaning, cultural, faith, cope, coping, resource, resources, education, educational, creative, creativity, music, movement, intervention studies, program evaluation, social support, 'religion and psychology', benefit, acceptance, positive, appreciation, or empathy*.

This search produced 2,199 articles. Titles were scanned and abstracts of 76 articles were retrieved for review by both authors of this article to identify studies evaluating psychosocial interventions for caregivers of patients with cancer. Any differences of opinion in these initial review phases were settled through discussion. Reference sections of the retrieved articles were also scanned for relevant studies, which produced an additional 42 articles to be reviewed.

Data were then abstracted twice from 49 relevant articles using a standardized data abstraction form. This involved a primary reviewer, who completed the data abstraction form, and a secondary reviewer, who checked the primary review for accuracy and

completeness. Data captured on the abstraction forms included the type of intervention evaluated and mode of delivery, the type of patients being cared for (including cancer diagnosis and stage), the relationship between the caregiver and patient (i.e., spouse, child, parent, friend), and study design. Both reviewers performed an independent assessment of the studies' eligibility, and unresolved disagreements between reviewers were adjudicated by a third reviewer from the Psychotherapy Laboratory in the Department of Psychiatry and Behavioral Sciences at Memorial Sloan-Kettering Cancer Center. Studies not eligible for review were categorized into one of the following reasons for exclusion: participants were not caregivers, caregivers were providing care for non-cancer patients, and articles were written in languages other than English.

RESULTS

A final sample of 49 interventions was reviewed. Seventy three percent ($n = 36$) of these were delivered completely in person, 6% ($n = 3$) were delivered over the phone, and 20% ($n = 10$) combined in-person and telephone-delivered components. Twenty-eight percent ($n = 14$) of the interventions were delivered individually to ICs, 47% ($n = 23$) were delivered to the IC/partner (or family) dyad/unit, 16% ($n = 8$) to groups of ICs, and 8% ($n = 4$) to groups composed of both ICs and patients.

In terms of the relationship between ICs and the patients for whom they provided care, 39% ($n = 19$) of the interventions were delivered specifically to spouse/partner ICs, 4% ($n = 4$) to parents, 45% ($n = 22$) to ICs in mixed relationships to patients, and 10% ($n = 5$) did not specify the relationship between the IC and patient. Additionally, 31% ($n = 15$) of the interventions targeted caregivers of patients with specific cancer diagnoses (i.e., breast (Christensen, 1983; Bultz et al., 2000; Northouse et al., 2005; Badger et al., 2007; Budin et al., 2008; Baucom et al., 2009), prostate (Manne et al., 2004; Campbell et al., 2006; Northouse et al., 2007), brain (Horowitz et al., 1996), hematopoietic stem cell transplantation (HSCT) (Bevans et al., 2010), and lung tumors (Goldberg & Wool, 1985), and pediatric cancers (Sahler et al., 2002; Stehl et al., 2009)). Additionally, 29% ($n = 14$) of the interventions specifically targeted ICs of patients who had advanced disease/were receiving palliative care (Walsh & Schmidt, 2003; Cameron et al., 2004; Harding et al., 2004; Hudson et al., 2005, 2008; Keefe et al., 2005; McMillan et al., 2005; Milberg et al., 2005; Northouse et al., 2005; Carter, 2006; Kissane et al., 2006; Duggleby et al., 2007; Walsh et al., 2007; Bowman et al., 2009), whereas the remaining 71% ($n = 35$) enrolled ICs of patients who were heterogeneous with regard to their disease stage.

Subsequently, we categorize these interventions into one of the following categories: psychoeducation, problem-solving/skills building interventions, supportive therapy, family/couples therapy, cognitive-behavioral therapy (CBT), interpersonal therapy (IPT), complementary and alternative medicine (CAM) interventions, and existential therapy. We recognize that many of these interventions are integrative in nature and as such, incorporate elements of several different types of interventions, but have categorized them according to what we believe is their primary focus.

Psychoeducation

The information needs of cancer caregivers are great (Aoun et al., 2005; Adams et al., 2009; Gansler et al., 2010). According to a review of information needs of ICs (Adams et al., 2009), these needs fall into the following 11 categories: treatment-related information; diagnosis-/prognosis-related information; coping information; information on self-care/homecare; cancer-specific information; information about impact on the family; information on support; information about impact of relationship with partners; information on practical issues; information on hospital care; and follow-up/rehabilitation information. In light of the wide range of needs of ICs, it is not surprising that a large number of psychoeducational interventions have been designed to provide them with these various types of information. Indeed, components of psychoeducation were incorporated in the majority of the interventions included in this systematic review. Additionally, of the studies retrieved, interventions that identified themselves primarily as psychoeducational made up the greatest number ($n = 13$; see Table 1).

The majority of the psychoeducational studies targeted ICs of patients who were recently diagnosed with cancer, or at early stages of their disease (e.g., Grahn & Danielson, 1996; Derdiarian, 1989; Bultz et al., 2000; Manne et al., 2004; Cartledge Hoff & Haaga, 2005; Budin et al., 2008), whereas three were developed specifically for ICs of advanced or palliative care patients (Hudson et al., 2005, 2008; Keefe et al., 2005). In all but three of the psychoeducational studies reviewed (Barg et al., 1998; Cartledge Hoff & Haaga, 2005; Keefe et al., 2005), ICs receiving the intervention were primarily spouses. Additionally, the majority of interventions were delivered to both patients and caregivers (Ferrell et al., 1995; Derdiarian, 1989; Cartledge Hoff & Haaga, 2005; Hudson et al., 2005; Keefe et al., 2005; Budin et al., 2008). All of the psychoeducational interventions reviewed had an in-person component, although some conducted follow-up sessions over the phone (i.e., Derdiarian, 1989; Hudson et al., 2005; Budin et al., 2008).

Overall, the psychoeducational interventions had a positive impact on ICs' knowledge and/or ability to provide care (e.g., Ferrell et al., 1995; Grahn & Danielson, 1996; Horowitz et al., 1996; Derdiarian et al., 1989; Pasacreta et al., 2000; Keefe et al., 2005; Hudson et al., 2008). Several also led to significant and positive changes in psychological correlates of burden (Horowitz et al., 1996; Bultz et al., 2000). Notably, although their intervention was delivered to ICs, Bultz et al. (2000) report that patients whose ICs received the intervention reported improved confidant (i.e., functional) support and marital satisfaction.

In the only psychoeducation study that collected outcome data but reported null findings, Cartledge Hoff and Haaga (2005) found that although enrollment of patients and their caregivers in their Cancer Center Orientation Program (which included psychoeducation about cancer and its related psychological and physical effects on patients and family members, a tour of the Radiation Oncology Department, and a description of the multidisciplinary services offered therein) did not lead to significant changes in anxiety or distress, it did lead to increased satisfaction with clinic care and psychological service utilization among patients. The authors hypothesize that their null findings may be a reflection of the significant yet transient effect of the orientation program on mood, as they evaluated mood up to 8 weeks after the program was delivered, and note that previous

evaluations of psychoeducation interventions that found significant mood outcomes had shorter follow-up periods. The authors also note that the orientation program may have had benefits that were not captured in their study, such as an impact on engagement in recreational activities, and suggest that future studies should include a broader assessment of the potential benefits of psychoeducation interventions.

Problem Solving/Skills Building Interventions

Caregivers are often unprepared to provide the care needed by the cancer patient (e.g., Bucher et al., 1999; Schubart et al., 2008) and such skills deficits contribute to the psychological burden they experience (Nijboer et al., 2001). Not surprisingly, enhancing caregivers' ability – and confidence in their ability – to provide care may attenuate burden (Sörensen et al., 2002). Problem-solving and skills building interventions aim to develop ICs' repertoire of caregiving skills, including the ability to assess and manage patients' symptoms. They also teach ICs how to quickly identify solutions to caregiving problems that arise, and enhance caregivers' ability to cope with cancer caregiving in general.

Ten of the interventions reviewed fell into this category of problem-solving and skills building interventions (see Table 2). There was more variability among these studies in terms of the types of patients to whom ICs were providing care; two studies targeted ICs of advanced/hospice patients (Cameron et al., 2004; McMillan et al., 2005), one specifically for ICs of HSCT patients (Bevans et al., 2010), whereas the remaining seven targeted patients at early and middle stages of the cancer trajectory. In eight of these interventions, ICs were limited to spouses/partners, whereas one study focused on mothers (Sahler et al., 2002) and two (those targeting advanced/hospice patients) did not specify the relationship between the patient and IC. Half of the interventions (Toseland et al., 1995; Blanchard et al., 1996; Sahler et al., 2002; Cameron et al., 2004; Kurtz et al., 2005) were delivered to ICs alone, whereas the other five (Heinrich & Schag, 1985; Nezu et al., 2003; McMillan et al., 2005; Campbell et al., 2006; Bevans et al., 2010) were delivered to IC/patient dyads.

All but two studies (Toseland et al., 1995; Kurtz et al., 2005) reported significant and positive effects of the interventions on psychological correlates of burden and/or problem-solving skills for ICs and/or patients. In terms of outcomes for patients, most interventions (Heinrich & Schag, 1985; Blanchard et al., 1996; Nezu et al., 2003; Bevans et al., 2010) reported positive effects, including decreased depressive symptomatology (Blanchard et al., 1996; Nezu et al., 2003) and attitudes toward treatment and coping (Heinrich & Schag, 1985). Additionally, the intervention designed to be delivered to HSCT patients and their caregivers concurrent with medical treatment (Bevans et al., 2010) was not only determined to be feasible, but resulted in clinically significant improvements in distress and problem-solving skills for both ICs and patients.

Kurtz et al. (2005) found that spouse ICs of predominantly advanced cancer patients enrolled in their 10 contact 20 week intervention did not experience decreases in depressive symptomatology that were significantly different from ICs in the control group. The intervention aimed to enhance caregivers' ability to support patients emotionally and instrumentally, and the authors hypothesized that symptoms of depression among ICs would decrease as their sense of mastery increased. The authors propose that their null findings

may be a reflection of the combination of their relatively short follow-up period and the potentially delayed effects on depressive symptomatology. Despite these null findings, Kurtz et al. reported that ICs with higher mastery scores tended to be less depressed than ICs who were less confident in their ability to provide care, which highlights the relationship between confidence in one's ability to perform tasks of caregiving and depression. Toseland et al. (1995) enrolled ICs of patients who were past the initial diagnostic phase but who were not yet terminal in a six session "Coping with Cancer" intervention, which included support, problem-solving, and coping skills training. The authors also found that the intervention did not have a significant impact on psychosocial outcomes for ICs, including health status, coping skills, help seeking, and marital functioning, which they attribute to the relatively low level of distress expressed by their sample of ICs (a hypothesis supported by exploratory analyses that examined differential changes in these indices for more and less distressed/burdened ICs). As the inclusion criteria did not involve meeting a certain distress or burden threshold, the authors hypothesize that significant effects would have been demonstrated had their sample been more distressed.

Supportive Therapy

ICs also have great need for emotional support (e.g., Hileman et al., 1992; Milberg & Strang, 2000), and hence, the majority of psychosocial interventions developed for this population seem to include at least some element of support. In Table 3 we summarize the eight studies included in this review that evaluated the effects of various interventions that were primarily supportive in nature. Five of these targeted caregivers of patients with advanced disease or who were receiving palliative care (Walsh & Schmidt, 2003; Harding et al., 2004; Milberg et al., 2005; Walsh et al., 2007; Bowman et al., 2009), whereas the other three were delivered to caregivers of patients at all stages of their disease. Six of these studies were conducted with samples composed at least 50% (and in two cases, 100%) of spouse/partner ICs. Three interventions were delivered to both patients and their ICs (Reele et al., 1994; Kozachik et al., 2001; Bowman et al., 2009), whereas five were delivered to ICs alone (Goldberg & Wool, 1985; Walsh & Schmidt, 2003; Harding et al., 2004; Milberg et al., 2005; Walsh et al., 2007). Three interventions were delivered in group format, with groups made up either solely of ICs (Harding et al., 2004; Millberg et al., 2005) or ICs and the patients for whom they provide care (Reele et al., 1994). Support was also delivered individually to ICs (or to pairs of ICs; Goldberg & Wool, 1985; Kozachik et al., 2001; Walsh et al., 2007; Bowman et al., 2009). All but one (Walsh & Schmidt, 2003, delivered over the telephone) of the supportive psychotherapeutic interventions reviewed were delivered at least partly in person, with two (Kozachik et al., 2001; Bowman et al., 2009) combining in-person and telephone sessions.

One study (Bowman et al., 2009) did not present outcome data, and in another two, statistical analysis of effects was impeded by high rates of attrition (Walsh & Schmidt, 2003; Harding et al., 2004). Only one intervention (Millberg et al., 2005) reported positive effects of the intervention on caregiver outcomes; ICs of palliative care patients reported increased perception of support and knowledge after six to seven 90-minute supportive psychotherapy sessions. However, the content of the groups was examined qualitatively and therefore no outcome data regarding caregiver burden and psychological correlates of burden exist.

The majority of studies for which outcome data were collected found no significant impact of the supportive interventions on psychological correlates of burden (i.e., emotional well-being, anxiety, depression; Goldberg & Wool, 1985; Reele et al., 1994; Kozachik et al., 2001; Walsh et al., 2007). A potential explanation for these null findings is the recruitment of ICs with low-to-moderate levels of distress, for whom the interventions may have had minimal impact. Indeed, both Kozachik et al. (2001) and Goldberg and Wool (1985) report that ICs who refused enrollment or were lost because of attrition were likely more distressed and had more psychopathology than ICs enrolled, and hence their samples were biased toward higher functioning ICs. Additionally, through a closer examination of changes in depressive symptomatology in ICs between follow-up intervals, Kozachik et al. (2001) suggested that their follow-up period may not have been long enough to capture clinically meaningful changes, which they believed would have manifested given more time.

Family/Couples Therapy

Eleven interventions reviewed were designed with the explicit intention of improving the functioning of the couple/family unit (versus many of the interventions reviewed previously, which were delivered to ICs and patients jointly but were not specifically focused on the functioning of the couple or family unit; see Table 4). Three of these interventions were delivered to advanced/palliative care patients (Northouse et al., 2005; Kissane et al., 2006; McLean et al., 2008), whereas the other eight enrolled patients at earlier stages of their disease. Seven interventions were delivered to couples (Christensen, 1983; Stehl et al., 1999; Kuijer et al., 2004; Scott et al., 2004; Northouse et al., 2007; McLean et al., 2008; Baucom et al., 2009) and four to families (Wellisch et al., 1978; Northouse et al., 2005; Kissane et al., 2006; Mokuau et al., 2008). All but two of the interventions were delivered entirely in person (Scott et al., 2004; Northouse et al., 2005).

All of the couples interventions reported positive and significant outcomes for ICs and patients, including improvements in relationship quality and functioning (Kuijer et al., 2004; McLean et al., 2008; Baucom et al., 2009), communication (Scott et al., 2004; Northouse et al., 2007) and sexual satisfaction (Christensen, 1983) in both partners, as well as improvements in physical functioning (Northouse et al., 2007) and psychological functioning (i.e., depression, anxiety, posttraumatic growth) in patients (Christensen, 1983; Scott et al., 2004; McLean et al., 2008; Baucom et al., 2009) and ICs (Christensen, 1983; Scott et al., 2004; McLean et al., 2008; Baucom et al., 2009).

The family-based interventions also led to significant improvements in psychological functioning in patients and ICs. For example, Kissane et al.'s (2006) study of family focused grief therapy found that the intervention (which involved four to eight family sessions delivered from the palliative care through bereavement phases) led to significant reductions in distress and depressive symptomatology for family members identified at baseline as having the greatest amount of distress, depression, and social adjustment problems. The intervention did not, however, lead to clinically significant changes in family functioning. The culturally sensitive six session intervention developed by Mokuau et al. (2008) for Native Hawaiian women with cancer and their family caregivers led to significant increases in coping skills for both ICs and patients, increased self-efficacy in ICs, and decreased

depressive symptomatology in patients. Northouse et al. (2005) evaluated the impact of the FOCUS intervention, which included three sessions conducted in the home and two follow-up phone calls, which focused on the following five components: family involvement, optimistic attitude, coping effectiveness, uncertainty education, and symptom management. The intervention led to significant decreases in negative appraisals of caregiving for ICs and decreased hopelessness and negative appraisals of illness in patients.

Of the family interventions reviewed that collected outcome data, only one failed to demonstrate a significant positive impact of the intervention on ICs' psychosocial well-being or relationship functioning. Stehl et al. (2009) evaluated the impact of the Surviving Cancer Competently Intervention Program-Newly Diagnosed (SCCIP-ND), a three session intervention for parent caregivers of a child newly diagnosed with cancer, which was designed to promote healthy family adjustment to pediatric cancer and prevent the development of longer-term cancer-related traumatic stress symptoms. There were no significant changes in anxiety or traumatic stress symptoms between ICs assigned to the intervention and control arms at the follow-up assessments. The authors attribute these results partly to the dynamic nature of distress in families at diagnosis and the high premorbid functioning of families at baseline, as well as to the preventive model of the intervention. As such, families who were enrolled and functioning well at baseline may not have found engagement in the intervention a priority. Attrition may have also been the result of the requirement that both parents of the patient be enrolled. The authors hypothesize that if the study had been open to single parent families who may have been isolated, financially strained, or with limited support, their likely higher levels of baseline distress would have yielded more significant outcomes.

Cognitive Behavioral Therapy

Three of the studies reviewed (Carter, 2006; Cohen & Kuten, 2006; Given et al., 2006) were Cognitive Behavioral Therapy (CBT) interventions. These interventions are summarized in Table 5. All three of these interventions led to clinically significant improvements in psychological functioning in ICs.

Carter (2006) evaluated the feasibility and effectiveness of the CAregiver Sleep Intervention (CASI), which incorporates stimulus control, relaxation therapies, cognitive therapy, and sleep hygiene, all of which have been found to be effective in the treatment of insomnia and other sleep disorders. The two 1 hour sessions of CASI were delivered to primarily spouse and child ICs of patients with advanced cancer. There were improvements in sleep quality and depressive symptoms for all ICs enrolled in the study (including those in the attention control group), although ICs who received the CASI demonstrated significantly better sleep quality at 5 weeks and 4 months. The study suggests that the integration of multiple elements of sleep interventions may have long-term beneficial effects for ICs. As insomnia is one of the most common, distressing, and debilitating comorbidities experienced by ICs (Hinds et al., 1999; Jepson et al., 1999; Nijboer et al., 1999; Carter & Chang, 2000; Kozachik et al., 2001; Carter, 2003), the ability of this brief intervention to affect clinically significant changes is noteworthy.

Cohen and Kuten (2006) assessed the effect of a nine session group CBT intervention on psychological distress and adjustment of ICs of patients with localized disease. The intervention, which was based on the cognitive theory of Beck (Beck, 1978), the cognitive-behavioral model of Moorey and Greer (2002) and the model of relaxation and guided imagery of Baider et al. (1994), led to significant decreases in psychological distress and improvements in sleep immediately after the intervention was completed, and improvements in perceived support at the 4 month follow-up assessment.

Given et al. (2006a) evaluated the impact of a 10 week cognitive behavioral intervention delivered separately to patients and their ICs that was intended to reduce symptom severity among patients and negative reactions to assisting with symptom management among ICs, in addition to more frequent assistance from ICs per symptom. The 10 week intervention, delivered primarily (65%) to spouse caregivers of patients with advanced disease (67%), focused on the etiology and maintenance of symptoms, the integration of assistance into daily lives, and communication with patients and physicians about symptom management for ICs (for patients, the intervention focused on self-care, cognitive reframing, and coping and communication strategies). The intervention was successful in reducing negative reactions of ICs to assisting with symptoms, and the total number of symptoms for which the patients required assistance.

Interpersonal Therapy

One intervention used an interpersonal therapeutic model delivered over the telephone (Table 6). Badger et al. (2007) conducted a randomized controlled trial of telephone interpersonal counseling (TIP-C) for breast cancer patients (stages 1–3) and their spouse caregivers, which was based on interpersonal counseling techniques (Weissman et al., 2000) and included an element of cancer education. The TIP-C intervention was delivered over the telephone to patients and their spouse caregivers separately for 6 weeks, and resulted in significant decreases in symptoms of depression and anxiety in both groups (phone calls were made weekly to patients, and every other week to caregivers).

Complementary and Alternative Medicine Interventions

Two of the interventions reviewed described complementary and alternative medicine (CAM) interventions (Table 7). Kozachik et al. (2006) conducted a quasi-experimental study to describe the use of an 8 week (five contact) nurse-delivered complementary therapy (CT) intervention that involved guided imagery, reflexology, and reminiscence therapy delivered to patients (heterogeneous with respect to cancer type and stage) and their primarily (78%) spouse caregivers. Sessions 1, 3, and 5 were conducted in person with the patient and IC conjointly, whereas sessions 2 and 4 were conducted individually with patients and ICs over the telephone. The study examined patterns of use of CT (as participants could choose which combination of the three they wanted to focus on), but not use of CT in relation to psychosocial outcomes. Therefore, we are unable to draw conclusions regarding the impact of CT on correlates of caregiver burden. However, the authors do suggest that one CT is the optimal number of such interventions to incorporate into patients' and ICs' lives during the course of cancer treatment.

Rexilius et al. (2002) evaluated the effects of massage therapy and healing touch on anxiety, depression, fatigue, and subjective burden of ICs of patients undergoing autologous hematopoietic stem cell transplantation. Caregivers received six, 30 minute massage therapy or healing touch treatments over a 3 week period. The results indicated a significant decline in anxious and depressive symptomatology and general fatigue, motivation fatigue, and emotional fatigue for participants who received massage therapy only. There were no significant changes in perceived burden for any participants.

Existential Therapy

Finally, one intervention focused on existential concerns experienced by ICs (Table 8). Duggleby et al. (2007) developed the Living with Hope Program (LVHP), a theory-based intervention designed to foster hope in ICs of patients with advanced cancer. The intervention, which was based upon the three subprocesses specified by the hanging on to hope theory (living in the moment, having a positive approach, and writing your own story), consisted of a hope-focused activity in which ICs wrote for approximately five minutes at the end of each day for 2 weeks, reflecting on their challenges and what gave them hope, in addition to watching a video entitled, "Living with Hope." The small sample size ($n = 10$) prevented statistical analysis of the relation between hope and quality of life outcomes, although the authors report that average scores on these outcomes did increase. Their qualitative analysis of themes that emerged in participants' writing suggests that the intervention fostered participants' search for hope in new and different ways (i.e., outside of hoping for recovery) and acknowledgement of the benefits of focusing themselves and having their feelings valued and heard. The results suggest that the intervention is acceptable and feasible among ICs in various relationships to palliative care patients, and may have the potential to lead to clinically significant changes in quality of life for ICs.

DISCUSSION

This systematic review produced 49 interventions developed specifically for ICs of patients with cancer. This large number of studies reflects the field's growing recognition of the severity of burden experienced by ICs, and the subsequent need to provide care to caregivers, in addition to cancer patients (Surbone et al., 2010).

Overall, 65% of the studies reviewed led to positive and significant improvements in functioning for ICs and/or the patients for whom they provide care. Had all of the interventions collected outcome data (three did not), and had statistical analysis of outcomes not been hindered by attrition (as was the case for three additional studies), an even greater percentage would have likely led to such positive outcomes.

Conclusions Regarding Specific Intervention Genres

As indicated in Table 1, the largest category of studies included in this review was psychoeducational interventions. These interventions positively impacted ICs' knowledge base and ability to provide care, and several also led to improvements in psychological correlates of burden (i.e., depressive and anxious symptomatology) and patient functioning, even when patients were not the direct recipients of the intervention (Bultz et al., 2000).

The majority of the problem solving/skills building interventions (Table 2) were successful in improving ICs' ability (and confidence in these abilities) to provide care, including the ability to assess and manage patients' symptoms, identify solutions to problems that arose during caregiving, and enhance ICs' overall ability to cope with this role. In the study conducted by Bevans et al. (2010), participants attended 90% of sessions and reported high levels of program satisfaction, which further highlights the benefits of delivery of treatment to ICs concurrent with patients' medical care. The efficacy of problem solving interventions across the caregiving trajectory is likely the result, in part, of their being structured and time limited (i.e., between 1 and 10 sessions in length), and addressing specific needs of ICs at particular points in caregiving (i.e., communication and coping skills at diagnosis, symptom management during palliative care).

Our review provided less support for the benefits of supportive psychotherapeutic interventions (Table 3) in mitigating burden among ICs. A large proportion of these studies were negatively impacted by attrition, which in some cases (i.e., Walsh & Schmidt, 2003; Harding et al., 2004) prevented statistical analyses of outcomes. It is possible that ICs who refused enrollment or who dropped out were already receiving sufficient support and did not believe in the utility of this additional resource. Indeed, our group has found that cancer patients and their caregivers often receive increased nonprofessional support as patients' disease status worsens (Applebaum et al., under review). These ICs may have been receiving sufficient support and concurrently experiencing heightened distress (i.e., depression) as a result of their loved one's physical decline, which prevented them from enrolling (a hypothesis in accord with the suggestions of Goldberg and Wool (1985) and Kozachik et al. (2001)). Therefore, in order to better understand the utility and appropriateness of supportive psychotherapy for ICs, future studies should attend to existing support and perceived need for support during the screening process, as well as during follow-up periods. Additional consideration should also be given to outcome measures (i.e., perceived support versus clinical depression), as it is likely that attention to changes in supportive needs and general distress may be more visible than clinically significant changes in depression over short time periods in this vulnerable population.

Overall, the family and couples interventions (Table 4) led to clinically significant improvements in IC functioning, in addition to the functioning of the couple or family unit as a whole. As indicated by several of the studies reviewed (e.g., Christensen, 1983; Kuijer et al., 2004), these positive results may have even been attenuated by low-to-moderate levels of baseline distress in ICs and patients and high rates of attrition. Family and couples interventions may therefore confer even greater benefits to ICs who are distressed than those reported in these studies.

The cognitive behavioral and interpersonal therapies (Tables 5 and 6) reviewed here also provide evidence for the efficacy of CBT and IPT to target psychological distress in ICs and patients. Rates of attrition in these studies were also notably lower than those reported in the supportive and psychoeducational interventions, which may be a reflection of the structured, manualized, and progressive nature of these therapy protocols. For example, none of the participants randomized to the TIP-C condition in Badger et al.'s (2007) study were lost to follow-up, whereas 18% in Given et al.'s (2006) CBT intervention were. The potential

benefits of such structured interventions in terms of retention should be considered, as new interventions are developed for this population.

Finally, it appears that interventions that were integrative in their approach (i.e., combining elements of psychoeducation and support or communication skills training) conferred multiple benefits for ICs (e.g., Bultz et al., 2000; Northouse et al., 2005; Campbell et al., 2006; Budin, 2008). For example, elements of psychoeducation were often combined with support (e.g., Bultz et al., 2000; Budin et al., 2008) and problem solving and coping skills training (e.g., Campbell et al., 2006). It appears that ICs have varying informational needs across the caregiving trajectory and despite targeting unique areas of functioning (i.e., couples communication), the inclusion of education (regarding cancer treatment, side effects, symptom management) augmented the overall impact of the treatment and may have contributed to the relatively lower rates of attrition in these studies. Given the temporal demands of caregiving, it is possible that interventions that offer multiple components are more attractive to ICs than those that are one-dimensional.

Conclusions Regarding Mode of Intervention Delivery

Overall, it is difficult to draw conclusions regarding the relative efficacy of interventions delivered in group or individual formats, those delivered in person versus over the telephone, or the appropriate number of sessions. With the exception of an ongoing family therapy group (Wellisch et al., 1978), all of the interventions reviewed were time limited and involved between 1 and 12 sessions. Moreover, whereas individually delivered therapies attend to the temporal demands faced by ICs, the group setting has the benefit of providing social support, even when support is not the focus of the intervention. Therefore, whereas individual psychotherapies clearly have the potential to be delivered more flexibly than groups, rates of attrition from both types of delivery varied significantly, and, therefore, this review does not provide convincing evidence that one modality is superior in terms of retention.

The majority of interventions reviewed were delivered completely in person. A closer examination of the three interventions delivered over the telephone (Walsh & Schmidt, 2003; Campbell et al., 2006; Badger et al., 2007) revealed that they were generally acceptable and feasible and conferred benefits to ICs and patients. The qualitative analysis of post-treatment interviews of couples enrolled in Campbell et al.'s (2004) six session telephone-based coping skills training program for spouses of early stage prostate cancer patients revealed that 27% of the sample found sessions conducted over the phone convenient and conducive to being more open regarding sensitive topics than they would have felt in person. However, five couples expressed a preference for some degree of face-to-face contact in spite of the acknowledged benefits of telephone-based participation. Whereas attendance in Campbell et al.'s telephone-based study was nearly perfect (as it was in Badger et al.'s [2007] study of telephone interpersonal counseling), attrition from Walsh & Schmidt's (2003) study of a four session supportive psychotherapy intervention delivered over the phone (Tele-Care II) was significant and prevented statistical analysis of results. Participants in the latter intervention included ICs of patients newly admitted to hospice care, and attrition was primarily because of the need/desire to attend to the dying patient. It is likely that the

flexibility of telephone-administered sessions may be attractive to many ICs and promote retention for those who are not providing care for a patient who is near death, whereas engaging in treatment in any modality is likely not a priority when the patient is actively dying. It is also likely that regardless of the type of intervention delivered or the length of the session, phone contact may be enough to promote therapeutic change, as indicated by the 94% adherence rate reported by Badger et al. (2007) for their self-managed exercise program control arm. Indeed, we have found that a strong therapeutic alliance and resultant benefits may be achieved over the telephone (Applebaum et al., in press) and are not limited to face-to-face therapy.

One of the strengths of this systematic review is its inclusive nature; the review did not have limitations on the type of relationship between ICs and patient, or the type and stage of cancer. This heterogeneity in the study samples included, however, precludes our ability to draw conclusions regarding the appropriateness of certain interventions for various caregiver populations. Whereas the family and couples interventions clearly targeted the functioning of the couple or family unit, and many of the interventions that specifically enrolled spouse ICs also focused on couple functioning, in general, the remaining studies did not address the ways in which the targeted interventions impacted IC functioning in the context of their relationship to the patient. Similarly, whereas the interventions that specifically enrolled ICs of patients with advanced disease or who were receiving palliative care did attend to end-of-life issues and those that enrolled HSCT or brain tumor patients attended to the specific nature of these patients' treatment, the remaining studies did not focus specifically on ways in which the patients' diagnosis or prognosis potentially mediated intervention efficacy. Instead, the majority of studies reviewed provided more general evidence for the utility of these treatment approaches more broadly for ICs of cancer patients. However, a growing body of evidence suggests that burden experienced by ICs is shaped by the multiple roles that they play, including their specified relationship to the patient (Nagatomo et al., 1999; Gaugler et al., 2009; Given et al., 2001a; Kim et al., 2006; Campbell, 2010; Wadhwa et al., 2011), in addition to the patient's functional status (Weitzner et al., 1999; Andrews, 2001; Dumont et al., 2006). Interventions that attend to the particular burden of ICs managing multiple caregiving roles (i.e., caring for a spouse with cancer, as well as young children and/or aging parents) and which incorporate a developmental perspective into their approach (i.e., acknowledge the unique experience of caring for an ill parent when one is in late adolescence/early adulthood versus late adulthood) may produce added benefits for cancer caregivers.

Conclusions Drawn from Studies with Null Findings

An additional strength of this review was its inclusion of studies of interventions that did not provide evidence of efficacy or effectiveness with ICs. A close examination of these nine studies highlighted several commonalities in design that may have potentially hindered the emergence of significant and positive results.

The first common theme that emerged was the timing of follow-up assessments. Cartledge Hoff and Haaga (2011), for example, highlighted the potential impact of a long follow-up period on findings of significant changes in quality of life outcomes. This and other

interventions may have had a significant – but transient – impact on participants’ mood (or other correlates of burden), which would have manifested in the results had such assessments occurred earlier. Another example comes from the CBT group intervention of Cohen and Kuten (2006), which was successful in reducing psychological distress and improving sleep quality in ICs. However, improvements in perceived social support were not observed during or immediately following the intervention, only at the follow-up assessment. The authors hypothesize that participants in the group setting were already receiving significant support from that context, which overshadowed additional support received outside of the group. It is likely, therefore, that assessments of fluctuations in perceived support for patients currently or recently engaged in a supportive group intervention may not be informative. Conversely, however, a short follow-up period may not allow for psychological changes to be internalized. Kurtz et al. (2005) found that spouse ICs of predominantly advanced cancer patients enrolled in their 10 contact 20 week intervention did not experience decreases in depressive symptomatology, and propose that their null findings may be a reflection of the combination of their relatively short follow-up period and the potentially delayed effects on depressive symptomatology. Therefore, attention to the appropriateness of the follow-up period should be considered in the context of chosen outcomes, with those that are more transient (i.e., state anxiety) warranting a more immediate assessment, whereas more global changes (i.e., clinically significant improvements in depression) would require a greater amount of time to emerge.

Additionally, it seems that outcome measures chosen should be tailored to match the targets of the interventions. For example, whereas Cartledge Hoff and Haaga’s (2011) psychoeducation intervention did not lead to clinically significant improvements in burden, it did lead to improvements in knowledge about radiation therapy and may have conferred other benefits not assessed, such as increased psychosocial service use or engagement in leisure activities. It is possible that, had several of the supportive psychotherapeutic interventions assessed perceived support as opposed to fluctuations in anxiety, depression, or general distress, they might have reported positive results. Broader assessments of ICs’ needs and quality of life rather than exclusively traditional categories of mental health may therefore be warranted.

Another theme that emerged was the low level of baseline distress in participants, which may have hindered the emergence of clinically significant changes in related outcomes (e.g., Goldberg & Wool, 1985; Toseland et al., 1995; Kozachik et al., 2001; Rexilius et al., 2002; Cohen & Kuten, 2006). For example, Toseland et al. (1995) examined the impact of a six session “coping with cancer” intervention, which included support, as well as problem-solving and coping skills training. The intervention did not have a significant impact on psychosocial outcomes for the spouse ICs enrolled, including health status, coping skills, help seeking, and marital functioning, which the authors attribute to the relatively low level of distress expressed by their sample (a hypothesis supported by exploratory analyses of differential changes in these indices for more and less distressed/burdened ICs). As the inclusion criteria did not involve meeting a certain distress or burden threshold, it is possible that significant effects would have been demonstrated had their sample been more distressed. Several other interventions reviewed recruited ICs with low-to-moderate levels of distress, for whom the interventions may have had minimal impact. For example, Kozachik

et al. (2001) and Goldberg and Wool (1985) reported that ICs who refused enrollment from their supportive psychotherapeutic interventions or who were lost because of attrition were likely more distressed and had more psychopathology than did ICs who accepted enrollment. Whereas overall, the family and couples interventions led to clinically significant improvements in IC functioning, these positive results may have even been attenuated by low to moderate levels of baseline distress in ICs, and it is possible that such interventions may confer even greater benefits than those reported for ICs who are distressed. Indeed, Kissane et al. (2006) found that their family focused grief therapy yielded the greatest significant reductions in distress and depressive symptomatology for family members identified at baseline as having the greatest amount of distress and depression.

LIMITATIONS

This systematic review was conducted in January 2011, and included articles that had been published between 1980 and 2011. As a result, studies of psychosocial interventions for informal cancer caregivers that were published after that date were not included. As mentioned previously, the inclusion of interventions delivered across the entire cancer trajectory and in a variety of formats was a strength of this review, but such inclusion hinders our drawing firm conclusions about the appropriateness of particular interventions at specific time points or in various modes of delivery.

FUTURE DIRECTIONS

The 2009 Institute of Medicine (IOM) report “Retooling for an Aging America: Building the Health Care Workforce” highlighted the responsibility of health-care professionals to prepare ICs for their role and the need to establish programs to assist them with managing their own stress that results from providing care (Institute of Medicine, 2008). This review highlighted the clinically significant benefits of certain interventions (i.e., problem solving and skills building interventions, CBT) and provided less evidence for such benefits of others (i.e., supportive psychotherapy). It also seems that ICs have a great need for education, the target of which shifts across the caregiving trajectory. Whereas it is likely that receiving any type of intervention may be beneficial and that attention alone to ICs who may otherwise feel isolated may contribute to improvements above and beyond specific techniques, structured, goal-oriented, and time-limited interventions that are integrative appear to be the most feasible and to offer the greatest benefits for ICs of cancer patients.

One domain that received limited attention was existential issues, a significant area of concern for ICs of patients with cancer, particularly those in the advanced/palliative care phase (Farran et al., 1991; Kim et al., 2007; Northfield & Nebauer, 2010; Thombre et al., 2010). Only one intervention specifically targeted existential concerns of ICs (Duggleby et al., 2007), whereas several others acknowledged the importance of existential issues, including the importance of finding meaning through the cancer caregiving experience (Toseland et al., 1995; Scott et al., 2004; Northouse et al., 2005; Kozachik et al., 2006; McLean et al., 2008). Our group (Applebaum, 2011) has developed a meaning-centered psychotherapy for informal cancer caregivers, designed to enhance meaning and ultimately

reduce suffering. Future studies are needed to examine the impact of making meaning of the caregiving experience on caregiver burden.

In regard to study design, it is critical for researchers to recognize that distressed participants are likely to self-select out, and interventions delivered to ICs who are only mildly distressed are less likely to yield significant outcomes. In order to capitalize on potential change, researchers should carefully attend to the choice of outcome measures, and match them to the type of intervention delivered, as well as the point of delivery in the caregiving trajectory. Psychoeducation and skills building interventions, for example, may be most appropriate for ICs who are recently diagnosed/receiving treatment, or during the survivorship phase, whereas supportive psychotherapy, CAM interventions, and existential therapies may be most appropriate for ICs of patients with advanced cancer and/or those receiving palliative care. Interventions that are integrative, and include elements of psychoeducation along with other components, are likely to be most beneficial and utilized.

Finally, as informal caregivers of cancer patients represent a vulnerable population that, despite a growing number of interventions developed in the setting of research, are underserved and difficult to reach, a primary challenge for future interventions is how to address the broader network of caregivers involved in the care of one patient. The increased use of telephone and alternative modalities (i.e., Skype) for intervention delivery is likely one solution to the barriers to delivery. Future studies should therefore examine the specific benefits and challenges of delivering interventions in these alternative modalities.

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Table 1

Psychoeducation interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Barg et al., 1998	Family Caregiver Cancer Education Program (FCCPEP); 6 hours taught over 1 – 3 sessions in person to N = 750 ICs; descriptive study; 31.82% attrition.	Heterogeneous	Unspecified/Unspecified	No outcome data collected.
Budin et al., 2008	DM v. SE v. TC v. TC + SE for N = 249 IC/pt dyads; 20.68% attrition.	54% spouse, 12.1% daughter, 12% sister, 11.3% friend, 9.6% other	Breast/Stage 0–3	Improved emotional adjustment in pts in SE/TC/TC + SE v. DM; no impact of tx on psych well-being or overall health of ICs.
Bultz et al., 2000	6, 1.5–2 hour in-person group for N = 35 IC/pt dyads; RCT; 11.11% attrition.	Spouse	Breast/Stage 1–2	Sig. decrease in mood disturbance in ICs; increased confidant support/marital satisfaction reported by pts.
Cartledge Hoff & Haaga, 2005	Orientation to cancer center; psychoed video + reading for n = 51 pts & n = 34 ICs; RCT; 15% attrition.	Heterogeneous	Heterogeneous/Heterogeneous	No sig. changes in anxiety, distress adherence, or info re: radiation tx; pts reported increased satisfaction w/care & psych service use.
Derdarian, 1989	2 in-person sessions + f/u phone calls for N = 60 IC/pt dyads; RCT; attrition not reported.	Spouse	Male melanoma/sarcoma/colon pts/Heterogeneous	Tx led to significant increases in information, and satisfaction with that information in ICs/pts.
Ferrell et al., 1995	3 in-home sessions for N = 50 ICs; quasi-experimental; 37.5% attrition.	66% spouse, 22% child	Heterogeneous elderly pts receiving analgesics/Heterogeneous	Tx improved knowledge/attitudes re: pain management and psych/social well-being and QOL in ICs.
Grahn & Danielson, 1996	8 2-hour in-person group sessions for N = 127 ICs/pts; qualitative; 36.91% attrition.	Significant others	Heterogeneous/Heterogeneous	Sessions promoted knowledge and facilitated coping for IC/pt.
Horowitz et al., 1996	Bimonthly in-person group for N = 10 ICs; descriptive/qualitative; attrition not reported.	Spouse	Brain tumor pts	Group participation facilitated pts' home care and reduced qualitatively assessed depression/anxiety
Hudson et al., 2005	2 home visits + f/u phone call for N = 106 ICs; RCT; 74.53% attrition.	88% spouse, 8% child	Heterogeneous/Palliative	Intervention increased ICs' sense of reward; no effect on preparedness to care, self-efficacy, competence, or anxiety.
Hudson et al., 2008	3 in-person group sessions for N = 74 ICs; descriptive/qualitative; 40.54% attrition.	59% spouse, 23% parent	Heterogeneous/Palliative	Significant positive effect on preparedness/competence in caregiving, rewards, and information needs.
Keefe et al., 2005	3 home visits for N = 82 IC/pt dyads; RCT; 31.71% attrition.	28% partner, 59% child, 3% other	Heterogeneous/Advanced	Significant increases in IC self-efficacy and trend to report improvements in caregiver strain.
Manne et al., 2004	6 in-person group sessions for N = 60 ICs; RCT; 11.76% attrition.	Spouse	Prostate/80% stage 1–2; 18% stage 3–4	No sig. impact on distress; ICs receiving tx reported positive contributions of cancer exp. and more adaptive coping.

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Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Pasacreta et al., 2000	Family Caregiver Cancer Education Program (FCCCEP); 6-hour in-person program for N= 187 ICs; pre/post test design; 32% attrition among male ICs.	71% spouse, 29% other	Heterogeneous/Unspecified	Program led to improved perception of health and confidence in ability to provide care.

IC= informal caregiver; pt = patient; DM = disease management; SE = standardized psychoeducation; TC = telephone counseling; RCT = randomized controlled trial; tx = treatment; QOL = quality of life.

Table 2

Problem solving/skills building interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Bevans et al., 2010	COPE intervention: 4 in-person sessions to N = 8 IC/pt dyads; pilot/feasibility study; 20% attrition.	Spouse	HCCST pts	Feasible tx during HSCT; small ES for IC/ moderate ES for pt distress and problem-solving skills.
Blanchard et al., 1996	6 in-person groups for N = 66 ICs; RCT; 23.26% attrition.	Spouse	Heterogeneous/Unspecified	Sig. decrease in depressive sx in pts, no effects for ICs.
Cameron et al., 2004	COPE intervention, 1-hour in-person session for N = 34 ICs; one sample, pre/post test design; 52.11% attrition.	Primary caregiver	Heterogeneous/Advanced	Sig. improvements in emotional tension, caregiving confidence and problem-solving orientation.
Campbell et al., 2006	6 telephone sessions of Coping Skills Training (CST) for; N = 30 IC/pt dyads; pilot; 25% attrition.	Spouse	Prostate/Early stage	Moderate effects observed for depression/fatigue/vigor in ICs.
Heinrich & Schag, 1985	Stress and Activity management (SAM) 6-week in-person group for n = 25 ICs + n = 51 pts; non-RCT; 22.45% attrition.	Spouses	Heterogeneous/Heterogeneous	SAM improved levels of information, attitudes toward tx, and perceived coping.
Kurtz et al., 2005	5 in-person/5 telephone sessions for N = 237 IC/pt dyads; RCT; 41.35% attrition.	Spouse	Solid tumor (39% breast/35% lung/26% other)/67% Advanced	Tx was not effective in decreasing IC depressive sx.
McMillan et al., 2005	COPE intervention; 3 in-person sessions for N = 329 pt/IC dyads; RCT; 68.69% attrition.	Unspecified	Heterogeneous/Hospice	Sig. improvements in IC QOL/task burden and pt sx burden.
Nezu et al., 2003	Problem-Solving Training w/Significant Other (PST-O); 10 in-person couples sessions for; N = 43 IC/pt dyads; prospective outcome study; 16.28% attrition.	Significant other	Heterogeneous/Stage 1-3	Tx led to decreased depressive sx/improved problem solving in ICs +pts, & improved QOL/global psych distress in pts, maintained 6 months.
Sahler et al., 2002	Problem Solving Skills Training (PSST); 8 1-hour in person sessions for N = 92 ICs; RCT; attrition not reported.	Mothers	Pediatric cancer pts/Unspecified	Tx led to sig. enhanced problem-solving skills and decreased negative affect.
Toseland et al., 1995	6, 1-hour in-person sessions w/N = 78 ICs; RCT; 9.3% attrition.	Spouse	Heterogeneous/Heterogeneous	Tx had no sig. impact on marital relationship, health status, coping activities or help seeking.

IC = informal caregiver; pt = patient; COPE: Creativity, Optimism, Planning, Expert; HCST = hematopoietic stem cell transplantation; ES = effect size; tx = treatment; sx = symptoms; RCT = randomized controlled trial; QOL = quality of life.

Table 3

Supportive psychotherapy interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Bowman et al., 2009	Coping and Communication Support (CCS): initial visit in-person, telephone f/u for 6 weeks for N = 132 ICs; pilot; attrition not reported.	60% spouses/adult children, 40% other	Unspecified/Advanced	Provides evidence for feasibility of CCS; no outcome data collected.
Goldberg & Wool, 1985	12 in-person sessions for n = 23 ICs/n= 20 pts; RCT; 59.43% attrition.	73% spouses, 17% adult children, 10% other	Lung/Heterogeneous	No significant changes in emotional, social, physical functioning of pt or IC.
Harding et al., 2004	6 90-min in-person group sessions for N = 73 ICs; mixed-methods prospective; 64.39% attrition.	Unspecified	Heterogeneous/Palliative	Statistical testing not possible; significant attrition.
Kozachik et al., 2001	Cancer Caregiver Intervention (CCI) 5 in-person joint sessions+ 4 phone calls to N= 89 ICs + pts separately; RCT; 28.80% attrition.	Primary caregivers	Heterogeneous/50% early, 50% late	No significant changes in IC depressive sx.
Milberg et al., 2005	6-7 1.5-hour in-person group sessions for N = 19 ICs; qualitative; 13.64% attrition.	Spouse/cohabitant	Heterogeneous/Palliative	ICs reported increased perception of support/knowledge.
Reele, 1994	8 2-hour weekly in-person groups for N = 32 ICs + pts; non-RCT; attrition not reported.	Family members	Heterogeneous/Unspecified	Tx did not impact IC/pt QOL.
Walsh et al., 2007	6 visits with N = 104 ICs (in-home or location chosen by IC); RCT; 61.62% attrition.	64% spouse, 25% child	Heterogeneous/Advanced	No sig. impact of tx on distress, QOL, strain, bereavement outcomes, or satisfaction w/care post pt death.
Walsh & Schmidt, 2003	Tele-Care II: 4-week phone intervention w/N = 9 ICs; pilot; 44.45% attrition.	50% spouse, 50% child	Heterogeneous/Hospice	Statistical testing not possible; significant attrition.

IC = informal caregiver; pt = patient; RCT = randomized controlled trial; tx = treatment; sx = symptoms; QOL, quality of life.

Table 4

Family/couples interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Baucom et al., 2009	6 75-min in-person couples-based relationship enhancement sessions for N = 14 couples; pilot; 50% attrition.	Spouse	Breast/Stage 1 – 3	Improved individual psychological and relationship functioning in IC/pt.
Christensen, 1983	4 in-person sessions for N = 20 IC/pt dyads; RCT; attrition not reported.	Spouse	Breast/Localized	Tx reduced emotional discomfort in IC/pt, depressive sx in the pt, and increased sexual satisfaction in IC/pt.
Kissane et al., 2006	Family Focused Grief Therapy (FFGT); 4–8 in-person family sessions over 9–18 months for N = 363 ICs + pts; RCT; 36.64% attrition.	Heterogeneous	Heterogeneous/Palliative	Significant reduction in distress and depression.
Kuijjer et al., 2004	5 90-min CBT oriented sessions for N = 59 couples; RCT; 33.9% attrition.	Spouse	Heterogeneous/Unspecified	Tx led to improved relationship quality and decreased perception of underinvestment/overbenefit; no improvement in IC distress.
McLean et al., 2008	8 in-person sessions of Emotion-Focused Couples Therapy for N = 16 couples; pilot; 6.25% attrition.	Spouse	Heterogeneous/Metastatic or recurrent	Sig. improvement in marital functioning and reduction in depressive sx for pts and ICs.
Mokuau et al., 2008	6 in-person sessions of family tx to N = 12 ICs + pts; pilot; 16.67% attrition.	Unspecified	Heterogeneous/Unspecified	Tx led to increased coping skills for ICs + pts, increase in self-efficacy in ICs, decreased psych distress in pts.
Northouse et al., 2005	FOCUS intervention; 3 home visits and 2 f/u phone calls with N = 182 IC/pt dyads; RCT; 26.37% attrition.	62% spouse, 16% adult children, 22% other	Breast/Advanced	ICs reported sig. less negative appraisal of caregiving; pts reported sig. less hopelessness and negative appraisal of illness.
Northouse et al., 2007	FOCUS intervention; 3 home visits w/N = 263 IC/pt dyads; RCT; 10.65% attrition.	Spouse	Prostate/65% localized, 21% advanced; 14% recurrent	Tx led to improved communication/less uncertainty in ICs/pts, improved QOL, neg. appraisals of caregiving, hopelessness, & sx distress in ICs.
Scott et al., 2004	CanCope (couples based coping training); 5 2-hour in-person sessions + 2 30-min phone calls for N = 94 couples; RCT; 24.5% attrition.	Spouse	Breast/GYN/Stage 1 – 3	Tx led to sig. improvements in communication, distress/coping effort, and sexual adjustment.
Stehl et al., 2009	Surviving Cancer Competently Intervention for Newly Dx Families (SCCIP-ND); 6 in-person sessions for N = 124 ICs; RCT; 23.46% attrition.	Parent primary IC + spouse	Pediatric cancer/All, excluding palliative	No sig. impact of tx on state anxiety or traumatic stress.
Wellisch et al., 1978	Family group therapy, in-person, ongoing for N = 40 families; descriptive study; attrition not specified.	Unspecified	Unspecified/Unspecified	No outcome data collected.

IC = informal caregiver; pt = patient; RCT = randomized controlled trial; CBT = cognitive-behavioral therapy; tx = treatment; sx = symptoms; QOL, quality of life; dx = diagnosed.

Table 5

Cognitive behavioral interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Carter, 2006	Caregiver Sleep Intervention (CASI); 2 in-person sessions w/N= 35 IC; prospective; 14.29% attrition.	57% spouse, 30% children	Unspecified/Advanced	Significant improvements in sleep quality and depressive sx.
Cohen & Kuten, 2006	9 in-person group sessions of CBT for N= 100 ICs; non-RCT; 30.07% attrition.	Heterogeneous	Unspecified/Localized	Significant decreases in psychological distress, improved sleep/perceived support at f/u.
Given et al., 2006a	10 in-person CBT sessions for N= 263 ICs/pt dyads; RCT; 44.11% attrition.	65% spouse, 35% other	Unspecified/67% advanced	Tx led to sig. reductions in distress related to assisting w/sx, and decreased sx severity in pts.

IC = informal caregiver; pt = patient; RCT = randomized controlled trial; CBT = cognitive-behavioral therapy; tx = treatment; sx= symptoms.

Table 6

Interpersonal therapy interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/tage	Outcome
Badger et al., 2007	3 30-min biweekly sessions of Telephone Interpersonal Counseling (TIP-C) to <i>n</i> = 87 ICs + <i>n</i> = 92 pts; RCT; 6.77% attrition.	Spouse	Breast/Stage 1-3	Significant decreases in sx of depression and anxiety in IC/pt.

IC = informal caregiver; pt = patient; RCT = randomized controlled trial; sx = symptoms.

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Table 7

Complementary and alternative medicine interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Kozachik et al., 2006	Complementary/Alternative medicine; 3 in-person + 2 phone sessions for $N=146$ ICs + pts; quasi-experimental; 18.89% attrition.	78% spouse, 22% parent, 4% child, 6% sibling, 8% other	Heterogeneous/48% stage 1 – 2, 52% stage 3 – 4	No outcome data collected.
Rexilius et al., 2002	6 30-min sessions of massage tx vs. healing touch for $N=36$ ICs; quasi-experimental; 18.89% attrition.	Unspecified	HSCT pts	Massage tx led to sig. decreases in anxiety, depression, & fatigue.

IC = informal caregiver; pt = patient; tx = treatment; HSCT = hematopoietic stem cell transplantation.

Table 8

Existential therapy interventions for informal cancer caregivers

Study	Design	Caregiving relationship	Cancer type/Stage	Outcome
Duggleby et al., 2007	“Hope-fostering” session (video + activity) in-person for <i>N</i> = 10 ICs; pilot; 20% attrition.	Live-in IC	Unspecified/Palliative	Small <i>N</i> precluded statistical determination of differences in hope and QOL (trend evident).

IC = informal caregiver; pt = patient; QOL = quality of life.

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