

A Review of Family Caregiving Intervention Trials in Oncology

Betty Ferrell, RN, PhD, MA, FAAN, FPCN, CHPN ¹; Elaine Wittenberg, PhD²

¹Director, Division of Nursing Research and Education, City of Hope National Medical Center, Duarte, CA; ²Associate Professor, Division of Nursing Research and Education, City of Hope National Medical Center, Duarte, CA.

Additional supporting information may be found in the online version of this article.

Corresponding author: Betty Ferrell, RN, PHD, MA, FAAN, FPCN, CHPN, Division of Nursing Research and Education, City of Hope National Medical Center, 1500 E. Duarte Road, Population Science Building 173, Duarte CA 91010; bferrell@coh.org

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Abstract: This article contains a review of literature published from 2010 to 2016 on family caregiving in oncology. An analysis of 810 citations resulted in 50 randomized trials. These trials describe the need to prepare family caregivers for the complex role they play in cancer care. Several studies have demonstrated improved quality of life for family caregivers and improved emotional support from interventions. Several studies addressed communication and relational intimacy, which are key concerns. An additional focus of these trials was in the area of caregiving tasks and ways to diminish the burden of caregiving and preparedness for this role. Further research is needed in this area given the shift to outpatient care and as family caregivers become the primary providers of care. Future research should include expanding tested models of family caregiver support in clinical practice and in diverse populations. *CA Cancer J Clin* 2017;67:318–325. © 2017 American Cancer Society.

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Introduction

Family caregivers (FCGs) play a vital role in the direct care and support of patients with cancer. The importance of FCGs is increasingly significant given the shift to outpatient and home-based care, an aging population, and social and demographic changes.^{1–3} Most literature, however, has documented serious deficiencies in the preparation of FCGs to assume what is often a physically and emotionally burdensome role.^{4–6}

In 2010, Northouse et al published a meta-analysis of randomized trials based on a review of 401 articles published from 1983 through 2009, which yielded 29 randomized clinical trials.⁷ Their analysis recognized 3 types of caregiver interventions, including psychoeducational interventions, skills training, and therapeutic counseling. The interventions were generally delivered jointly to patients and caregivers, resulting in reduced caregiver burden, improved caregiver coping, increased self-efficacy, and improved aspects of quality of life (QOL).

The purpose of this report is to present results of a review of the literature published since the previous meta-analysis for the period from 2010 through 2016.⁷ The results described below demonstrate an increasing body of literature related to family caregiving in oncology and growing evidence of the need for caregiver support and outcomes.

Background

The QOL concept is often applied to oncology patients, and it has equal relevance to FCGs. It includes dimensions of physical, psychological, social, and spiritual well-being.⁵ In the area of physical well-being, caregivers are tasked with the physical care of the patient, including complex symptom management. Caregivers often experience physical symptoms of their own, including insomnia, fatigue, and overall diminished health because of the strains of caregiving.^{5,8} The literature suggests that higher caregiver burden is even associated with increased caregiver mortality risk.⁸ FCGs who reported higher burden at 4-year follow-up in one study had a

63% greater mortality risk than those family members who did not provide care. The psychological impact of caregiving is most often addressed, including anxiety, depression, distress, fears, and uncertainty. These emotions exist throughout the trajectory of initial diagnosis, treatment, remission, recurrence, and end of life or during long-term survival.^{9,10} The social domain of QOL addresses the interaction between the patient and family and the impact of cancer on relationships. Financial concerns, sexuality, and altered family roles are impacted by the disease and treatment, and there is increased recognition that FCGs are not passive observers of the illness; rather, they are intimately involved in all aspects of care.¹¹ Communication between patients, primary FCGs, other family members, and clinicians is also a key element of the family experience.¹²

In the spiritual well-being domain, FCGs struggle to maintain hope, rely on religion or other aspects of spiritual support, and examine issues of life purpose and meaning in the caregiving experience.^{5,13} FCGs report many positive aspects of their caregiving role and opportunities during the cancer experience to strengthen relationships.¹⁴

Reexamining the evidence regarding family caregiving in oncology is very timely given the changing social and demographic factors, including distance caregivers, ethnic diversity, an aging cancer population, and cancer care advances, which have resulted in prolonged courses of treatment and long-term survival.¹⁵⁻¹⁷

Societal changes are important influences to consider. For example, in the previous intervention studies reviewed in the meta-analysis by Northouse et al, 84% of the caregivers were white.⁷ Yet there are important cultural meanings related to cancer and caregiving that may influence interventions. In 2015, the American Association of Retired Persons released a report on “Caregiving in the United States,” stating that Hispanics have the highest prevalence rate of caregiving across ethnic groups, that they are older caregivers, and they have the highest rate of living with the person for whom they provide care.¹⁸ Cancer is the fourth most common illness for Hispanic caregivers but is rated as the illness with the highest burden.⁸ Socioeconomically disadvantaged families across ethnicities also face greater challenges in caregiving, including the burden of out-of-pocket costs, transportation, disrupted employment, and less available family support.¹⁹⁻²⁴ The goal of this article is to present an updated review of randomized controlled trials (RCTs) of interventions involving cancer caregivers.

Research Method

Identification and Selection of Studies

By using the same focus as Northouse et al in the earlier review, the literature search targeted only intervention studies involving caregivers of adult patients with cancer.⁷ The

same eligibility criteria used in the study by Northouse et al were applied: 1) the intervention was for caregiver or caregiver-patient dyads; 2) the intervention was psychosocially, cognitively, or behaviorally oriented; and 3) random assignment was included as part of the study design. Studies did not need a control group to qualify for analysis, and studies comparing 2 interventions were included in the analysis. Studies were excluded if they did not include a cancer caregiver or if no intervention was described. Interventions conducted in pediatric settings (such as parents as caregivers) and pharmacological interventions were excluded.

Four literature databases were searched: PubMed, Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycInfo, and Web of Science. The original search terms were used (“family caregiver,” “cancer patient,” “spouse,” “partner,” “couple,” and “intervention”), and additional terms were applied (“neoplasms,” “oncology,” “oncologic,” “leukemia,” “lymphoma,” “sarcoma”), including more terms to search for interventions (“therapy,” “treatment”). The exact searches for the different databases are available on request.

The search was limited to articles published in peer-reviewed journals, published in the English language, research involving human subjects, and publication date from January 2010 to October 2016. Articles from the search were reviewed for inclusion criteria, and tables were constructed to record extracted data. Both authors read and analyzed the research articles. The analysis was conducted by culling data into tables to organize content. The exclusion criterion to determine article selection was used from the original study, and 2 additional categories were added: 1) studies that included caregivers across diseases rather than cancer caregivers only and 2) studies with only qualitative methodology. Data were extracted from each article using the same content analytical framework from the original study, and tables were created to capture this information.⁷ The primary outcome measure for each study was recorded, and, when it was not explicitly stated in the article, both authors came to agreement on which outcome should be recorded. Data were entered into SPSS (IBM Corporation, Armonk, NY) for frequency distributions of the characteristics of cancer caregiver interventions.

Results

The initial search yielded 998 articles, with 188 duplicate titles found across the 4 databases; thus, 810 articles were reviewed. Overall, 50 articles reporting on RCTs that included cancer caregivers and were published between January 2010 and October 2016 were reviewed for this study. Figure 1 provides an overview of the selection review process.

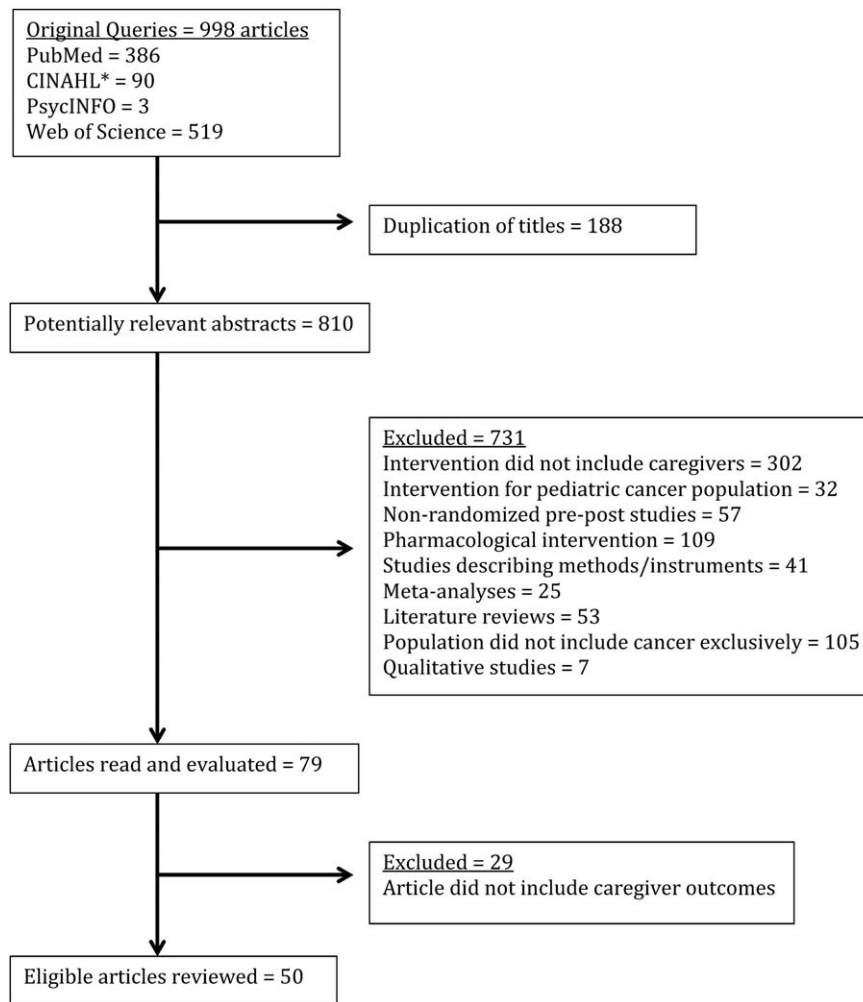


FIGURE 1. Selection Process of Randomized Trials. *CINAHL Cumulative Index to Nursing and Allied Health Literature.

Type, Dose, and Format

In some instances, the RCT study design involved more than 2 arms, such as a comparison of 2 interventions with or without a usual care group; and, as a result, 72 interventions were identified within the 50 articles reviewed. Data extraction did not include control group or usual care group information. Supporting Information Table 1 provides a summary of the content of cancer caregiver interventions in RCTs (see online supporting information).²⁵⁻⁷⁴ The contents of intervention protocols were primarily psychoeducational ($n = 46$; 64%), followed by skills training ($n = 16$; 22%), and therapeutic counseling ($n = 11$, 15%). Caregiver interventions averaged 5 sessions/contacts, ranging from one (eg, to provide the caregiver with brief teaching and an educational booklet)^{30,33,69,74} to 48 sessions/contacts (eg, an exercise program that involved twice weekly activities over 6 months).⁵² The average duration was 84 days; however, one intervention spanned 2 years and, with this outlier removed, the average duration of interventions declines to 72 days. Overall, 11% of interventions

involved fewer than 3 hours (from 20 minutes to 3 hours).^{25,30,33,35,43,44,69,74}

One-half of all interventions offered to cancer caregivers were couples-based interventions that involved both the patient and the caregiver ($n = 38$; 53%), with 40% ($n = 29$) offered to the caregiver only and 13% ($n = 9$) offered independently to the caregiver and the patient. Two intervention protocols were offered with options for couples-based or independent participation and were included in both coding categories.⁶¹ The majority of interventions involved a combination of face-to-face visits ($n = 26$; 36%) and telephone contact ($n = 33$; 46%), with less use of group formats ($n = 5$; 7%). These coding categories were not mutually exclusive. One-quarter of interventions involved video/audio materials, such as a CD or DVD for home use or Web-based education and support (including video conferencing or videophones). Regardless of format, the majority of interventions ($n = 48$; 67%) included print materials, such as an instructional manual or booklet. Interventions were delivered by a nurse ($n = 25$; 35%) or provided by a specialist health

care provider (n = 28; 39%), such as a behavioral therapist, psychologist, or mental health professional. The remaining studies (n = 12; 17%) had no or limited interventionist involvement (eg, training or orientation to technology^{40,49}), because they involved a Web site intervention,^{34,40,57,59} self-directed writing tools and written materials,^{25,45,53,61} workbooks and take-home videos,^{37,74} and self-directed protocols.⁴⁹ One intervention protocol examined the impact of a patient intervention on caregivers.⁶⁰

Content

Intervention content was coded into topics related to patient caregiving (information and skills related to caregiving tasks), marital/family care (information and skills related to coping and relationships), and caregiver self-care (information and skills related to caregivers' own management of stress related to caregiving). The majority of interventions included patient caregiving content (72%), focusing on symptom management and general physical care. Secondary to content on patient caregiving was caregiver self-care (68%), highlighting health and emotional self-care, social support, and accessing resources. Finally, less than one-half of the caregiving interventions across the 50 studies involved marital/family care content. Of these interventions, the primary focus involved relationships and communication between the patient and caregiver. Overall, 54% (n = 39) of studies included a reference to a theoretical framework for the intervention, and only 34% (n = 24) addressed intervention fidelity.

Characteristics of Caregivers

The mean sample size was 150 caregivers (median, 116; range, 7-477) across all 50 studies. The average baseline data enrollment rate was 54%, with rates varying from 13% to 100%, and 5 studies did not provide enrollment rates. The caregiver attrition rate ranged from 0% to 71%, with patient decline or death the most common attrition reason. Supporting Information Table 2 summarizes the characteristics of cancer caregivers in RCTs (see online supporting information).²⁵⁻⁷⁴ The majority of caregivers were spouses/partners (77%); followed by parents, friends, and siblings (15%); and adult children (8%). Caregivers were predominantly female (72%), with one study focusing exclusively on male caregivers. Across all studies, the majority of caregivers were white (86%). Three studies predominantly focused on nonwhite caregiving populations (eg, Hispanic/Latino caregivers, Asian caregivers); however, 46% of all studies did not report caregiver race. The average age of caregivers was 55 years. Caregiving interventions targeted heterogeneous cancer populations representing a variety of cancer types (51%) as well as homogenous patient populations (49%). The most common homogenous patient population was men with prostate cancer, representing 45% of all homogenous

studies. Nine studies did not report detailed demographic information on patients.

Caregiving Measures

The most common caregiver outcome measures were QOL, stress, and communication and intimacy. Supporting Information Table 3 summarizes the primary outcome variables and measures used across all 50 studies (see online supporting information). Measures of QOL included the Functional Assessment of Cancer, Caregiver Quality-of-Life Scale-Cancer, the Caregiver Quality-of-Life Index-Cancer, the Center for Epidemiologic Studies Depression Scale, and the City of Hope Family Caregiver Quality-of-Life Scale. Assessment of caregiving stress ranged from perceived stress (Perceived Stress Scale), mood (Profile of Mood States), psychological distress (National Comprehensive Cancer Network Distress Thermometer), and measures of anxiety and depression (Hospital Anxiety and Depression Scale; State-Trait Anxiety Inventory).²⁵⁻⁷⁴ Finally, couples-based interventions targeted dyadic communication and relational intimacy, which were assessed using measures grounded in family theory, including the Family Relationship Index, the Dyadic Coping Inventory, the Dyadic Adjustment Scale, and assessments of intimacy.

Study Outcomes

Supporting Information Table 3 also summarizes the primary outcomes from the FCG intervention studies. The outcomes can be summarized across 4 general areas. First, many of the interventions do demonstrate improved QOL for FCGs. Although QOL is measured using various instruments, these generally include QOL dimensions of physical, psychological, social, and spiritual well-being.

The second key outcome is emotional support. Studies have targeted and measured outcomes encompassing several different emotional constructs, including depression, spiritual distress, anxiety, emotional distress, mood, and coping. A key theme in the literature and studies is the very real need to allow caregivers to share their emotional responses to the illness.

A third area is communication and relational intimacy. Interventions, especially those that are couples-based, have provided coaching in how to communicate shared concerns, address the impact of the illness on intimacy, and overcome the isolation or avoidance common as patients and their caregivers attempt to protect each other from the realities of the illness.

The fourth theme across the study interventions and outcomes is the caregiving tasks. Studies have assessed and documented interventions focused on the tasks or activities required in caregiving and improvements in areas, including caregiver fatigue, burden, confidence, self-efficacy, and preparedness.

Discussion

There are several notable differences between the 2010 meta-analysis by Northouse et al⁷ and this review. Notably, there has been an increase in RCTs involving FCGs. There were 401 citations reviewed over a 26-year period in the previous review and 810 citations reviewed over a 7-year period for this review. The increase in research involving FCGs may be the result of increased funding in this area. One-half of all published RCTs reviewed for this analysis were funded by the National Institutes of Health, with the remaining trials funded largely by international agencies.

Similar to the findings of Northouse et al, psychoeducational interventions remain the predominant approach to FCG intervention research. The literature suggests that models of caregiver support are being developed, but there is a need to translate these models for realistic application to clinical practice settings. For example, the analysis revealed that only 11% of interventions involved fewer than 3 hours of time, which was generally by research staff. There has also been a decrease in the reporting of intervention fidelity, which was addressed in 75% of studies in the 2010 meta-analysis yet in only 34% of studies in this review. It is unclear whether there was less rigor between 2010 and 2016 or whether there was less reporting of study methods related to intervention fidelity.

Couples-based interventions also remain a prolific approach. Similar to a systematic review conducted in 2012 by Regan et al,⁷⁵ couples-based interventions were most effective in improving communication, distress, and relationship functioning. In addition, our current review indicated an increase in interventions solely targeting caregivers and not patients. Although nurse-delivered interventions were prevalent in both reviews, findings from this analysis show an increase in the use of various health care providers to intervene with FCGs; notably, we observed that social workers were less frequently used as interventionists than providers from other disciplines. This is surprising given the very significant role of social work in supporting family members.

The greatest change in RCT interventions with FCGs in the last 7 years has been in the format of the intervention. Northouse et al found face-to-face visits in the clinical setting in two-thirds of the RCTs reviewed, with telephone delivery accounting for only one-fifth of the interventions. This review shows increased attention to interventions that can be done by FCGs in their home, with telephone contact now most prevalent and the use of self-directed technology on the rise. However, combined format approaches (eg, face-to-face and telephone), along with an option for the caregiver and patient to work independently or collaboratively, make it difficult to determine whether these formats are acceptable to caregivers and efficacious. In addition, the variety of teaching content being covered within these interventions, ranging

from self-care to physical care, adds to the complexity of determining overall effectiveness based on format. Because there was such diversity in designs, methods, and outcome measures across studies, as depicted in the supporting tables, it is not possible to compare studies to definitively determine which are most effective. Current research shows a research trend toward developing caregiving interventions that are flexible and adaptable, making the routine use of validated measures by researchers necessary.

In both the meta-analysis and this review, the focus on patient-care content in the intervention remains the same. There is a general consensus that caregivers need pain-management skills specifically, and skills-based interventions in this review focused largely on general physical care and symptom assessment, including instruction assessing side effects (eg, Chambers et al^{32,33}), techniques for assisting in pain management (eg, Belgacem et al³⁰), and general training in problem-solving skills (eg, Sherwood et al⁶⁶). However, skills-based interventions are still second to psychoeducational approaches, and it is not yet known which approach is best. Compared with the prior meta-analysis, there is an increase in caregiver skill development for health, self-care, and coping skills, such as learning to write emotional disclosures (eg, Arden-Close et al²⁵) and cognitive reframing and relaxation (eg, Badr et al²⁹). More research is needed to determine specific skills needed by caregivers and to compare skill development and informational interventions.

Overall, this review shows that sample sizes are larger, likely because of increased funding and support for projects. Enrollment of FCGs across all RCTs in both reviews remains the same. Caregiver samples remain largely white, and there is a noticeable tendency for researchers to exclude caregiver race and ethnicity as a reported caregiver demographic variable.

The topic of family caregiving has gained prominent attention by most all leading oncology organizations. The American Cancer Society has provided significant attention to family caregiving, as have other research and advocacy groups in oncology. Table 1 includes a list of key resources related to family caregiving. Many of these resources provide teaching materials and information useful for clinical practice. Much of the information on these Web sites is empirically based, and resources address both emotional support and caregiving knowledge and skills. There have been some efforts to educate oncology clinicians on available resources to support family caregiving.⁷⁶ The National Cancer Institute released a research proposal request in 2016 to test FCG interventions, and the National Academies of Sciences, Engineering, and Medicine in 2016 published a major report on family caregiving.⁷⁷

This updated review found continued focus across studies on predominantly white populations. This is in

TABLE 1. Key Resources Related to Family Caregiving

Name	Link
American Cancer Society ^a	cancer.org
CancerCare ^a	cancercare.org
Cancer Support Community ^a	cancersupportcommunity.org
Family Caregiving Alliance ^a	caregiver.org
National Alliance for Family Caregiving ^a	caregiving.org
National Cancer Institute ^a	cancer.gov
Palliative Care Research Cooperative (PCRC)/Family Caregiver Core	palliativecareresearch.org

^aThese Web sites have resources and information designed for access by family caregivers.

contrast to current demographic trends as well as a growing body of literature addressing strong cultural influences on family caregiving.⁷⁸⁻⁸¹ The limited research that has included ethnic minorities has focused largely on Hispanic communities. There is a clear need for research testing interventions that are more representative of changing demographics.

Limitations

This review was limited to English-language publications, and it excluded unpublished or ongoing studies, abstracts, or dissertations. Given the increased attention to this area and greater emphasis on testing interventions, there may be emerging models that were not reviewed. The limited space available in journal publications made it difficult to assess details, content, or procedures of the FCG interventions. With the greater ability to share resources through the Web, hopefully these interventions can be shared with other investigators and clinicians.

Clinical Implications

There is very strong consensus that FCGs are central to cancer care, and there is an increased interest in developing models of FCG support, which is linked to patient outcomes, with FCGs becoming clinician partners at a time of major shift in oncology to outpatient care. The preparation of FCGs for their role, increased emphasis on FCG self-care, and the translation of tested interventions into practice will be challenges for the future of oncology. Table 1 includes a list of key resources available online for clinicians, including many materials that were designed for FCG access.

Although there are substantial needs for additional research in this area, a review of the literature and analysis of interventions can provide some clear implications for clinical practice. A key implication is the need for clinicians to include a family assessment as a component of new patient admissions. Identifying caregivers who may also have serious illness, preexisting emotional concerns, and limitations in their ability to take on complex cancer caregiving is vital. While time and resources are very limited in clinical settings, there is opportunity to apply some of the tools used in FCG research, such as tools measuring caregiver burden or preparedness, to identify caregiver needs.

The literature related to couples interventions supports the need to assess for communication between patients and partners. Intimacy concerns are also common and become a strain in the family cancer experience. The resources listed in Table 1 offer several written materials Web sites, telephone resources, and ideas that can be applied in clinical settings. All of these issues also speak to the need for an interdisciplinary approach to cancer care, as FCGs can be supported through involvement of social work, psychology, chaplaincy, medicine, nursing child-life specialists, and others.

This review of the family caregiving literature has captured the increased interest in this important aspect of cancer care. The support of FCGs is vital given their essential role as the key workforce in patient care, from diagnosis through long-term survivorship or end of life. ■

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