

## ARTICLES

# Helping Families of Patients With Cancer

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**Purpose/Objectives:** To discuss the impact of cancer on families of patients with cancer.

**Data Sources:** National reports on caregiving and research articles related to cancer and families.

**Data Synthesis:** Family caregivers are the bedrock of chronic care in the United States. They provide an enormous amount of unpaid care that is often invisible. Cancer can affect the emotional, social, physical, and spiritual well-being of family members.

**Conclusions:** Family intervention research can have a positive effect on patient and family caregiver outcomes. More intervention research with families is needed that is theoretically based, uses randomized clinical trial designs, and uses instruments that are sensitive to intervention effects.

**Implications for Nursing:** Although family intervention research is limited, descriptive and exploratory research has identified protective factors and risk factors that need to be addressed in clinical practice.

Families are deeply affected when one of their members becomes ill. Not only do they experience anxiety and worry about patients' recovery, but they frequently become the primary caregivers until patients recover. Although there is growing recognition that the family is central to the patient's recovery, information is limited on how to help families as they manage the demands associated with family caregiving. In this article, five areas will be addressed. First, the broader area of caregiving in the United States will be presented to provide a context for examining how cancer affects families. Second, research pertaining to the specific effects of cancer on the family will be reviewed. Third, family intervention studies will be discussed along with a brief summary of the family intervention research we have been conducting at the University of Michigan. Fourth, the article will discuss the implications of family research for clinical practice, and finally, it will identify directions for future research.

## Who Are the Caregivers in the United States?

This was a question asked by the National Alliance for Caregiving and AARP, who joined forces to describe unpaid caregivers in the United States. They formed a research team that conducted a telephone survey with 6,139 adults in the United States, from which 1,247 caregivers were identified. Caregivers were defined as anyone 18 years of age or older providing unpaid care for an adult who required help with at

least one activity of daily living (ADL) (e.g., bathing, dressing) or one instrumental activity of daily living (IADL) (e.g., managing finances, housework). Findings of this comprehensive study were reported in *Caregiving in the U.S.* (National Alliance for Caregiving & AARP, 2004).

Based on the proportion of caregivers and caregiving households identified in the national survey, researchers estimated that there are 44.4 million unpaid caregivers in the United States (National Alliance for Caregiving & AARP, 2004). These caregivers provide care to adults with a variety of conditions (8% reported providing care to someone with cancer). Most caregivers provide care to one person (69%), and an additional subgroup of caregivers (22%) provide care to two people. Because most caregivers (59%) are employed either full time or part time, caregiving is the "second job" for many. A sizeable number of caregivers (39%) report that they had "no choice" in becoming a caregiver.

According to the national survey, most caregivers in the United States are family members (83%). In more demanding care situations, family members are even more likely to be the caregivers (89%). Higher estimates have been reported by Emanuel et al. (1999), who found that among the terminally ill in the United States, 96% of the caregivers were family members. These high percentages underscore the central role that family members play in managing the care of people who are ill in the United States. It is no surprise that the family has been called the bedrock of our nation's chronic care system (Arno, Levine, & Memmott, 1999).

In regard to gender, a majority of caregivers in the United States are female. Although the number of male caregivers is increasing, women bear a greater responsibility than men with caregiving. When investigators compared the caregiving experience of women to that of men, they found that women provide more hours of care per week, provide care at higher levels of burden, are more likely to report "no choice" in becoming a caregiver, and report more emotional strain associated with the caregiving role than male caregivers (National Alliance for Caregiving & AARP, 2004).

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Digital Object Identifier: 10.1188/05.ONF.743-750

As a part of the national study on caregiving, investigators also examined the level of burden associated with caregiving. “Burden” was derived from the amount of help needed by an ill person with ADL or IADL, in combination with the number of hours of caregiving provided per week. Burden was categorized into five levels, with level 1 being the lowest burden level and level 5 being the highest. As indicated in Table 1, approximately one-third of caregivers provide care at the lowest level of burden, averaging 3.5 hours of care per week. However, looking at levels 4 and 5 combined, it is evident that another one-third of the caregivers provide care at the highest two levels of burden. Of note is that at level 4, caregivers are averaging 33.1 hours of care and at level 5, they are averaging 87.2 hours of care per week. Although only 10% of the caregivers report caregiving at the highest level of burden, 71% of these caregivers are women, and 30% of these caregivers report that their own health is poor (National Alliance for Caregiving & AARP, 2004).

Comparisons were made between the experience of caregivers providing care for patients with cancer versus those without cancer and are shown in Table 2 (G. Hunt, personal communication, November 18, 2004). As indicated, a greater percentage of cancer caregivers reported taking time off from work, having less time to socialize with family and friends, and wanting help managing stress than noncancer caregivers. Cancer caregivers also are more likely to provide care in situations with higher levels of burden. More than half of cancer caregivers (56%) provide care at the two highest levels of burden in contrast to less than one-third of noncancer caregivers (31%). These findings suggest that many caregivers of patients with cancer are dealing with high levels of burden and would benefit from interventions that would help them to manage stress associated with their caregiving role.

Before leaving this broader perspective on caregiving, it is important to consider the economic value of unpaid caregiving to society. Arno et al. (1999) examined the economic value of caregiving using large national datasets. They calculated the value of unpaid caregiving by estimating the average number of hours of care provided per week (17.9 hours), multiplied by the number of caregivers in the United States, and a hypothetical wage of \$8.18 per hour if the caregiver had been paid slightly more than minimum wage. From these calculations, the investigators estimated that family caregivers contribute \$196 billion every year in unpaid care to ill people in the United States. Arno et al. contended that the economic value of family caregiving dwarfs the national spending for formal home care (\$32 billion) and nursing home care (\$83 billion), even though it is not counted as a part of the national healthcare expenditure. Clearly, family caregivers provide

**Table 1. Caregiver Burden in the United States**

Burden Level	Average Hours per Week	Caregivers (%)*
1	3.5	33
2	9.8	17
3	12.0	15
4	33.1	21
5	87.2	10

\* Missing data accounted for 4%.

*Note.* Based on information from National Alliance for Caregiving & AARP, 2004.

**Table 2. The Experience of Cancer Caregivers Versus Noncancer Caregivers**

Caregiver Burdens	Cancer Caregivers (%)	Noncancer Caregivers (%)
Time off from work	65	57
Less time for family and friends	67	51
Want help managing stress	41	29
Burden levels 4 or 5	56	31

*Note.* Based on information from Hunt, 2004.

an enormous amount of unpaid care that benefits society but remains largely invisible to others. Family caregivers are the core of long-term care providers in the United States, and more effective ways are needed to support and sustain them (Arno et al.)

## Effects of Cancer on the Family

Shifting from the broader view of caregiving in general, what have we learned about the effects of cancer on the family? In this section, research will be examined along the four dimensions of quality of life: emotional well-being, social well-being, physical well-being, and spiritual or existential well-being.

### Emotional Well-Being

Of the four domains of quality of life, most of the research with families has been on the emotional effects of cancer (Edwards & Clarke, 2004; Ell, Nishimoto, Mantell, & Hamovitch, 1988; Ey, Compas, Epping-Jordan, & Worsham, 1998; Hilton, 1993). There is clear evidence across a number of studies that cancer affects the emotional well-being of both patients and their family members. In an earlier study, my colleagues and I compared adjustment problems reported by women diagnosed with breast cancer and their husbands versus women diagnosed with benign breast disease and their husbands during the first year following diagnosis (Northouse, Templin, Mood, & Oberst, 1998). Dyads facing breast cancer reported significantly more adjustment problems than dyads with benign breast disease. Although it was not surprising that women with breast cancer had more adjustment problems than women with benign disease, clear differences also were found between the husbands in each group. Husbands of women with breast cancer had significantly more adjustment problems than husbands of women with benign disease, indicating that they also were affected by the cancer.

There are other emotional effects experienced by family members of patients with cancer. Some family members report persistent worry even though a patient’s treatment may be completed. Family members are surprised when patients do not quickly return to normal and continue to be distressed after treatment (Lethborg, Kissane, & Burns, 2003). Family members also report uncertainty about the future and fear that the cancer may recur. Husbands in a study by Walker (1997) reported moderate levels of fear that their wives’ breast cancer would recur. Matthews (2003) found that family caregivers reported more fear than patients themselves that the cancer would recur. Research suggests that the emotional effects of cancer linger for 12–24 months following diagnosis (Zahlis & Shands, 1993). However, if no further problems develop,

family members report few negative emotional effects at three years after diagnosis (Mellon, 2002) and mood scores return to a normal range four years after diagnosis (Gritz, Wellisch, Siau, & Wang, 1990).

But what if the cancer returns? Research suggests that cancer recurrence creates serious impairment in the emotional well-being of both patients and family members. In a study conducted with women with recurrent breast cancer and their family caregivers, both patients and family caregivers reported lower mental well-being scores than patients dealing with a new diagnosis of breast cancer (Northouse, Mood, et al., 2002). In addition, family members, in comparison to patients, had higher levels of uncertainty and perceived less support from others. Given et al. (2004) found moderate to high levels of depression in family caregivers of patients at the end of life. Clearly, the emotional toll of the illness increases as patients' health deteriorates. When 750 cancer caregivers were asked what was the most difficult emotional aspect of cancer, they reported that watching patients' health deteriorate and not knowing what to do was the most distressing to them (Barg et al., 1998).

Does it matter if family members are distressed? It matters a great deal. Our research indicates that distressed family caregivers hinder the adjustment of patients (Northouse, Templin, & Mood, 2001). Furthermore, how well families cope can affect how well patients cope; each affects the other. Research also indicates that not all families are distressed. Rather, there appears to be a subgroup of about 20% of the families that experience high levels of distress in response to cancer (Edwards & Clarke, 2004). It is important to identify these high-risk families early in the course of illness because without intervention, their adjustment problems are likely to persist.

### Social Well-Being

Investigators also have examined the social or interpersonal effects of cancer on patients and their family members. These studies have been primarily with married couples and have examined the effect of cancer on their marital relationships. The good news is that there is little evidence of divorce in couples dealing with cancer. Marital satisfaction scores of couples dealing with cancer are within the normal range and comparable to couples not dealing with cancer (Northouse et al., 1998). Furthermore, couples who report high marital satisfaction prior to diagnosis continue to report high satisfaction following diagnosis and into survivorship (Gritz et al., 1990). Research indicates that cancer actually may draw some couples closer together; these couples tend to appreciate one another more and place greater priority on their relationships (Gritz et al.; Harden et al., 2002).

Although there is little evidence of divorce among couples, there are factors that can create marital strain. Lewis and Hammond (1992) and Lewis, Woods, Hough, and Bensley (1989) found that depression in either patients or partners negatively affected their marital relationships. This research points to the need to assess for depression and intervene early to lessen the stress on marital relationships. Another factor that creates strain is partners' different styles of communicating about or coping with cancer. Some partners prefer frequent discussions, whereas other partners prefer little discussion about the cancer. These conflicting styles can create strain in relationships. Even though partners' preferences may differ,

researchers have identified certain communication patterns that help couples deal with the stress of cancer. These include communication patterns that are open but selective, avoid indiscriminant catharsis, use high empathy, and limit the use of criticism and withdrawal (Hilton, 1994; Manne, Pape, Taylor, & Dougherty, 1999).

In addition to research on the marital relationship, there is a small amount of research that has examined the effects of a parent's cancer on children. The research indicates that the stress of the parent's cancer reverberates to the children regardless of whether children openly express their concerns (Kristjanson, Chalmers, & Woodgate, 2004). The research also indicates that children's responses vary by their developmental stage and that communication with children about a parent's cancer needs to be appropriate to their age (Lewis, Ellison, & Woods, 1985). Some investigators have found that adolescents may be at greater risk for having more problems adjusting to a parent's cancer than younger children (Kristjanson et al.; Welch, Wadsworth, & Compas, 1996). Adolescents may be at greater risk because developmentally they are trying to separate from their parents but at the same time they are drawn closer to assist the parent with cancer. This emotional tug-of-war can create conflicts within adolescents.

### Physical Well-Being

We know very little about the physical effects of cancer on family members. Few studies have examined the physical effects, and those that have report that family caregivers' physical well-being scores are within normal range on standardized measures. However, some research indicates that as patients' cancer progresses, the illness has a more detrimental effect on the physical well-being of family members (Given & Given, 1992). Increased fatigue and sleep disturbances also have been reported by family members (Carter, 2002; Jensen & Given, 1993).

Although the documentation of physical effects is limited, research with family caregivers who are managing other types of chronic illness suggests that family caregivers who experience strain associated with their role may have an increased mortality risk of their own. Schulz and Beach (1999) compared the mortality risk of four groups of spouses of patients with cardiovascular disease: (a) spouses whose partners were not ill, (b) spouses whose partners were ill but did not require care, (c) spouses whose partners were ill and needed care but whose care created no strain for the caregiver, and (d) spouses whose partners were ill, needed care, and whose care created strain for the caregiver. Four years following initial assessment, a significant difference was found between two groups of spouses. Spouses who reported caregiver strain had a 63% greater mortality risk at the four-year follow-up than spouses who were not providing care. Investigators identified possible reasons for the increased mortality risk. Strained caregivers were less likely to engage in preventive health practices and less likely to seek medical care when they were sick. Although this study used couples dealing with cardiovascular disease, the findings may be relevant for spouses of patients with cancer with strain or high levels of burden associated with caregiving.

### Spiritual or Existential Well-Being

Spiritual well-being refers to the way in which people make sense of their lives and find meaning and purpose in

the challenges that they face. Research suggests that family members, as well as patients, try to find meaning in the cancer experience. In a study of long-term survivors, Mellon (2002) found that, for many families, cancer was a transformative experience. As a result of the cancer, some families reconsidered their priorities and gained a greater appreciation of everyday life. Both survivors and family members reflected on the past and thought about ways to make the most of the present and future. According to some researchers, the more families are able to find meaning in the cancer illness, the more positive their adjustment to the illness (Germino, Fife, & Funk, 1995).

## Family Intervention Studies

Moving from the description of how cancer affects the quality of life of family members, the next section will address interventions used to assist families to manage the effects of illness in their lives.

### Family Interventions in Chronic Illness

Martire, Lustig, Schulz, Miller, and Helgeson (2004) conducted a meta-analysis to determine what effects, if any, interventions conducted with families managing a chronic illness had on patient outcomes and on family caregiver outcomes. The investigators established rigorous criteria for including studies in the meta-analysis, such as the use of a randomized clinical trial design with treatment and control groups, sample sizes with a sufficient number of family caregivers, and outcome measures that assessed either physical or mental health. Seventy family intervention studies met the above criteria and were included in the meta-analysis. Of these 70 studies, most used a multicomponent family intervention that provided information, support, or skill building.

The results of the meta-analysis indicated that family interventions significantly reduced two patient outcomes: patient depression and patient mortality. Family interventions also significantly decreased two family caregiver outcomes: caregiver depression and caregiver burden. According to the findings, family interventions had little effect on patients' or family caregivers' relationship satisfaction or on patients' physical disability. The results of the analysis indicated that family interventions, whether offered jointly to patients and caregivers or to family caregivers alone, have significant positive effects on both patient and caregiver outcomes.

### Family Interventions in Cancer

There is a limited amount of information available on the effects of family interventions in the cancer area. Only a few studies have used randomized clinical trials, and some of the published studies are pilot studies with small samples (Donnelly et al., 2000; Hoskins et al., 2001). In addition, family intervention studies in the cancer area have been plagued by low accrual and retention rates (Blanchard, Toseland, & McCallion, 1996). Some family interventions have been offered when families were experiencing very few problems; hence, there was little room for improvement and little effect of the interventions on outcomes (Toseland, Blanchard, & McCallion, 1995). Furthermore, family intervention studies have not always assessed both patient and family caregiver outcomes

in the same study. Studies that have assessed both patient and caregiver outcomes often have published the results in separate manuscripts, making it difficult to locate findings on how the interventions affected both patients and family caregiver outcomes.

Even though the literature is limited, there are examples of family intervention studies in the cancer area that used randomized clinical trials and that also found significant effects (see Table 3). In an early study, Christensen (1983) conducted a study with a small sample of patients with breast cancer and their husbands. Among couples who participated in the family intervention, patients reported less distress and couples reported more sexual satisfaction. Blanchard et al. (1996) offered a six-session counseling intervention to partners of patients with cancer. Although no significant changes were found in outcomes for partners, as a result of partners' participation in the intervention, patients reported less depression. Bultz, Specia, Brasher, Geggie, and Page (2000) offered a psychoeducational group to a small number of partners of patients with breast cancer. Results indicated that partners' participation in the intervention resulted in less mood disturbance in both patients and partners. Finally, Kuijer, Buunk, De Jong, Ybema, and Sanderman (2004) offered an intervention that addressed equity in the relationships between patients with cancer and their partners. Couples who received the intervention reported greater marital satisfaction, and patients reported less distress. Although the preceding discussion provides only a brief overview of the family intervention studies in cancer, the findings of these few studies parallel the findings of Martire et al.'s (2004) meta-analysis. Family interventions, directed to either dyads or family caregivers alone, can have positive effects on both patient and family caregiver outcomes.

From reviewing the family intervention research in cancer, it is evident that there are various challenges that confront researchers in this area. One challenge is determining where the family intervention fits within the broader theoretical framework guiding the study. Martire et al. (2004) found that many family intervention studies did not identify a theoretical framework or describe how theory was used to develop the intervention. A second challenge is determining what "dose" or how many sessions of a family intervention are needed to obtain significant effects. Family interventions have ranged from one session (Bucher et al., 2001) to 11 sessions (Donnelly et al., 2000). In an era of cost constraints, it is necessary to consider what dose of an intervention is essential, and under which conditions, to obtain the desired intervention effects. A third challenge is rethinking one-size-fits-all interventions.

**Table 3. Examples of Family Intervention Studies in Cancer Care With Significant Effects**

Study	Sample	Findings
Christensen (1983)	Dyads (N = 20)	Decreased patient distress Increased sexual satisfaction
Blanchard et al. (1996)	Spouses (N = 66)	Decreased depression in patients
Bultz et al. (2000)	Partners (N = 36)	Less partner mood disturbance Less patient mood disturbance
Kuijer et al. (2004)	Dyads (N = 39)	Less patient distress More relationship satisfaction

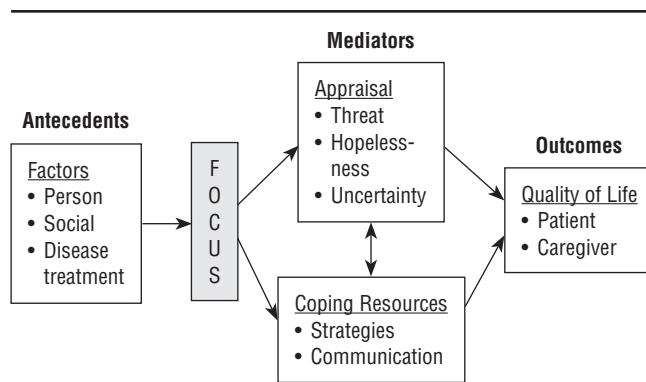
My colleagues and I have found in our intervention work that not all families need the same amount of an intervention. Some families have many resources and need less help; other families have few resources and need more help. Considering ways to tailor or target a family intervention to the needs of individual families remains a challenge for researchers.

A fourth challenge in conducting family research is finding ways to extend the duration of an intervention's effect. In some studies, the strongest effect of an intervention was obtained just after the intervention was delivered, with the effect of the intervention lessening over time (Mishel et al., 2002). Although booster sessions may be one way to extend intervention effects, other strategies are needed to lengthen the effect of an intervention over an extended period of time. A final challenge is finding instruments that are short and sensitive to measure the effects of a particular intervention. Many of the conceptually refined, psychometrically strong instruments that have been used in previous exploratory studies are not sensitive to the effects of an intervention on outcomes. Identifying instruments that are brief yet sensitive to patient and family caregiver outcomes remains a significant challenge.

### Research With Families at the University of Michigan

Our research team has been conducting intervention studies with patients with cancer and one of their family caregivers for the past 10 years, in collaboration with investigators from Wayne State University and other cancer centers. Our first intervention study was with women with recurrent breast cancer and their family caregivers and was funded by the American Cancer Society. We developed a family intervention program called the FOCUS Program (Northouse, Walker, et al., 2002). Each letter of the acronym FOCUS represents one of the core components of the intervention program: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. The FOCUS Program was offered jointly to women with recurrent breast cancer and a family caregiver in five sessions (three home-visit sessions and two phone sessions) by master's-prepared nurses. The participants reported high satisfaction with the program (Northouse, Walker, et al.). Dyads that participated in the FOCUS Program reported a more positive appraisal of the illness and caregiving, and patients reported less hopelessness associated with their recurrent breast cancer (Northouse, Kershaw, Mood, & Schafenacker, 2005).

For our second intervention study, we adapted the FOCUS Program to the needs of men with prostate cancer and their spouses or partners. This study was funded by the National Cancer Institute. We were interested in determining whether the program would be relevant to dyads managing a different type of cancer (prostate cancer versus breast cancer) and for male patients and their partners rather than for female patients and their family caregivers. The program was offered to men who were at one of three phases of prostate cancer: (a) newly diagnosed phase; (b) post-treatment phase, with rising prostate-specific antigen (biochemical recurrence); or (c) advanced phase. The theoretical framework used to guide this study was adapted from stress-coping theory (Lazarus & Folkman, 1984) and family systems theory (McCubbin & McCubbin, 1996). Figure 1 illustrates a simplified version of the theoretical model and the placement of the family in-



**Figure 1. Theoretical Model With Placement of FOCUS Intervention**

tervention (FOCUS Program) within the model. We hypothesized that the family intervention would have a direct effect on the appraisal factors (threat, hopelessness, uncertainty) and the coping resources (strategies, communication) and an indirect effect on patient and caregiver quality of life. For the second test of the FOCUS intervention with dyads facing prostate cancer, we retained the five sessions of the intervention and used the same core content that was used in the initial study with dyads managing breast cancer. However, we tailored the intervention materials for men dealing with prostate cancer and their spouses and developed self-care materials for the symptoms commonly experienced by men with prostate cancer (e.g., sexual concerns, incontinence, hormone changes). This study is progressing well, and no outcome data are available at this time.

My colleagues and I are in the process of starting our third family intervention study. This study, which builds on our prior two intervention studies, will compare outcomes associated with a Brief FOCUS Program (three sessions), an Extensive FOCUS Program (six sessions), and standard care (control group). This study is being funded by the National Cancer Institute. In our earlier studies, we found that families have different needs for intervention; as discussed previously, some families are managing well and have a low need for an intervention, whereas other families are struggling and have a high need for intervention. We are taking these differences into consideration by offering two doses of the family intervention (brief versus extensive). The study is being conducted with patients with advanced lung, colorectal, prostate, or breast cancer and one of their family caregivers. All patients will complete a risk for distress measure at baseline, be stratified into high or low risk for distress groups, and then be randomly assigned (along with their family caregiver) to one of three arms of the study (Brief FOCUS, Extensive FOCUS, or control condition). We anticipate that patients at higher risk for distress and their caregivers will obtain more benefit from the Extensive FOCUS and that dyads with less risk for distress will benefit more from the Brief FOCUS. We hypothesize that dyads in both intervention groups will have more positive outcomes than dyads in the control condition.

From our intervention work, we have learned that it is important to intervene jointly with patients and caregivers. This allows each person to gain a better understanding of the other person's perceptions and needs. Based on this greater

understanding, patients and caregivers can work more effectively as a team to manage the stress associated with cancer. We also have learned that it is important to offer information and support to both patients and their family caregivers. This enables each person to get first-hand information and direct support as they cope with the demands of cancer. Finally, we believe it is important to offer core content to all dyads but tailor the information to the particular needs and experiences of each dyad.

## Implications of Family Research for Clinical Practice

Although there has been only a limited amount of family intervention research in the cancer area, there is a large body of descriptive and exploratory research to guide clinical practice. The research clearly documents that cancer affects both patients and their family members, especially family members who assume the role of primary caregiver. Therefore, it is important to target interventions to both patients and family caregivers because each is affected by the illness. In clinical settings, it is helpful to acknowledge the presence of family members, ask them how they are managing, and offer information and support to both patients and family caregivers.

### Encourage Protective Factors

The research literature points to several factors that can help patients and family members manage the stress associated with cancer. These include mobilizing support (Giese-Davis, Hermanson, Koopman, Weibel, & Spiegel, 2000), using active coping strategies (Heim, Valach, & Schaffner, 1997), practicing optimistic thinking (Kurtz, Kurtz, Given, & Given, 1995), and finding meaning in the illness (Germino et al., 1995). In the clinical setting, it may be helpful to assist families to identify various sources of support such as other family members, friends, neighbors, or ministers who may provide them with emotional or spiritual support as well as tangible support to manage work and household demands. Encouraging family members to engage in active coping strategies such as problem solving and exercise may facilitate decision making and reduce tension. Practicing optimism by reframing negative events, surrounding themselves with positive people, and setting achievable goals may help families feel more able to handle their situation and the demands associated with it. Finally, by finding meaning in the illness, families may reconsider their priorities and identify unexpected benefits associated with the cancer.

### Address Risk Factors

The research also is clear about factors that can place patients and families at greater risk of having more problems adjusting to cancer. These factors include higher symptom distress (McCorkle & Quint-Benoliel, 1983), higher uncertainty about the illness or treatments (Mishel, Hostenetter, King, & Graham, 1984), multiple demands on the family (Northouse, Mood, et al., 2002), and age. There is clear documentation that higher symptom distress in patients or in family caregivers is associated with poorer adjustment to the illness. Families need practical information on how to manage symptoms such as fatigue, pain, sleep disturbances, and hormonal changes. Higher uncertainty also has been associated with poorer

adjustment. Some families need help obtaining information from various healthcare providers or from appropriate Internet Web sites. In addition, some families need help learning how to live with the uncertainty that is pervasive during the cancer experience. It may help families to know that feelings of uncertainty are a normal part of the cancer experience, which may ebb and flow, and that these feelings are not symptoms of poor coping.

Multiple demands on families also can use up limited family resources and interfere with their ability to respond to the demands associated with cancer. Some families may need help problem solving the multiple, competing demands they encounter. Other family members may need permission to limit work, family, or social responsibilities so they can focus their energies on getting through demanding treatments such as radiation or chemotherapy.

Finally, age may be a risk factor for some families. Younger patients and their family members often experience more emotional distress associated with a cancer diagnosis (Northouse, 1994), whereas older patients and their caregivers experience more functional difficulties associated with cancer and other comorbid health problems. Clinicians may need to tailor their interventions with patients and family members in younger and older age groups to address their specific concerns.

## Directions for Future Research

There are a number of directions for future research. First, there is a need for more intervention studies with patients and their family caregivers. These studies need to test interventions that can be transported into standard care and should include an examination of the costs involved. In light of the greater burden and higher emotional distress reported by female family caregivers, more research is needed to examine the experience of female caregivers and identify strategies to help them manage the demands associated with providing care. Most studies in the area of cancer and the family have been with Caucasian families. We need more information about ethnically diverse families and nontraditional families regarding the ways that they manage the effects of cancer. Although there has been a growing interest in genetic testing and in families at inherited risk of cancer, few programs of care have been developed and tested to assist family members to manage this information and to communicate effectively among themselves and others about their increased risk. Finally, although early studies have highlighted the stress associated with cancer, more research is needed on ways that families can restore themselves and derive meaning from the cancer experience.

In summary, the research clearly indicates that cancer affects the emotional, social, physical, and spiritual well-being of patients and their family members. Many families have difficulty dealing with the stress caused by cancer and need our help in managing the demands of illness. Family interventions assist families to better adapt to the cancer experience and produce positive outcomes for both patients and their family caregivers.

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## References

- Arno, P.S., Levine, C., & Memmott, M.M. (1999). The economic value of informal caregiving. *Health Affairs, 18*, 182–188.
- Barg, F.K., Pasacreta, J.V., Nuamah, I., Robinson, K.D., Angeletti, K., Yasko, J., et al. (1998). A description of a psychoeducational intervention for family caregivers of patients with cancer. *Journal of Family Nursing, 4*, 394–413.
- Blanchard, C., Toseland, R., & McCallion, P. (1996). The effects of a problem-solving intervention with spouses of cancer patients. *Journal of Psychosocial Oncology, 14*(2), 1–21.
- Bucher, J.A., Loscalzo, M., Zabora, J., Houts, P.S., Hooker, C., & BrintzenhofeSzoc, K. (2001). Problem-solving cancer care education for patients and caregivers. *Cancer Practice, 9*, 66–70.
- Bultz, B.D., Specia, M., Brasher, P.M., Geggie, P.H., & Page, S.A. (2000). A randomized controlled trial of a brief psychoeducational support group for partners of early stage breast cancer patients. *Psycho-Oncology, 9*, 303–313.
- Carter, P.A. (2002). Caregivers' descriptions of sleep changes and depressive symptoms. *Oncology Nursing Forum, 29*, 1277–1283.
- Christensen, D.N. (1983). Postmastectomy couple counseling: An outcome study of a structured treatment protocol. *Journal of Sex and Marital Therapy, 9*, 266–275.
- Donnelly, J.M., Kornblith, A.B., Fleishman, S., Zuckerman, E., Raptis, G., Hudis, C.A., et al. (2000). A pilot study of interpersonal psychotherapy by telephone with cancer patients and their partners. *Psycho-Oncology, 9*, 44–56.
- Edwards, B., & Clarke, V. (2004). The psychological impact of a cancer diagnosis on families: The influence of family functioning and patients' illness characteristics on depression and anxiety. *Psycho-Oncology, 13*, 562–576.
- Ell, K., Nishimoto, R., Mantell, J., & Hamovitch, M. (1988). Longitudinal analysis of psychological adaptation among family members of patients with cancer. *Journal of Psychosomatic Research, 32*, 429–438.
- Emanuel, E.J., Fairclough, D.L., Slutsman, J., Alpert, H., Baldwin, D., & Emanuel, L.L. (1999). Assistance from family members, friends, paid caregivers, and volunteers in the care of terminally ill patients. *New England Journal of Medicine, 341*, 956–963.
- Ey, S., Compas, B.E., Epping-Jordan, J.E., & Worsham, N. (1998). Stress responses and psychological adjustment in patients with cancer and their spouses. *Journal of Psychosocial Oncology, 16*(2), 59–77.
- Germino, B.B., Fife, B.L., & Funk, S.G. (1995). Cancer and the partner relationship: What is its meaning? *Seminars in Oncology Nursing, 11*, 43–50.
- Giese-Davis, J., Hermanson, K., Koopman, C., Weibel, D., & Spiegel, D. (2000). Quality of couples' relationship and adjustment to metastatic breast cancer. *Journal of Family Psychology, 14*, 251–266.
- Given, B., & Given, C.W. (1992). Patient and family caregiver reaction to new and recurrent breast cancer. *Journal of the American Medical Women's Association, 47*, 201–206.
- Given, B., Wyatt, G., Given, C., Sherwood, P., Gift, A., DeVoss, D., et al. (2004). Burden and depression among caregivers of patients with cancer at the end of life. *Oncology Nursing Forum, 31*, 1105–1117.
- Gritz, E.R., Wellisch, D.K., Siau, J., & Wang, H.J. (1990). Long-term effects of testicular cancer on marital relationships. *Psychosomatics, 31*, 301–312.
- Harden, J., Schafenacker, A., Northouse, L., Mood, D., Smith, D., Pienta, K., et al. (2002). Couples' experiences with prostate cancer: Focus group research. *Oncology Nursing Forum, 29*, 701–709.
- Heim, E., Valach, L., & Schaffner, L. (1997). Coping and psychosocial adaptation: Longitudinal effects over time and stages in breast cancer. *Psychosomatic Medicine, 59*, 408–418.
- Hilton, B.A. (1993). Issues, problems, and challenges for families coping with breast cancer. *Seminars in Oncology Nursing, 9*, 88–100.
- Hilton, B.A. (1994). Family communication patterns in coping with early breast cancer. *Western Journal of Nursing Research, 16*, 366–388.
- Hoskins, C.N., Haber, J., Budin, W.C., Cartwright-Alcares, F., Kowalski, M.O., Panke, J., et al. (2001). Breast cancer: Education, counseling, and adjustment—A pilot study. *Psychological Reports, 89*, 677–704.
- Hunt, G. (2004). [Comparison of caregiver burdens among cancer caregivers and noncancer caregivers]. Unpublished raw data from the Caregiving in the U.S. Study by National Alliance for Caregiving and AARP.
- Jensen, S., & Given, B. (1993). Fatigue affecting family caregivers of cancer patients. *Supportive Care in Cancer, 1*, 321–325.
- Kristjanson, L., Chalmers, K., & Woodgate, R. (2004). Information and support needs of adolescent children of women with breast cancer. *Oncology Nursing Forum, 31*, 111–119.
- Kuijjer, R.G., Buunk, B.P., De Jong, G.M., Ybema, J.F., & Sanderman, R. (2004). Effects of a brief intervention program for patients with cancer and their partners on feelings of inequity, relationship quality and psychological distress. *Psycho-Oncology, 13*, 321–334.
- Kurtz, M.E., Kurtz, J.C., Given, C.W., & Given, B. (1995). Relationship of caregiver reactions and depression to cancer patients' symptoms, functional states and depression—A longitudinal view. *Social Science and Medicine, 40*, 837–846.
- Lazarus, R.S., & Folkman, S. (Eds.). (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lethborg, C.E., Kissane, D., & Burns, W.I. (2003). 'It's not the easy part': The experience of significant others of women with early stage breast cancer, at treatment completion. *Social Work in Health Care, 37*(1), 63–85.
- Lewis, F.M., Ellison, E.S., & Woods, N.F. (1985). The impact of breast cancer on the family. *Seminars in Oncology Nursing, 1*, 206–213.
- Lewis, F.M., & Hammond, M.A. (1992). Psychosocial adjustment of the family to breast cancer: A longitudinal analysis. *Journal of the American Medical Women's Association, 47*, 194–200.
- Lewis, F.M., Woods, N.F., Hough, E.E., & Bensley, L.S. (1989). The family's functioning with chronic illness in the mother: The spouse's perspective. *Social Science and Medicine, 29*, 1261–1269.
- Manne, S.L., Pape, S.J., Taylor, K.L., & Dougherty, J. (1999). Spouse support, coping, and mood among individuals with cancer. *Annals of Behavioral Medicine, 21*, 111–121.
- Martire, L.M., Lustig, A.P., Schulz, R., Miller, G.E., & Helgeson, V.S. (2004). Is it beneficial to involve a family member? A meta-analysis of psychosocial interventions for chronic illness. *Health Psychology, 23*, 599–611.
- Matthews, B.A. (2003). Role and gender differences in cancer-related distress: A comparison of survivor and caregiver self-reports. *Oncology Nursing Forum, 30*, 493–499.
- McCorkle, R., & Quint-Benoliel, J. (1983). Symptom distress, current concerns and mood disturbance after diagnosis of life-threatening disease. *Social Science and Medicine, 17*, 431–438.
- McCubbin, M.A., & McCubbin, H.I. (1996). Resiliency in families: A conceptual model of family adjustment and adaptation in response to stress and crises. In H.I. McCubbin, A.I. Thompson, & M.A. McCubbin (Eds.), *Family assessment: Resiliency, coping, and adaptation—Inventories for research and practice* (pp. 1–64). Madison, WI: University of Wisconsin.
- Mellon, S. (2002). Comparisons between cancer survivors and family members on meaning of the illness and family quality of life. *Oncology Nursing Forum, 29*, 1117–1125.
- Mishel, M.H., Belyea, M., Germino, B.B., Stewart, J.L., Bailey, D.E., Jr., Robertson, C., et al. (2002). Helping patients with localized prostate carcinoma manage uncertainty and treatment side effects: Nurse-delivered psychoeducational intervention over the telephone. *Cancer, 94*, 1854–1866.
- Mishel, M.H., Hostetter, T., King, B., & Graham, V. (1984). Predictors of psychosocial adjustment in patients newly diagnosed with gynecological cancer. *Cancer Nursing, 7*, 291–299.
- National Alliance for Caregiving & AARP. (2004). *Caregiving in the U.S.* Retrieved May 23, 2005, from <http://www.caregiving.org/data/04finalreport.pdf>
- Northouse, L., Kershaw, T., Mood, D., & Schafenacker, A. (2005). Effects of a family intervention on the quality of life of women with recurrent breast cancer and their family caregivers. *Psycho-Oncology, 14*, 478–491.
- Northouse, L., Templin, T., & Mood, D. (2001). Couples' adjustment to breast

- disease during the first year following diagnosis. *Journal of Behavioral Medicine*, 24, 115–136.
- Northouse, L.L. (1994). Breast cancer in younger women: Effects on interpersonal and family relations. *Journal of the National Cancer Institute Monographs*, 16, 183–190.
- Northouse, L.L., Mood, D., Kershaw, T., Schafenacker, A., Mellon, S., Walker, J., et al. (2002). Quality of life of women with recurrent breast cancer and their family members. *Journal of Clinical Oncology*, 20, 4050–4064.
- Northouse, L.L., Templin, T., Mood, D., & Oberst, M. (1998). Couples' adjustment to breast cancer and benign breast disease: A longitudinal analysis. *Psycho-Oncology*, 7, 37–48.
- Northouse, L.L., Walker, J., Schafenacker, A., Mood, D., Mellon, S., Galvin, E., et al. (2002). A family-based program of care for women with recurrent breast cancer and their family members. *Oncology Nursing Forum*, 29, 1411–1419.
- Schulz, R., & Beach, S.R. (1999). Caregiving as a risk factor for mortality: The Caregiver Health Effects Study. *JAMA*, 282, 2215–2219.
- Toseland, R.W., Blanchard, C.G., & McCallion, P. (1995). A problem solving intervention for caregivers of cancer patients. *Social Science and Medicine*, 40, 517–528.
- Walker, B.L. (1997). Adjustments of husbands and wives to breast cancer. *Cancer Practice*, 5, 92–98.
- Welch, A.S., Wadsworth, M.E., & Compas, B.E. (1996). Adjustment of children and adolescents to parental cancer: Parent's and children's perspectives. *Cancer*, 77, 1409–1418.
- Zahlis, E.H., & Shands, M.E. (1993). The impact of breast cancer on the partner 18 months after diagnosis. *Seminars in Oncology Nursing*, 9, 83–97. 