

# Helping Patients and Their Family Caregivers Cope With Cancer

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**F**amily caregivers face multiple demands as they care for their loved ones with cancer, and these demands have increased dramatically in recent years. Patients with cancer now receive toxic treatments in outpatient settings and return home to the care of their family members. Some patients receive in-home infusions, which were unheard of a few years ago. Family caregivers provide tasks that were previously provided by nurses; however, caregivers lack the educational preparation that nurses receive.

Many family caregivers want more information because they feel unprepared to provide the care expected from them. In a large study of caregivers (N = 667) of newly diagnosed patients with cancer, van Ryn et al. (2011) found that almost half of the caregivers reported needing, but not receiving, training for administering medications, managing nausea and pain, changing dressings, and managing other symptoms. These caregivers also wanted more information about ways to deal with patients' emotional concerns (only 50% of them felt confident addressing patients' emotional needs). Family caregivers have difficulty dealing with patients' depression, anxiety, and uncertainty, and they need more guidance from health professionals on how to deal with the emotional aspects of cancer (Giarelli, McCorkle, & Monturo, 2003).

Family caregivers also lack the support they need to deal with their own emotional distress. Since 1988, in every study that my research team and I have conducted (e.g., Northouse, 1988; Northouse, Mood, Montie, et al., 2007), family caregivers reported receiving less support than patients. Although cancer is not in caregivers' bodies, its impact affects their lives and all aspects of their quality of life. Family caregivers are co-sufferers who also need support.

Having a well-prepared, confident family caregiver is beneficial. Research has documented that when caregivers feel more confident in providing care, patients have better symptom management (Campbell et

al., 2004), spend less time in bed, have more energy, and have higher physical quality of life (Keefe et al., 2003). In addition, more confident caregivers facilitate better patient medication management (Lau et al., 2010), and have less fatigue themselves, less caregiver strain, and more positive moods (Keefe et al., 2003).

## Key Concept of Interdependence

As we consider the role of caregivers, one key concept does stand out—interdependence. Patients with cancer and their family caregivers have an interdependent relationship. Each person affects the other. Two meta-analyses (Hagedoorn, Sanderman, Bolks, Tuinstra, & Coyne, 2008; Hodges, Humphris, & Macfarlane, 2005) reviewed a large number of studies and found that a reciprocal relationship (i.e., correlation) existed between the emotional distress reported by patients with cancer and their spouse caregivers ( $r = 0.29-0.35$ ). Their findings indicated that patients' distress affected spouses' distress and, conversely, spouses' distress affected patients. In another study, Segrin, Badger, Dorros, Meek, and Lopez (2007) examined how anxiety was transmitted between patients with cancer and their caregivers and found that the pathway from caregiver to patient had a greater effect on the transmission of anxiety within couples than did the pathway from patient to caregiver. According to Segrin et al. (2007), the pathway of influence from caregiver to patient often goes unrecognized by healthcare professionals. Their findings suggest that interventions that decrease caregivers' anxiety may decrease patients' anxiety and, subsequently, have a calming effect on patients.

Because patients with cancer and their family caregivers have an interdependent relationship, healthcare professionals need to treat the patient-caregiver dyad as the unit of care. Research indicates that the more we, as healthcare professionals, help caregivers, the more we will help patients (Bultz, Specia, Brasher, Geggie, &

Page, 2000). Treating them together creates a synergistic effect that is stronger than treating the patient alone (Scott, Halford, & Ward, 2004). In addition, many nursing interventions (e.g., those promoting more effective pain management) are likely to be more effective when they are offered jointly to patients and caregivers and when dyads are encouraged to work together to manage problems related to the illness.

## Multiple Effects of Illness on Caregivers' Quality of Life

The patient's cancer can have multiple effects on the caregiver's quality of life. The effects are manifested primarily on caregivers' emotional, physical, social, and spiritual well-being.

### Emotional Effects

Cancer takes an emotional toll on patients and their family caregivers. Research indicates that couples coping with cancer report more emotional distress than those without cancer, and that the distress levels of patients with cancer and their caregivers are similar (Hagedoorn et al., 2008). In some studies, caregivers even report more distress and depression than patients. For example, Braun, Mikulincer, Rydall, Walsh, and Rodin (2007) found that the incidence of clinical depression in spouse caregivers was significantly higher than it was in patients they were caring for with advanced cancer (39% versus 23%,  $p < 0.0001$ ). Northouse, Mood, Montie, et al. (2007) found similar results regarding emotional quality of life; spouse caregivers reported significantly lower emotional well-being than patients, particularly during the advanced phase of cancer.

Although caregivers often experience distress, research indicates that a subgroup of caregivers exists (20%–30%) who report higher levels of emotional distress or depression than other caregivers (Edwards & Clarke, 2004, 2005; Zwahlen, Hagenbuch, Carley, Recklitis, & Buchi, 2008). Identifying these caregivers early in the course of illness is important because, without intervention, caregivers' distress is likely to persist over time (Edwards & Clarke, 2004; Northouse, Templin, & Mood, 2001). A number of risk factors have been associated with higher levels of caregiver distress, such as low social support (Bishop et al., 2007), less confidence in providing care (Northouse, Mood, et al., 2002), high symptom distress in patients (Kurtz, Kurtz, Given, & Given, 2004), and high caregiver strain (Roth, Perkins, Wadley, Temple, & Haley, 2009).

Of these risk factors, caregiver strain is particularly problematic for caregivers. Caregiver strain is defined as the amount of stress or perceived stress associated with providing care. The relationship between caregiver strain and depression was examined in a large

study by Roth et al. (2009) in which 43,099 adults aged 45 years or older in the United States were interviewed. It was found that about 12% were caregivers of patients with chronic disease. Roth et al. (2009) assessed caregiver strain with one question: "How much mental or emotional strain is it for you to provide care?" Caregivers with high strain reported about three to four times more depression than caregivers with lower levels of strain and more than study participants who were not

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caregivers. These findings suggest that assessing caregiver strain is essential, as is providing caregivers with information and support to help lessen their strain.

**Fear of cancer recurrence:** During survivorship, fear of recurrence often is thought of as a concern of patients only, but it concerns caregivers as well and can be contagious in families. Mellon, Northouse, and Weiss (2006) surveyed patients with cancer and their caregivers in a population-based sample and found that family caregivers reported significantly higher fear of recurrence than patients. A possible explanation for caregivers' higher fear was that they had less contact and communication with health professionals, as well as fewer opportunities to get their own questions answered or their fears addressed.

### Physical Effects

What are the physical effects of the illness on caregivers? The most commonly reported effects are sleep problems and fatigue (Jensen & Given, 1993). Monin et al. (2010) found that caregivers may experience cardiovascular effects from stress and greater cardiovascular reactivity (i.e., increased blood pressure and heart rate), particularly in those caregivers who see suffering in their loved ones (Monin et al., 2010). Research also indicates that, because of the effects of stress hormones on disease processes and immune function, caregivers may be at increased risk for infections, exacerbations of their chronic diseases, and flare-ups in previously stable autoimmune illnesses (Bevans & Sternberg, 2012; Rohleder, Marin, Ma, & Miller, 2009). Investigators examined the amount of systemic inflammation, measured with C-reactive protein, in caregivers of patients with brain cancer versus matched controls over a one-year period (Rohleder et al., 2009). Caregivers of patients with cancer had significantly greater increases in their C-reactive protein during the interval between the patient's diagnosis and one year follow-up than did the controls who were not caregivers.

In addition to changes in immune function, a tendency exists among caregivers to use fewer healthy behaviors following the cancer diagnosis. In an Australian study conducted with caregivers of women with ovarian cancer, 52% of the caregivers reported a negative change in at least one healthy behavior after becoming a caregiver (Beesley, Price, Webb, & Australian Ovarian Cancer Study Group, 2011). Forty-two percent reported a decrease in their physical activity level, 35% gained weight, and 12% increased their use of alcohol. The odds of caregivers reporting at least one negative health behavior was greater among caregivers who were clinically depressed or anxious than those who were not.

## Social Effects

The social effects of the illness are manifested in relationship strain, limits in social life, and in patient-caregiver communication issues. The strains in family relationships often are caused by changing roles in the family, and role overload in caregivers. Patients and caregivers also engage in fewer social activities because of health problems in patients and role overload in caregivers. As their social activities become restricted, caregivers may perceive less support from others, and have a tendency to feel more consumed by the illness.

Communication issues also are common among families coping with cancer (Manne, Dougherty, Veach, & Kless, 1999; Zhang & Siminoff, 2003). Four communication issues are commonly identified. First, patients and family caregivers may have different communication styles or preferences. For example, a patient may prefer to discuss the illness openly but their family caregiver may prefer very limited discussion. Their different preferences can create conflict. Second, some patients and family members hide their feelings from one another. The problem with that approach is that their worries can build up, increase their distress, hinder their ability to support one another and, therefore, they may cope less effectively with the illness. Third, some families avoid discussing sensitive topics such as cancer progression, end-of-life issues, and the need for hospice. By avoiding these topics, families are less effective at problem solving or discussing their changing needs. Fourth, in some families, long-standing conflicts can re-emerge and interfere with the family's ability to cope with cancer. Those situations may require outside help to address the preexisting conflicts.

## Spiritual Effects

Research on the spiritual effects of cancer on patients and caregivers has increased in recent years, and this is an area in which we are more likely to see the positive effects of cancer on patients and their caregivers. For the most part, findings indicate that cancer can be a transformational experience (Kim, Schultz, & Carver,

2007). Patients and family members reconsider their priorities and reflect on what is important in their lives. Some may find new meaning and purpose in life. Research indicates that patients and family caregivers who are able to find more meaning in the illness also report better quality of life (Mellon & Northouse, 2001).

Research on the benefits of caregiving suggests that positives can come out of difficult situations. Six domains of benefit associated with caregiving include greater acceptance of things, more empathy, a greater appreciation of others, closer family relationships, more positive self-view, and better reprioritization of goals (Kim et al., 2007).

## Intervention Research With Patients and Family Caregivers

Since 1996, my colleagues and I have developed and tested nursing interventions to help patients and caregivers cope with cancer. Our intervention program focuses on the patient-caregiver dyad as the unit of care. The goal of the program is to provide patients and caregivers with information and support.

### Intervention Content and Delivery

The intervention we developed is called the FOCUS program, which is an acronym for the five core content areas in the program. The F stands for family involvement. Patients and caregivers are encouraged to communicate openly about the illness, provide mutual support, and work together as a team. The O is for optimistic attitude. Dyads are encouraged to set short-term goals and maintain a hopeful outlook in spite of the cancer diagnosis. The C addresses coping effectiveness. Patients and caregivers are encouraged to use active versus avoidant coping strategies (e.g., problem-solving versus denial) and engage in healthy lifestyle behaviors such as exercise to reduce stress. The U stands for uncertainty reduction. Patients and caregivers are provided with information about the illness and treatments. Finally, the S stands for symptom management. A unique aspect of our program is that we assess the physical and emotional symptoms of both patients and caregivers, and provide each person with self-care strategies (Northouse, Walker, et al., 2002).

The program is typically delivered in five sessions, consisting of three home visits and two follow-up phone sessions with a nurse, but shorter and longer versions of the program also have been tested (Northouse et al., 2012). Patients and caregivers report high satisfaction with the program (Harden et al., 2009).

### Intervention Effects

We tested the effects of the FOCUS program in three randomized clinical trials. The first trial was with

women with recurrent breast cancer and their primary family caregivers (N = 200 dyads) (Northouse, Kershaw, Mood, & Schafenacker, 2005). The second trial was conducted with men with prostate cancer and their spouses or partners (N = 263 dyads) (Northouse, Mood, Schafenacker, et al., 2007). The third trial was conducted with patients with advanced lung, colorectal, breast, and prostate cancer and their primary caregivers (N = 484 dyads) (Northouse et al., 2012). We decided to test the program solely on patients with advanced cancer and their caregivers because of the high distress and poorer quality of life they report. Table 1 shows the significant outcomes (all  $p < 0.05$ ) for patients and caregivers in each study. Fewer effects were noted in our first trial and, subsequently, we assessed other outcomes with more sensitive measures. As shown in Table 1, interventions had more significant effects for caregivers than for patients. We believe that caregivers have more unmet needs and, as a result, benefited more from the intervention. Based on our research and on a meta-analysis of intervention studies conducted by others (Northouse, Katapodi, Song, Zhang, & Mood, 2010), strong evidence suggests that interventions offered to patients and their caregivers can improve their ability to manage and cope with the illness. We are continuing the intervention research with families. Currently, an implementation study of the FOCUS program is being conducted within the Cancer Support Community (CSC). In addition, we are adapting our in-person program to a tailored, Internet-based format (Zulman et al., 2011).

### Interventions in Practice

Practical, concrete ways to help patients with cancer and their caregivers are apparent from the lessons learned in intervention work. Figure 1 lists the interventions that are supported by research evidence.

**Form an alliance with caregivers:** One of the first actions needed is to form an alliance with family

caregivers of patients with cancer. Some confusion exists about which professional is responsible for helping caregivers; however, nurses are uniquely suited to form an alliance with caregivers and to advocate for them. Nurses spend more time with patients with cancer and their family caregivers than any other healthcare professional. Nurses also share the caregiving role with family members as patients transition from one setting to another (e.g., hospital to the home). Research indicates that an effective nurse-patient-family alliance can improve patient and caregiver outcomes (Northouse, Mood, Schafenacker, et al., 2007).

**Assess both caregivers and patients:** Nurses are experts at assessing patients and this expertise should extend to the assessment of caregivers. Figure 2 lists a series of key questions that can be used to assess caregivers in a relatively brief period of time. Assessing caregiver strain is particularly important because it closely relates to caregiver depression. Nurses need to listen to caregivers' stories, obtain their perceptions about the illness, and learn more about their caregiving responsibilities to gain a better understanding about how their lives are affected by the illness.

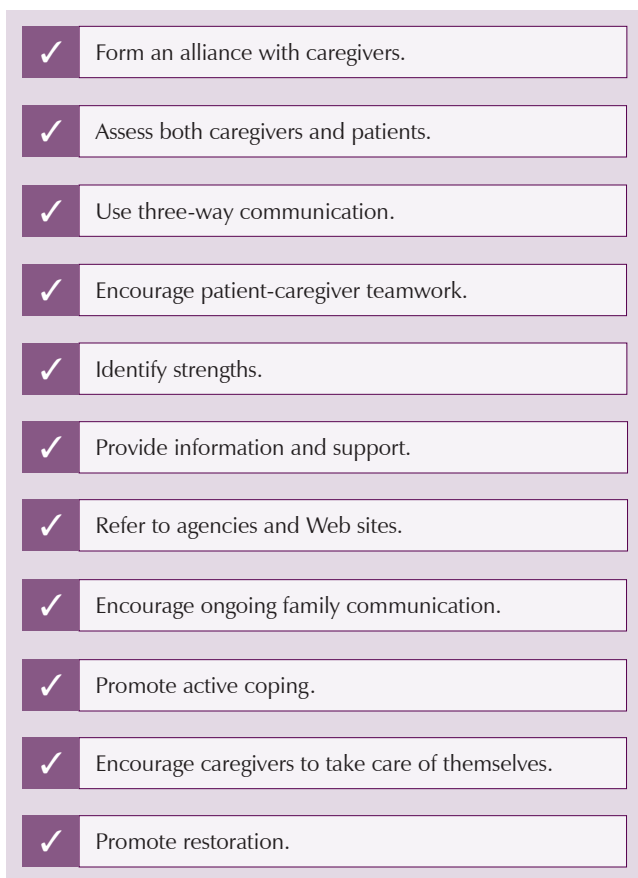
**Use of three-way communication:** Three-way communication means that the perceptions of both patients and caregivers are intentionally sought as we interact with them. This is the most important intervention that we use with families. Three-way communication does not need to be a long, time-consuming conversation. Even a brief interaction can be helpful, but the key is to interact with the patients and caregivers jointly. Following a three-way conversation, patients and caregivers often report that the interaction enabled them to learn more about the other person's thoughts or feelings that they were unaware of previously. Triadic communication enables them to increase their understanding of one another.

**Encourage patient-caregiver teamwork:** Teamwork implies that it is not just the caregiver helping the

**Table 1. Intervention Effects for Patients and Caregivers**

Clinical Trial	Study	Patient Effects	Caregiver Effects
Breast cancer N = 200 dyads	Northouse et al., 2005	Less negative appraisal of illness and less hopelessness	Less negative view of caregiving
Prostate cancer N = 263 dyads	Northouse, Mood, Schafenacker, et al., 2007	Less uncertainty and better dyadic communication	Less negative view of caregiving, less hopelessness, less uncertainty, more active coping, more self-efficacy, better dyadic communication, less caregiver symptom distress, less bother with patient's urinary symptoms, and higher quality of life
Advanced cancer N = 484 dyads	Northouse et al., 2012	Better coping, more healthy behaviors, higher self-efficacy, and higher social quality of life	Better coping, more healthy behaviors, higher self-efficacy, higher social quality of life, and higher emotional quality of life

Note. Some intervention findings varied according to assessment time (e.g., three or six months postintervention).



**Figure 1. Practical Interventions With Caregivers and Patients**

patient, but also the patient helping the caregiver, and both working together to manage the illness. We often say to families, “Since the illness affects both of you . . .” to verbally acknowledge that they are both affected by the illness, and to foster teamwork. We also encourage them to look for ways to support each other, work together to solve problems, express appreciation to one another, and to take one another’s concerns seriously.

**Identify strengths:** When faced with stress, we often lose sight of our own strengths and can easily be overwhelmed. The same thing happens to patients and their caregivers. By identifying their strengths, nurses can help bolster their confidence and awareness of the assets they have as a dyad. For example, one nurse said to a dyad, “You both do a good job of supporting one another during these difficult times. . . . You make a good team.” That statement acknowledged their ability to support one another as one of their strengths. Identifying strengths is important because it builds patients’ and caregivers’ self-efficacy, and research has documented that higher self-efficacy is related to many important outcomes for both patients and caregivers, including higher quality of life (Kershaw et al., 2008).

**Provide information and support:** Although information is provided routinely to patients, the healthcare

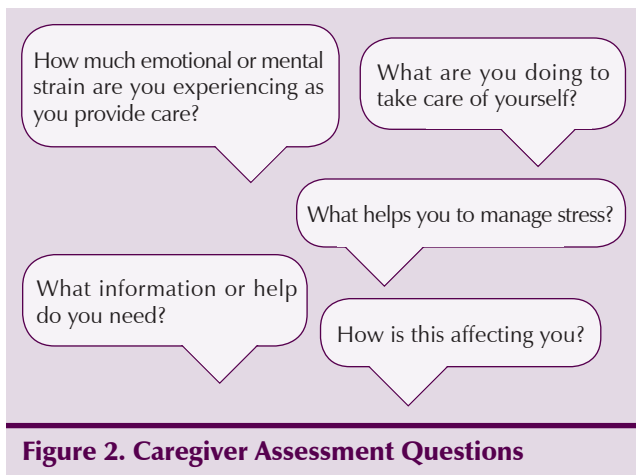
teams should be more intentional about inviting caregivers to be present when information is provided to patients because that enables them to have their questions addressed. Caregivers often report more uncertainty about the illness than patients; providing them with information helps to reduce that uncertainty (Northouse, Mood, Schafenacker, et al., 2007).

**Refer to agencies and Web sites:** Two valuable agencies are the CSC and CancerCare. These agencies provide excellent psychosocial care to patients with cancer and their caregivers at no cost. CSC has more than 50 community-based agencies throughout the United States that patients and caregivers can use, as well as an informative Web site ([www.cancersupportcommunity.org](http://www.cancersupportcommunity.org)). CancerCare provides free telephone counseling, telephone workshops, and also offers valuable psychosocial information on their Web site ([www.cancercares.org](http://www.cancercares.org)).

**Encourage ongoing family communication:** As mentioned previously, many families have issues with communication and need to find ways to maintain ongoing communication and support. Families should set aside time for “kitchen table” talk and share their concerns regularly because it makes each concern less overwhelming if they can obtain support from one another. Criticism from family members can be very difficult to handle when patients and caregivers are trying to cope with cancer. Encourage them to be patient with one another.

**Promote active coping:** Two types of coping generally exist: active and avoidant. Use of avoidant coping is associated with more distress and poorer quality of life (Kershaw et al., 2008). Families should be encouraged to more actively cope to reduce cancer-related stress by engaging in enjoyable activities, maintaining supportive relationships, considering the meaning and purpose of the illness, and using acceptance, which is a powerful active coping strategy. Acceptance involves acknowledging that something serious has happened, and then trying to move forward to deal with it.

**Encourage caregivers to take care of themselves:** Caregivers often focus on patients’ needs and overlook their own health needs. At times, caregivers need encouragement from health professionals to follow-up on their own health problems. For example, an oncology nurse described a caregiver who came to the clinic with her husband. The caregiver appeared anxious and, when questioned, said she had a history of hypertension. The nurse took her blood pressure and found it was very elevated. The nurse encouraged the caregiver to call her primary care provider for an appointment as soon as possible. That example illustrates how a nurse used a brief assessment and intervention to help the caregiver to address her own health needs.



**Promote restoration:** In addition, research has indicated that restorative activities, such as spending time in nature, can enhance cognitive function (Cimprich, 1993). Caregivers, as well as patients with cancer, are prone to cognitive fatigue (e.g., trouble concentrating, making decisions). Encourage patients and caregivers to spend time in nature by going for a walk, gardening, and even enjoying a view of nature through a window to help restore cognitive function.

## Future Challenges

Challenges, such as educating professionals on the needs of family caregivers, integrating caregivers into oncology care, and finding ways to reimburse professionals for services they provide to caregivers, still remain. Champions are needed in the practice settings who will advocate for family caregivers and identify evidence-based interventions to assist them. We also need to actively implement psychosocial care with patients

and their caregivers. It will not happen if left to chance or if we wait until all other care activities are completed.

## Conclusion

In summary, we know that patients and caregivers are interdependent, each person affecting the other. Research has clearly documented the effect that the patient's cancer has on the emotional, physical, social, and spiritual well-being of the caregiver. Research indicates that psychosocial interventions can help both patients and caregivers to cope with the illness and maintain their quality of life. However, to address their needs more effectively, the patient-caregiver dyad must be treated as the unit of care.

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