

## CHAPTER 1

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# The Psychosocial Impact of Cancer on the Individual, Family, and Society

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*We are not ourselves when nature, being oppressed, commands the mind  
to suffer with the body.*

—William Shakespeare

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It is now known that psychosocial issues affect patients in all stages of cancer. Emotional response can influence both morbidity and mortality (Holland, 2002). The increased emphasis on psychosocial oncology in recent years has led to more research, education, and training programs as more professionals appreciate the importance of this aspect of care. Psychosocial care of patients is needed in all phases of the cancer experience. Holland (2003) identified three factors contributing to psychological adaptation: (a) type of cancer, (b) personal coping skills, and (c) society's prevailing attitudes toward cancer.

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## Diagnosis

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The anxiety and uncertainty of a cancer diagnosis can create extreme disruption in the life of almost any individual. A cancer diagnosis can create a threat to one's general sense of security and orderliness in life. Although the vast majority of cancers are treatable, many people retain deep-seated fears that any cancer represents pain, suffering, and death. Holland (2002) noted that no disease has sustained as strong of a negative stigma as cancer. These fears can contribute to a person's reaction to a new cancer diagnosis. Whatever the type of cancer, people are faced with ongoing uncertainty about their future as they deal with the potential for an unpredictable course (Dankert et al., 2003). A cancer diagnosis leads to a complex set of issues, including dealing with physical symptoms from the disease and treatment, facing

the existential dimension of the illness, and seeking a comforting philosophical, spiritual, or religious belief structure or values that give meaning to life and death (Holland, 2002).

## **Awareness**

Prior to the diagnosis, the individual may be aware of body changes that could indicate cancer (e.g., a lump, abnormal bleeding). Nail (2001) called this the Recognition Phase. This awareness creates a state of hyperalertness that eventually leads to action in most people. How quickly this action occurs depends on many variables, including past experience with cancer in oneself or one's family. An experience with cancer may encourage some to seek quick medical attention. The experience of others may cause them to avoid medical attention because they are fearful of what the symptoms could mean. Pain or discomfort created by the symptoms tends to motivate people to seek medical attention (Mood, 1996). Other factors may contribute to delays, such as feeling uncomfortable around healthcare providers, financial considerations, fear of dependency, and fear of disfigurement. Fear of cancer treatment may contribute to an individual's acknowledgment of symptoms. Family members with similar values may inadvertently promote the same delaying behaviors that the patient is using. Lack of knowledge about symptoms also may cause a delay.

## **Receiving the Cancer Diagnosis**

In the United States, adherence to the ethical principle of autonomy has resulted in physicians directly telling patients about the diagnosis of cancer. The principle of autonomy dictates that the individual has the right to determine his or her own course of action with a self-determined plan (Beauchamp & Childress, 2001). In the healthcare field, this means one has the right to know and participate in all healthcare decisions. The original 1847 Code of Ethics of the American Medical Association (cited in Katz, 1984) noted that a physician's duty is to avoid all things that could discourage or depress the spirit. This philosophy contributed to physicians receiving limited education in medical school about how to deliver bad news (Girgis & Sanson-Fisher, 1995). In 1961, 90% of surveyed physicians preferred not to directly tell patients about a cancer diagnosis (Oken, 1961). In 1977, more than 90% of physicians favored sharing such information with patients (Novack, Plumer, & Smith, 1978). This dramatic change in practice reflected the social changes of the 1960s and 1970s that resulted in an emphasis on openness. Access to oncology specialists who had experience in sharing bad news became widely available during that time. The development of research protocols emphasizing informed consent was another factor (Holland, 2002).

At times, families still ask that patients not be told about the diagnosis. This creates ethical dilemmas for healthcare providers about obtaining informed consent for treatment from their patients. Being pressured to use words like "growth" for the cancer or "special medicine" for chemotherapy makes providing care to these patients more difficult. Dunn, Patterson, and Butow (1993) noted that not being open about the diagnosis still leads to patients suspecting it and thinking that the cancer must be so horrible that even physicians or nurses will not acknowledge it. Avoiding the use of the word "cancer" reinforces the fear associated with the word (Holland, 2002, 2003).

If physicians do not tell patients the diagnosis, a risk always exists that someone will inadvertently share the information with the patient, causing the patient to greatly distrust the healthcare team and family. Dunn et al. (1993) identified the tendency of healthcare professionals and family members to avoid patients who have not been told the truth because of the fear of misspeaking. Openness about the diagnosis and prognosis enables patients to think more realistically about their condition and participate actively in treatment planning. Most individuals are able to adjust to the diagnosis over time (Dunn et al.). It is important to note that autonomy is not practiced worldwide. Patients and families from other cultures may be unprepared to receive the diagnosis directly. Healthcare professionals need to address the family's fears about sharing the news and offer suggestions for assisting the patient. Creating a balance between providing some information without alienating the patient and family can be difficult.

How one receives news of a cancer diagnosis is an important factor in how one responds (Dias, Chabner, Lynch, & Penson, 2003; Rabow & McPhee, 1999; Tulsky, 1998). Figure 1-1 lists some helpful guidelines for sharing the news of a cancer diagnosis. Healthcare professionals, including oncology nurses, need to develop skills in presenting information accurately yet gently, thus maintaining hope regardless of the prognosis. Although nurses may not deliver the initial diagnosis, they often are in a position to reinforce information, provide support, and consult with physicians about sharing the news. Schofield et al. (2003) reported that patients experience less anxiety associated

**Figure 1-1. Guidelines for Giving a Cancer Diagnosis**

- Provide privacy and adequate time to share the information and provide support.
- Ask the patient how much he or she wants to know.
- Encourage the patient to bring a family member to the meeting.
- Consider taping the meeting or providing a written summary of the information.
- Monitor for signs of emotional distress and respond as needed.
- Give the information gradually rather than starting with the diagnosis.
- Listen to the patient's and family's concerns.
- Assess their understanding of what has been shared throughout the process.
- Develop an alliance with the patient about the treatment plan.
- If needed, ensure that professional interpreters are available.
- If the prognosis is very poor, avoid giving a definite time frame.
- Reinforce information given on subsequent visits and when the patient and family see other healthcare professionals.
- Provide resources for follow-up support.

*Note.* Based on information from Buckman, 1992; Fried et al., 2003; Girgis & Sanson-Fisher, 1995; Tulsky, 1998.

with the following communication style of how news is given: The physician prepares the patient ahead of time for a possible cancer diagnosis, provides written information, and openly discusses life expectancy and severity of the cancer; the patient has someone with him or her when information is given; questions are addressed on the same day as the initial discussion; and the patient is involved in treatment decisions.

## **The Patient's Response to the Diagnosis**

Whether a person anticipates the diagnosis, his or her initial response usually is disbelief, numbness, and anxiety. Receiving a cancer diagnosis is associated with a

peak of negative mood and distress for many (Nail, 2001). Waves of intense emotions similar to a grief reaction with periods of calmness are common. Generally, following the initial days after receiving the diagnosis, most individuals are able to develop a constructive plan of action. Healthcare professionals must remember that no matter how compassionate and skilled the person is in giving the bad news, patients still may experience extreme emotional reactions (Shell & Kirsch, 2001).

To integrate the idea of having cancer into one's psyche, the patient may feel the need to identify the cause. Asking "why me?" may be part of this process. Seeking information about the type of cancer and its treatment can give the person some sense of control. Information seeking is a more common coping mechanism in the early stages of the disease, when the diagnosis is new and the patient is dealing with a variety of new healthcare professionals (Nail, 2001).

Some individuals initially respond with denial. They cannot allow themselves to think about what will happen if the treatment does not work or how this will affect the family. Denial is a protective mechanism from this tremendous threat. It is a common initial reaction to the overwhelming threat but generally decreases over time. Some individuals are able to forestall any emotional reaction to the news as they research the disease, consider treatment options, and interview physicians. This allows patients to remain more focused on the decision making. However, an emotional reaction can surface at any time.

In a landmark study, Weisman and Worden (1976–1977) examined 120 patients in the first 100 days after receiving a cancer diagnosis and described the extreme distress commonly experienced in hearing the news. Intermittent periods of anxiety and depression were common. Some of the factors they found that contributed to poor overall psychosocial adaptation included having more physical symptoms, perceiving the physician as being less helpful, having a psychiatric history, and having a pessimistic view of the world. The most significant variables were a perceived lack of a personal support system, having a more advanced illness, and viewing the physician as being unsupportive. Lampic, Thurffjell, Bergh, Carlsson, and Sjoden (2003) found that patients with a new diagnosis of breast cancer attributed significantly more importance to closer and more positive relationships with people in their lives.

As the patients return to their normal routine, some of the initial intense reactions tend to decrease, with intermittent periods of increased intensity. Everyone needs to view life as existentially meaningful, and cancer undermines this effort (Northouse & Northouse, 1996). Weisman and Worden (1976–1977) found that within three months of the diagnosis, most individuals began examining and reviewing their lives, as well as looking for meaning in what was happening to them. This period of intense existential analysis can be difficult and painful for patients and their families. Patients may challenge long-held beliefs and values of the family and search for new areas of meaningfulness that family members do not share.

## **Family Reactions**

When cancer enters an individual's life, it also enters the lives of family members and close friends. Research clearly indicates that cancer enters the emotional, social, physical, and spiritual well-being of patients and their family members (Northouse, 2005). It presents a major crisis for them as well as the patient (Glajchen, 2004). Walk-

ing the illness journey with a loved one can contribute to many reactions, including feelings of loss of control, disrupted family organization, and altered relationships (Shell & Kirsch, 2001). They also noted that the initial uncertainty contributes to many extremes in reactions. The initial response is similar to the patient's: extreme distress and disruption. A sense of vulnerability and awareness of the inability to protect a loved one can lead to an intense sense of helplessness. Because family members and patients often share common beliefs, the reactions of family members may parallel those of patients (Lederberg, 1998). Denial or blaming others for the diagnosis may occur in close family members as well. Family members may experience vulnerability with the realization that this could happen to themselves.

Seeing a loved one vulnerable and fearful can create much distress, especially if this is a big change from the patient's normal personality. Family members often face many role changes at the time of the cancer diagnosis. Disruptions in schedules and taking on new roles of caregiving, meal preparation, and other family duties may put a strain on some family members. Role changes can contribute to communication problems if one is not sure of the usual routines or schedules. The financial demands of treatment options can create concerns about the need to continue working. The strain of feeling continuously "on duty" to provide physical and emotional support, on top of dealing with their own fears, adds to the pressures of family members. They also may need to conceal their own feelings and fears of what will be expected of them in the future if the disease progresses.

Some family members may assume the role of cheerleader to remain upbeat and encourage the patient to remain optimistic. This role can become very draining. It can lead to resentment if one's own needs are not being recognized or met. Resentment can occur regarding the stress and inconvenience imposed on the family, as well as past behaviors that they attribute to causing the cancer (e.g., smoking, high-stress lifestyle) (Mood, 1996). Some members may take on additional roles, such as assisting with research and treatment decisions, if the patient is paralyzed by anxiety or is too ill to participate.

Family members play a key role in the support system of most patients. How to provide support to patients and best meet their needs may require a period of trial and error. For example, patients may want to be more independent, whereas family members may feel the need to be protective, leading to resentment and increased stress on both sides. A lack of communication can lead to feeling that one's needs are going unrecognized and feelings of being smothered or isolated from family life.

Spouses often feel devastated because they have not considered what life together with illness would involve (Shell & Kirsch, 2001). A cancer diagnosis can bring couples closer or can distance them as more stress is added to the relationship (Glajchen, 2004).

## **Life Span Considerations**

The response of family members to the diagnosis of a childhood cancer often is profound shock and disruption. Parents particularly are overwhelmed with the realization of their child's vulnerability to this disease. Parents may experience high levels of anxiety as they try to protect their child from any distress. In addition to the emotional distress, family members must face the disease-related demands that affect the entire family. These can include financial demands, transportation to multiple

medical visits, supporting other family members, and conducting research related to the disease (Kristjanson & Ashcroft, 1994).

A child's response to a cancer diagnosis in a family member depends on the child's developmental and cognitive level, as well as on how the parent responds (Northouse, Cracchiolo-Caraway, & Appel, 1991). During the time of family disruption caused by the diagnosis, the child may exhibit behavioral and adjustment problems (e.g., problems with school attendance, sleep, aggression) in response to his or her anxiety. Children need to become more adaptive to change at these times (King, 2003). Children must receive information about what is happening, but it must be at a level that they can comprehend.

Cancer is increasingly more likely to occur as one ages (Jemal et al., 2005). Thus, older adults are more at risk. The strain on an older couple, especially when one is already frail, can be overwhelming. This can create an added burden for the patient with cancer who wants to protect the other spouse. Financial demands as well as limited support systems and problems with caregiving are other concerns.

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## Cancer Treatment

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As the diagnostic phase is completed and treatment decisions are made, the patient and family face new experiences that will affect them psychosocially. These include hospitalization, surgery, insertion of a central line, starting chemotherapy or other treatments, and frequent doctor visits. An urgency often exists to begin treatment, and no matter how much education the patient receives, he or she still may feel unprepared to enter this unfamiliar world. Each type of treatment creates its own psychosocial impact.

### Surgery

Surgery is the oldest form of cancer treatment (Jacobsen, Roth, & Holland, 1998). Surgery alone as a cancer treatment may not be associated with the same negative view as other treatments that are more closely aligned to cancer. Patients are more familiar with surgery than other types of cancer treatments because surgery is routinely performed for noncancerous conditions with positive outcomes. It is viewed as a way to eliminate the cancer from one's body. However, mastectomies, genital surgeries, head and neck surgeries, and colostomies generally are associated with more distress because of the obvious changes in appearance and body function (Jacobsen et al.). For the individual who receives the news of the cancer diagnosis postoperatively, pain and weakness from the surgery will add to the distress and depression created by the new diagnosis. Borneman et al. (2003) found that caregivers for patients undergoing palliative surgery experienced more intense psychological distress.

### Chemotherapy

The public often views chemotherapy negatively. This may be based on irrational fears, misperceptions, and inaccurate or outdated information (Knobf, 1998). Most individuals have preconceived ideas about chemotherapy and its side effects. While still reeling from the diagnosis, starting chemotherapy can intensify the sense of

vulnerability to one's already weakened coping reserves. The protective equipment worn by staff members who administer chemotherapy may add to this fear. However, chemotherapy is an active treatment that can give patients a sense of strength as they hope for a cure. Many patients are under the impression that chemotherapy must be given through IV to be effective. However, many new oral agents with lower side effect profiles are now available and can increase survival (Bedell, 2003).

Nausea and vomiting from chemotherapy tend to be major concerns for patients. Education about the medications available to control these symptoms can address these concerns. Alopecia has the emotional impact of being a constant reminder of the diagnosis, forcing patients to immediately integrate the diagnosis into their lives. It is a visible reminder to the world that a person has cancer, impeding the opportunity to keep the diagnosis private (Freedman, 1994). Fatigue and risk for infection also contribute to psychosocial distress.

Chemotherapy forces the patient and family to adhere to schedules of medical appointments or hospitalizations and to reallocate family roles because the patient usually cannot meet obligations because of fatigue or other side effects. Seeing the patient in a vulnerable state while coping with the effects of chemotherapy may increase the distress on family members who must watch their loved one suffer. Fatigue and irritability experienced by the patient and family can increase the negative impact on the family system.

## **Radiation Therapy**

People are taught to fear and avoid radiation. However, the patient then is told that radiation is a treatment for the cancer. This dichotomy can create deep-seated anxieties related to the cancer treatment (Greenberg, 1998). Radiation presents many unknowns to the patient. Meeting a new physician and treatment team in the radiation therapy department and lying alone on a table with a large machine overhead can create a sense of isolation and anxiety. Fears about being burned and having visible skin tattoos may contribute to one's distress and create self-consciousness. Patients may have heard myths concerning the side effects of this therapy and need extensive education about what to expect. Patients with many side effects from the radiation treatment experience more negative emotions and intrusive negative thoughts about the cancer while receiving radiation therapy than patients with fewer side effects (Walker, Nail, Larsen, Magill, & Schwartz, 1996). This emphasizes the need for ongoing education and assessment of the effects of treatment.

## **The Patient's and Family's Response to Cancer Treatment**

As the patient continues to receive chemotherapy, radiation therapy, or other treatments (e.g., stem cell transplants, immunotherapy), the patient and family hope for and seek a return to the former routines of their daily lives. Weeks and months of disruption and emotional upheaval throughout the treatment process can create a yearning for normalcy. Hilton (1996) found that families of patients with early-stage breast cancer achieved normalcy by viewing the cancer as "temporary" (with a focus on the belief that it would be cured); de-emphasizing the illness by keeping busy or adding distractions to their daily lives; maintaining flexibility in roles; and

de-emphasizing or minimizing the demands and changes brought on by the treatment. The patient's and family's ability to return to usual patterns of activities is a way to put the cancer behind them. Congruency between family members in regard to their beliefs about the cancer also was important. This congruency made supporting each other easier for family members. Hilton found that the negative perceptions that patients or families retained about the cancer or its treatment affected their ability to enhance normalization. The ability to view the cancer as a temporary, short-term problem was extremely important in this process. Patients and families also face burdens of shortened hospital stays with patients returning home with more care needs (Holland, 2003) and the need for more involved home care and monitoring (Rawl et al., 2002). Family members are therefore likely to take on the role of caregiver (Given et al., 2004).

## **Nursing's Role**

Patients who are receiving a new diagnosis, starting treatment, and continuing treatment are part of the daily practice of most oncology nurses. These patients and their families are facing one of the biggest crises of their lives. The oncology nurse's role must incorporate an awareness of the tremendous psychosocial implications that exist. Northouse and Northouse (1996) delineated the important interpersonal roles of oncology nurses as imparting information, communicating hope, and dealing with the many emotions that are part of the patient's cancer experience. They viewed the major issues confronting patients as maintaining a sense of control, obtaining information, searching for meaning, and disclosing feelings.

Nurses play an important role in assisting patients in all of these areas. Although nurses are not able to control the disease, they still can provide support in controlling patients' responses to the illness and education about the disease and its treatment. Education will provide patients with the control necessary to deal with side effects and will help them to make the best decisions. Providing education enhances emotional support and fosters development of a trusting relationship with patients. Helping patients to confront intense and confusing emotions is a key role for nurses and is an important component of the nurse/patient relationship.

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## **Recurrence**

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Because of the unpredictable nature of cancer, many individuals facing a diagnosis and initial treatment eventually must face recurrence. Recurrence is defined as the return of the disease after an initial course of treatment with a disease-free period. The disease may recur at the same site, recur near the site, or metastasize to a distant site. The threat of recurrence is one of the reasons why cancer is such a feared disease. Long-term survivors continue to experience distress over fear of recurrence (Gill et al., 2004). Although recurrence does not necessarily lead to terminal illness, it certainly increases its likelihood (Mahon, 1991). Pasacreata, Minarik, and Nield-Anderson (2001) noted that recurrence is a period characterized by increased pessimism, renewed preoccupation with death, and disenchantment with the medical system. Frost et al. (2000) found that recurrence was associated with increased



uncertainty and symptom distress as well as less hope. It also means returning to active treatment, which can bring back memories of past suffering (Glajchen, 1999). At this time, patients not only face the realization that treatment has failed and cure may be unattainable, but they must prepare themselves, as well as loved ones, for the possibility of death. Dankert et al. (2003) reported that recurrence is one of the main fears of people with cancer. Patients may face multiple recurrences during their lifetimes; therefore, psychological response to recurrence remains a common concern for patients, families, and healthcare professionals (Vickberg, 2001).

## **Psychosocial Response to Recurrence**

Fear of recurrence continues after the initial diagnosis (Ferrell, Grant, Funk, Otis-Green, & Garcia, 1998; Vickberg, 2001). If the cancer returns, it is a distinctly different emotional event from the initial cancer diagnosis (Mahon, 1991). Although recurrence entails different stressors and the need for different interventions, research has not conclusively indicated that it is necessarily more stressful. Mahon, Cella, and Donovan (1990) noted that the majority of patients in their study found recurrence to be more upsetting than the initial diagnosis and that they were less hopeful than they were at the time of the initial diagnosis. Sarna et al. (2005) found that women with lung cancer had more distress over fears of recurrence and metastasis. Conversely, Munkres, Oberst, and Hughes (1992) found no significant differences in mood scores between patients with an initial cancer diagnosis and those with recurrence. Schulz et al. (1995) reported similar results; however, financial problems, less social support, and lower levels of optimism were associated with more psychological distress. Weisman and Worden (1986) found that the degree of psychological distress at the time of recurrence depended on the degree of symptomatology from the recurrence. Thirty percent of their sample actually reported less distress with the recurrence. This group was less surprised by the recurrence and had not let themselves believe they were cured. In fact, for some, recurrence was a relief from the distressing uncertainty with which they had been living as they waited for the disease to return (Holland, 1998). For these patients, the uncertainty can be more distressing than the actual return of disease.

Psychosocial problems that emerged from the initial diagnosis and treatment will resurface in recurrence (Holland, 1998). For example, a patient who initially responded to the diagnosis with severe anxiety or serious depression could be expected to respond to news of recurrence in a similar way. This demonstrates the need to obtain a thorough psychosocial history to assess the initial response. Initial responses to recurrence typically include insomnia, restlessness, anxiety, and poor concentration; however, depression and anxiety are the predominant responses.

Because these patients already have been through some type of cancer treatment, preparing for treatment again may be more difficult because they know what to expect. If patients had severe side effects with the initial treatment, they may need more encouragement or more aggressive symptom management. Patients with recurrence experience higher levels of symptom distress, particularly fatigue and pain (Mahon & Casperson, 1995). These patients also may face decisions regarding more aggressive treatment, such as stem cell transplants, immunotherapy, and/or clinical trials. These treatments may not have been considered the first time around, thus creating more unknowns (Pasacreta et al., 2001). In other cases, these therapies may have been offered at the time of initial treatment, and the patient may have decided on a

more conservative approach. This can result in feelings of guilt or regret. Mahon et al. (1990) found that 80% of the patients facing recurrence in their sample believed they should have “fought the cancer more” following the initial diagnosis, and 50% believed they should have sought more opinions or more treatment with the initial diagnosis. This self-blame, anger, and guilt will contribute to patients’ negative emotional responses.

The realization that treatment has failed can contribute to depression and a feeling of hopelessness. The patients’ sense of hope may have provided the encouragement needed the first time around when a cure was anticipated. The loss of hope may contribute to the realization that one must consider the possibility of death. Holland (1998) described the existential crisis of recurrence as the individual having to consider for the first time that death could be the outcome and that one’s goals may not be realized. Loss of confidence, increased fearfulness, and hopelessness are other reactions (Shell & Kirsch, 2001).

Loss of faith in the medical establishment may be a reaction as the individual realizes the initial treatment did not provide a cure. This can contribute to anger and consideration of alternative therapies or even to refusal of further therapy. Some individuals may experience a sense of personal failure in thinking that they have disappointed their physicians by not being cured. A sense of injustice, noted by a comment such as “it is not fair because I did everything they asked of me,” can create more anxiety, anger, and helplessness.

Recurrence may present financial demands if the patient is considering aggressive or experimental treatment. An inability to work, problems with insurance coverage, and a need to relocate may contribute to this challenge and present additional stresses for patients and families. Another fear may be that of facing a more physically disabling illness as the disease progresses and treatment becomes more aggressive.

## **The Family’s Response to Recurrence**

As with the patient, family members must struggle with depression, anger, guilt, and the fear of death. Family members’ responses also may be similar to their response at the time of initial diagnosis. However, the emotional climate of the family may be much different at the time of recurrence, especially if many disease-free years have passed. Changes in relationships caused by divorce or loss of family members may affect the family’s emotional climate and the emotional support available for the patient.

Recurrence may create so much distress that family members and friends will react with detachment because they fear reinvesting in the patient’s treatment when the outcome may be less positive. This particularly may be common when the patient experiences multiple remissions and exacerbations. The patient may wish to have less contact with family members and friends because of depression or fatigue (Mahon & Casperson, 1995). Maintaining a positive attitude may be more difficult for family members and friends, and providing emotional support to the patient could be more draining. On the other hand, family crises faced at the time of initial diagnosis may have strengthened the family members to better face this new challenge. Whereas in the past spouses or siblings may have thought that they never could have coped with a loved one having cancer, getting through the initial treatment may have given these individuals confidence in their ability to face whatever happens.

Weisman and Worden (1986) found that marriages that survived the challenges of the initial diagnosis mobilized well for the stressors of recurrence. However, Lewis and Deal (1995) found in their study that in 40% of couples facing recurrent breast cancer, one or more of the partners experienced depression. Northouse et al. (2002) reported that a family-based cancer care program resulted in more satisfaction and optimism and less uncertainty.

The response of parents to recurrence in a child may be very difficult as they realize that a cure may not be possible. Facing the realization that the situation is out of their control is particularly trying. Parents facing the news of recurrence have been found to curb their immediate response to the bad news to maintain hopefulness and to attempt to remain focused on curative therapy (Hinds et al., 1996).

### **Nursing's Response to Recurrence**

Identifying how a patient coped at the time of initial diagnosis is an important early part of the treatment plan that may predict the patient's response to the news of recurrence. Knowing what physicians told patients also can provide important information to gauge the response. Reinforcement of hope may help to maintain emotional balance. Patients may fear abandonment by the healthcare team after "failing" the first-line treatment. Regardless of the treatment goal, physicians and nurses must present a treatment plan that communicates a continued commitment to patients.

Patients experiencing a recurrence will face many choices about treatment and need information to help them to make decisions. Mahon et al. (1990) found that 90% of their sample reported that healthcare professionals assumed patients had more knowledge about their disease and treatment than the patients felt they actually had. Also, 75% of their sample reported that professionals assumed that the patients were coping better than they actually were. This provides nurses with important information regarding the need to take the time to talk with patients about their coping as well as to reinforce teaching about the disease, treatment, and side effects. Making important treatment decisions during a time of emotional upheaval requires patients to have access to a variety of information at different times. Written material may be helpful for patients to review after receiving oral instructions. Access to alternative resources such as the Internet and cancer information hot lines may be useful as patients seek more opinions about their options.

Patients and family members need an opportunity to share fears in a safe environment. They may be reluctant to express their deepest fears to one another in order to provide a measure of "protection." The oncology nurse is in a key role to provide this important outlet.

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## **Terminal Illness**

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Patients must face terminal illness when aggressive, curative treatment is no longer an option and the focus moves to palliative care. For some, this may come as a gradual awareness that the disease is progressing despite aggressive treatment. For others, this

realization may be sudden. Some may continue to pursue aggressive treatment until the end, and others may reject treatment at the time of diagnosis. Still others may face life-threatening complications during active treatment. However the realization comes, it remains a difficult and emotional journey. At this time, patients and families experience many fears. Death is a threat with many common themes.

## The Patient's Fears

**Fear of the unknown:** Death is one of the strongest fears of all human beings (Rando, 1984), and it presents the greatest “unknown” for many people. Questions such as what will happen to my family, my life plans, my life’s work, and my body are difficult to face, and they are difficult questions for others, such as family members, to hear. Some of these thoughts can be acknowledged by talking about the concerns and making preparations to care for loved ones or to achieve a hoped-for goal. Other questions can be acknowledged only in a supportive environment. Spiritual support may provide some comfort.

**Fear of pain and suffering:** Pain is one of the most common and greatest fears for those at the end of life (Ng & von Gunten, 1998). Many individuals believe dying must mean terrible pain, loss of dignity, and uncontrollable suffering. Patients may have images of relatives screaming in torment while dying of cancer. The majority of people with terminal illness can obtain relief (Paice & Fine, 2001). However, the patient may need to be more sedated to obtain this relief in some cases (Panke, 2003). Unfortunately, this fear becomes a reality for some patients when healthcare professionals provide inadequate analgesia. Patients and their caregivers need to be educated about the options for pain control. Pain can produce feelings of guilt for patients who view pain as a cause of suffering for their family. Other common symptoms that cause suffering include dry mouth, shortness of breath, and lack of energy (McMillan & Small, 2002).

**Fear of abandonment:** As patients weaken and begin to lose some control, the fear that others involved in the care may abandon them can be intense. Patients may particularly fear abandonment by their physicians when the focus of care moves away from aggressive treatment. Physicians may have said, “There is nothing more I can do,” which reinforces this fear. In most cases, physicians’ continued involvement during the terminal stage is an important part of supportive care. Even when patients are under hospice care, attending physicians usually remain actively involved. Individuals who feel helpless and anxious around a dying patient may need encouragement to maintain their involvement with the patient to alleviate the patient’s fears of being left alone.

**Loss of control:** When advancing cancer causes progressive weakness, fatigue, and confusion, patients have less opportunity to maintain control of the environment and what is happening to them (American Medical Association Council on Scientific Affairs, 1996). Because American society values self-reliance and independence, this loss can be humiliating and provoke anxiety. Loss of control can induce feelings of guilt because patients may feel uncomfortable relying on others and can maintain a belief of needing to be strong. Others inadvertently can add to this fear by taking over decision making and other responsibilities for patients out of a desire to help. Advancing disease that treatment can no longer control represents a loss of patients’ power over the cancer. The act of stopping aggressive treatment may represent a major loss of control as patients feel they are “giving in” to the cancer.

Encouraging the completion of advanced directives and estate planning to ensure that personal wishes are known by others and will be followed can help patients to maintain a sense of control. Caregivers can be sensitive to the urge to take over for patients when they are still able to complete tasks. Helping patients to conserve energy and establish priorities in order to focus on things that are the most important can enhance a sense of control.

**Loss of identity:** As the individual becomes weaker, more aspects of self can be lost as the patient can no longer maintain skills, interests, and relationships. Individuals' abilities often define and affirm who they are, and when this is lost, they can feel more distressed and confused. Loss of dignity as patients become more dependent may increase this fear. Those patients with enough energy can leave a legacy by making video or audio recordings, which helps them to achieve a desired goal and enhances a sense of purpose and identity. For others, maintaining their self-respect and dignity by acknowledging their value as a person can address this fear.

**Loss of body image/self:** Valued physical traits may be lost as weakness and emaciation occur. Patients may be less able to complete normally important personal care routines (e.g., shaving, applying makeup). An individual may no longer be recognized as the same person by others. This can cause patients to feel shame or that they are not lovable. Maintaining patients' dignity, respecting modesty, and assisting with personal care are all important supportive care measures.

**Loss of loved ones:** Perhaps one of the most poignant fears that patients encounter is facing the loss of relationships with loved ones. Just as family members anticipate losing the patient, the patient, too, is anticipating separation and loneliness (Worden, 2000). For some people, the opportunity to acknowledge the grief, complete unfinished business with important people in their lives, and spend time with loved ones reminiscing about past joys and sorrows all can be therapeutic to patients and family members. Recognizing the limited time one has to right wrongs with a loved one or achieve forgiveness is a struggle for some. Borneman and Brown-Saltzman (2001) defined forgiveness as letting go of expectations that one will be vindicated for pain and loss. It can provide an opportunity for healing and possible reconciliation.

**Loss of hope:** Hope is a natural part of human existence. When hope for a cure is no longer possible, individuals often are able to alter wishes for the future. Hope can thrive in the presence of terminal illness even with the realization that cure is no longer possible (Ersek, 2001). Patients may begin to hope for an easy death, to resolve a conflict with an estranged relative, or to believe one's spouse will be prepared to face life alone. To help patients to reframe hope by focusing on the present and specifics, rather than vague uncertainties in the future, can be helpful.

## The Family's Fears

**Loss of the relationship:** Anticipating the loss of the patient is the beginning of the grieving process, which includes facing sadness, struggling with anger, and anticipating life without this loved one. If the dying person is part of a family member's everyday life, as with a spouse or parent who lives with the family, the loss is more intense. During the dying process, family members begin to realize what life will be like as the patient weakens, is sleeping more, and is less a part of the daily routine. The patient may turn more inward, and there can be less emotional contact for the family (Davies, 2001). The approach of death may generate an awareness of losing

a special relationship (e.g., a daughter losing her father who has always been her protector), loss of a part of oneself (e.g., losing one's wife means giving up a role as husband), or empathy and concern for others (e.g., the adult child who sees his or her parent anticipating facing life alone).

As family members realize that they are losing the relationship, they may fear that if the patient is too sedated to interact, they will be faced with the loss more quickly. Although family members may want the patient to be comfortable, they may try to keep him or her awake out of fear of having to face the painful realization of the loss of the relationship. Helping family members to acknowledge this fear and to reinforce the need to grieve this loss can be helpful along with reassuring them of the patient's need to be comfortable.

**Loss of control:** As with the patient, family members must face the loss of control when they can do nothing to stop the disease. This can generate many feelings, with anger often being the most pronounced. As a way to maintain some control, this anger may be expressed to physicians for not doing enough for the patient or to nurses whose actions are viewed as unhelpful (e.g., not being able to restart an IV on the first try, not bringing a medication immediately). For individuals who have never faced the death of a loved one before, this can be a particularly difficult experience because the sense of loss of control can be overwhelming. Helping family members to face the losses, acknowledging their efforts to advocate for the patient, and helping them to identify ways to maintain some control can be useful interventions. Family members may be facing loss of control in other areas of their lives as schedules are disrupted, sleep is interrupted, and conflicts arise with relatives and friends—all perhaps occurring at the same time. Some family members may need to maintain a job or child care while simultaneously helping to care for a dying loved one. Loved ones may need to take on a more proactive role as decision makers as the patient deteriorates (Zhang & Siminoff, 2003).

**Fear of sorrow:** The growing realization of the impending loss may generate intense emotions that are frightening to some individuals. Family members may have used avoidance as a means of protection from feeling pain. Once it is experienced, depression, anger, preoccupation, irritability, and difficulty making decisions can occur. This is part of the grieving process. As the patient grows more ill and eventually begins to withdraw from day-to-day life, the reality of the impending loss intensifies. This may be felt more strongly if the family member had protected himself or herself by using denial or avoidance. Helping the family member to be open to the grieving process and providing support and acceptance regardless of the reaction are very important. Family members also must recognize and help children in the family through their grief regardless of age (Hames, 2003).

**Fear of pain and suffering:** Family members may anticipate that the patient will have to endure much suffering during the dying process. This may cause them to seek assistance related to dying, such as physician-assisted suicide or euthanasia. The thought of seeing their loved one suffer can be so overwhelming that some individuals may act rashly to avoid even the remotest possibility of this happening. Education of the family about the dying process must begin early. This should include encouraging family members to express their fears about what they think will happen and then providing information to alleviate those fears. Koop and Strang (2003) found that family caregivers had improved bereavement outcomes when they felt they had accomplished something valuable by providing comfort and caring for their loved one.

## **The Role of the Oncology Nurse in End-of-Life Care**

Cancer is now the leading cause of death in the United States for people younger than 85 years of age (Jemal et al., 2005). Therefore, it is vital for oncology nurses in all settings to be skillful in addressing the fears of patients and families when cancer is progressing. As part of the interdisciplinary team, the oncology nurse often is a leader in identifying palliative interventions and support needs for these patients.

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### **Survivorship**

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Survivorship has become an important area of study for oncology professionals (Dow, 2003; Holland, 2002). The National Coalition for Cancer Survivorship (2004) defined a cancer survivor as “any individual that has been diagnosed with cancer, from the time of discovery and for the balance of life.” Survivors comprise a significant segment of society, but survivorship is a relatively new concept to oncology. With the advances in treatment, people with a cancer diagnosis are now living longer, and because of the aggressiveness of the treatment approaches, physical and psychological aftereffects are common. These changes have contributed to the development of the concept of survivorship to encompass the phases and changes the individual experiences after a cancer diagnosis (see Chapter 2).

Until the 1990s, relatively little research examined this period for patients with cancer, particularly in regard to the psychosocial sequelae (Quigley, 1989). This may be because of the assumption that quality of life returns to normal after treatment (Ferrans, 1994). Leigh (1997) postulated that in the past it was thought that recovery from a once-fatal illness was reward enough, so no need existed to study the quality of survivors’ lives. However, growing evidence has suggested that the effects of treatment, both physically and emotionally, remain long after therapy is completed (Dow, 2003). Dow noted that the National Cancer Institute has identified cancer survivorship as a major area of research.

Survivorship is a dynamic, lifelong process (Pelusi, 1997) that is viewed as a continuum or ongoing role rather than an event that occurs at some designated point in time (e.g., five years). The perception of the quality of one’s life as a survivor may change over time as new symptoms or treatment effects recede or increase or as one’s coping abilities change. This definition not only includes people with no evidence of disease but also those living with cancers not associated with cure or cancers controlled by treatment but that periodically progress. Leigh (1997) noted that survivors also are called victors, graduates, and veterans. These all are terms that connote power rather than implying dependency (e.g., patient, victim).

### **Personal Growth for Cancer Survivors**

Survivors often report positive outcomes, including a heightened sense of appreciation of family members and friends, feelings of being a better person for having gone through this difficult experience, and the changing of priorities in life for the better. Some studies of survivors have revealed an increased desire to be of service to others, and many survivors volunteer to help other patients with cancer (Ferrans,

1994; Pelusi, 1997; Wyatt, Kurtz, & Liken, 1993). Living through a life-threatening cancer experience can increase one's desire to move quickly to accomplish one's goals because of a heightened sense of the preciousness of life and how quickly it can be altered. Others may make difficult decisions more easily (e.g., leaving a destructive relationship, completing work toward a degree) because of a sense of urgency created by having a potentially fatal illness.

## **Quality of Life for Cancer Survivors**

The World Health Organization (1993) defined quality of life as individuals' perceptions of their position in life in the context of the culture and value system in which they live and in relation to their goals, standards, and concerns. Grant and Dean (2003) identified the domains of quality of life to include physical health, emotional state, level of independence, social relationships, environment, and spiritual state. Initially included as part of clinical trials, the measurement of quality of life in oncology now is being used to compare types of treatment, side effects, and the consequences of cancer treatment. How each individual cancer survivor perceives the effects of the cancer and its treatment on day-to-day life is a very personal experience. A person's subjective perception and expectations create the actual quality of life experienced. Coping with limitations such as lymphedema, chronic pain, sexual dysfunction, and fears about the disease can greatly affect one's perception of health and satisfaction with his or her life. Individuals may make decisions about whether to seek more aggressive treatment based not just on prolonging life but on the risk of creating more of a burden related to their quality of life. Although grateful to be alive, survivors may have difficulty adjusting to the trade-offs of survival, including the long-term and potentially unknown late effects of the disease and treatment. Ferrell et al. (1998) noted that breast cancer survivors continue to experience fatigue, pain, fear of breast cancer recurrence, fear of breast cancer in female relatives, and the stress of living with uncertainty and maintaining hope. Psychological well-being is influenced by the ability to maintain a sense of control in the face of a potentially life-threatening illness and can contribute to problems such as anxiety, mood swings, and depression. Ferrell, Smith, Cullinane, and Melancon (2003) found that women who survived ovarian cancer demonstrated resourcefulness and perseverance by sharing coping mechanisms and survival strategies. Social well-being involves family issues, including sexual and marital problems, adjustment of children, work-related problems, and financial concerns. Factors affecting spiritual well-being include the ability to maintain hope and derive meaning from the cancer experience, which is characterized by uncertainty. Any change in one domain will affect other domains. For example, problems with fertility will affect the emotional, spiritual, and social domains.

## **Cancer as a Chronic Illness**

For survivors who experience advancing cancer or the ongoing effects of or disabilities from cancer and its treatment, survivorship may include the challenge of living with a chronic illness. Nail (1997) noted that the public generally does not view cancer as a chronic illness, so when cancer treatment is over, survivors are expected to move on with their lives. Yet, because of long-term, late effects of the disease and treatment,



survivors may have to continue dealing with the illness. Rather than being encouraged to move on with their lives, survivors may need support in managing the chronic aspects of the condition. Often, the support that patients received at the time of diagnosis and treatment becomes less available once they enter extended survivorship.

## **The Oncology Nurse’s Role in Survivorship**

In whatever setting a nurse works, cancer survivors will be part of the patient population. Educating survivors and potential survivors about what to expect is a key role for oncology nurses. “The individual’s experience with cancer and quality of life is profoundly influenced by nursing care” (Ferrell, 1996, p. 915). In addition to being educators about survivorship issues, oncology nurses need to consider sharing knowledge about the impact of survivorship with nononcology nurse colleagues, who will be the nurses more likely to see survivors after treatment.

Cancer survivors need information about the psychological changes that will occur, the long-term physical effects of treatment, reentering the work world, the financial impact of the disease, and the effect of the disease on the family. Preparing the survivor for the anxiety that is associated with follow-up medical appointments, self-monitoring of symptoms, the end of treatment, reactions when returning to work, and anniversary-related emotions can provide important support and reassurance for patients experiencing these feelings. Providing encouragement to continue medical follow-up and support group involvement is another role for nurses. See Appendix for resource information.

Family members and friends also need preparation and education about the process of survivorship. Members of the patient’s support system may assume that life will return to normal. Nurses need to encourage them to recognize that the individual’s ongoing need to share his or her memories or feelings can be important to recovery.

Recognizing the uniqueness of the cancer experience for each individual is an important element to remember when assessing survivors. Each individual will respond differently to this process. Some may easily talk about it; others may avoid bringing up the topic of cancer for fear of “jinxing” themselves, whereas others may become anxious and depressed. Each individual interprets the disease and circumstances around it to fit his or her perception of the world.

Cancer survivorship has emerged as an important area for oncology professionals. Professional organizations, including the Oncology Nursing Society and the American Society of Clinical Oncology, have recognized and supported the needs of survivors. The National Cancer Institute has established the Office of Cancer Survivorship to create more recognition of the issues faced after cancer treatment. The quality of life of cancer survivors needs to be the focus of future research, and the oncology nurse has a key role in this area.

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## **Conclusion**

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A cancer diagnosis clearly has significant physical effects on an individual—effects that result from the disease itself and its treatment. Few other diseases, however, wreak

the additional psychosocial havoc that cancer does. The psychosocial ramifications are serious, long-lasting, and broad, and they affect not only individuals with cancer but also their extended network of family, friends, and acquaintances. At every stage along the cancer continuum, the care delivered must address physical aspects of the illness in addition to the mental health and coping strengths of the patient and family. Nurses are very much partners in this endeavor, taking their place beside physicians and other allied healthcare providers. The oncology nursing specialist, as well as any nurse caring for patients with cancer, cannot be effective without a respect for and a command of a broad range of psychosocial nursing skills. In no other specialty is nursing quite so instrumental in facilitating emotional care.

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