

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

A cancer diagnosis is a universally stressful experience (Payne, 2014). Psychosocial distress is highly prevalent and diverse at all stages of cancer care and can create as much distress as cancer's physical effects (Holland & Alici, 2010). Psychosocial oncology (also called psycho-oncology) has grown as an interprofessional specialty in recent years to address the emotional effects of cancer and the importance of psychosocial care throughout the disease course. Dr. Jimmie Holland, one of the founders of psycho-oncology, has stressed that the emotional response to cancer can influence both morbidity and mortality (Holland, 2002). A principal goal of psychosocial care in this population is to recognize and address the effects that cancer and its treatment have on the mental status and emotional well-being of patients, families, and professional caregivers (Jacobsen, Holland, & Steensma, 2012). Holland (2003) identified three contributing factors to psychological adaptation: type of cancer, personal coping skills, and society's prevailing attitudes toward the disease.

This chapter will review the psychosocial effects of cancer on the patient and family from initial diagnosis throughout the disease process and will show how the oncology nurse can affect psychosocial patient care throughout the cancer continuum.

Diagnosis

The word *cancer* evokes fear and shock in most individuals. It has been referred to as the “defining plague of our generation” (Mukherjee, 2010). A cancer diagnosis can cause anxiety and uncertainty and disrupt an individual's life by threatening the person's sense of security. In addition, cancer can affect an individual's quality of life by creating negative consequences on physical and psychological well-being (Epplein et al., 2011). Although most

cancers are treatable, many maintain profound fears that any cancer diagnosis represents pain, suffering, and death. Holland (2002) noted that no disease has sustained as strong a negative stigma as cancer. Despite advances in earlier detection, treatment, and survivorship, the phrase “you have cancer” is almost always viewed as a death sentence. The prevalence and visibility of cancer are two social factors in the fear of a cancer diagnosis. Most people know someone with cancer and have witnessed the sometimes-devastating effects of the disease and its treatments. Most people also know of someone who has died from cancer (Ferrell & Coyle, 2008).

Whatever the type of cancer, patients are faced with ongoing uncertainty about their future as they deal with the potential for an unpredictable disease trajectory. A cancer diagnosis can lead to a complex set of issues for the patient, 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). It will also affect how the individual views the future (de Vries & Stiefel, 2014).

Awareness

Prior to a diagnosis, an 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 hyper-alertness in individuals, which eventually leads them to take action and seek medical attention. How quickly this action occurs depends on many variables, including previous experience with cancer in oneself or a family member or friend. An experience with cancer may encourage some to seek quick medical attention. However, this may cause others to avoid medical attention for fear of what the symptoms could mean. Pain or discomfort created by symptoms tends to motivate people to seek medical attention. Other reasons that influence action or inaction include feelings of embarrassment or worry, fatalistic beliefs, financial considerations, inadequate knowledge, and fears regarding dependency or disfigurement (Smith, Pope, & Botha, 2005). In addition, young adults may not have the knowledge or experience to recognize or understand a symptom of cancer (Katz, 2015).

Receiving the Cancer Diagnosis

In the United States, adherence to the ethical principle of autonomy has resulted in physicians directly telling patients about their cancer diagnosis. The principle of autonomy dictates that individuals have the right to determine their own course of action with a self-determined plan (Beauchamp & Childress, 2012) (see Chapter 27).

In the healthcare field, this means the patient has the right to know and participate in all healthcare decisions. The original *Code of Ethics of the American Medical Association* noted that the physician’s duty is to avoid all things that could discourage or depress the spirit (Katz, 1984). This philosophy contributed to physicians receiving limited education about how to deliver bad news (Girgis & Sanson-Fisher, 1995). In 1961, 90% of surveyed physicians preferred not to directly tell patients about their cancer diagnosis (Oken, 1961). In 1977, however, more than 90% of physicians preferred to share this information with their patients (Novack, Plumer, & Smith, 1978). This dramatic change in practice reflected the social changes of the 1960s and 1970s, which encouraged an emphasis on openness. Access to oncology specialists with experience in sharing bad news became widely available during that time. The development of research protocols emphasizing informed consent was

another factor (Holland, 2002). Holland and Wiesel (2015) emphasized that the stigma associated with cancer diminished in the late 20th century only when patients began being told their diagnosis.

At times, families still ask that patients not be told about their diagnosis. This creates an ethical dilemma for healthcare providers when obtaining informed consent for treatment. Being pressured by families to use words such as “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 will cause patients to become suspicious and believe that their diagnosis must be so horrible that even the healthcare team will not acknowledge it. Avoiding use of the word *cancer* reinforces the fear associated with the word (Holland, 2002, 2003).

If a physician does not tell the patient about the diagnosis, it introduces the risk that a family member or friend will inadvertently disclose the diagnosis to the patient. This can cause the patient to greatly distrust the healthcare team. 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 their diagnosis over time (Dunn et al., 1993).

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 first 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 or family can be challenging but is important to establish and maintain a trusting relationship.

Delivering bad news is one of the most difficult tasks oncology professionals must undertake (Buckman, 2005). 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 (Dahlin & Wittenberg, 2015). 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 accurately and gently presenting information. In doing so, they can maintain hope regardless of the patient’s prognosis. Some studies indicate that the way information is delivered can affect the response and recall of information (Sep, van Osch, van Vliet, Smets, & Bensing, 2014). The timing of delivering bad news to a patient and family can be challenging. If possible, giving information to the patient and family at the same time ensures that everyone involved has been given the same information. Back, Arnold, and Tulsy (2009) have suggested “talking about serious news” rather than the often-used phrase “breaking bad news.” The first phrase emphasizes communication rather than just a one-way conversation of giving the information.

The SPIKES model (Setting, Perception, Invitation, Knowledge, Empathy, and Summary and Strategy) is one approach used to present bad news (Buckman, 2005):

- **Setting**—Choose a setting that is private.
- **Perception**—Ask for the patient’s perception of the medical situation.
- **Invitation**—Ask what the patient would like to know and his or her wishes in receiving detailed prognostic information.
- **Knowledge**—Give the patient a warning that bad news is coming with a statement such as, “Unfortunately, the news is not what I hoped.”
- **Empathy**—Respond to the patient’s emotions.
- **Summary and Strategy**—Summarize the discussion and plans for next steps.

Using an effective, organized approach to these conversations can ensure that the professional can effectively communicate with the patient as well as provide support and empathy.

Another communication approach is **Ask, Tell, Ask**: ask permission to present information, tell the patient the information, then check for understanding, and ask for agreement and questions (Back, Arnold, Baile, Tulsky, & Fryer-Edwards, 2005).

As new approaches are being developed, more medical schools and specialty programs are implementing training for physicians in delivering news to their patients in their curriculums and through clinical training (Bousquet et al., 2015; Reed et al., 2015). Advanced practice nurses need to develop skill in this area as well.

Responding to the Diagnosis

Whether or not a person anticipates the diagnosis, the initial response usually includes disbelief, numbness, and anxiety. Receiving a cancer diagnosis is associated with a peak of negative feelings and distress for many (Nail, 2001). Waves of intense emotions similar to a grief reaction with periods of calmness are common. Following the initial days after receiving the diagnosis, most individuals generally are able to develop a constructive plan of action. Healthcare professionals must remember that no matter how compassionate and skilled they are in delivering bad news, patients may still experience extreme emotional reactions (Shell & Kirsch, 2001). Whether the diagnosis is an early-stage cancer or stage IV disease, the common psychological denominator is the experience of profound life threat and uncertainty (Ganz & Stanton, 2015).

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 patient some sense of control. Information seeking is a more common coping mechanism in the early stages of the disease, when

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- 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 recording 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.
 - Validate the patient's feelings.
 - 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.
 - Use the key components of the SPIKES model: demonstrate empathy, acknowledge the patient's feelings, explore the patient's understanding and acceptance of the bad news, and provide information about possible interventions. Having a plan of action provides structure for this difficult discussion and helps support all involved.
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Figure 1-1. Guidelines for Giving a Cancer Diagnosis

Note. Based on information from Back et al., 2009; Backman, 2005; Fried et al., 2003; Girgis & Sanson-Fisher, 1995; Kaplan, 2010.

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 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 decision making. However, an emotional reaction can surface at any time. See Chapter 16 for more information on denial.

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. Though prognoses and treatments have improved dramatically, many of the same responses are seen today.

Spittler, Pallikathayil, and Bott (2012) found that after being diagnosed with breast cancer, women commonly are exposed to numerous doctors in a short time span to discuss the disease process, prognosis, and treatment options. For many women, the need to assimilate new information can be overwhelming. The resulting stress adds to a perceived urgency of the circumstances, potentially leading some women to make hasty decisions they later regret, such as their choice of treatment center or drug regimen.

Sherman, Rosedale, and Haber (2012) found that patients with breast cancer exhibited different reactions that were often paradoxical. For example, some patients viewed themselves as victims while viewing others as survivors. After treatment, some patients viewed cancer as an ongoing diagnosis while others viewed it as a past event. Khalili, Farajzadegan, Mokarian, and Bahrami (2013) found that patients with breast cancer often use acceptance, positive thinking, denial, reframing, distraction, and religion as ways to adjust to their diagnosis.

DellaRipa et al. (2015) found that patients with ovarian cancer experienced intensified distress related to witnessing the effect of the diagnosis on those they loved. All were concerned for those around them and found it hard to watch others suffer because of their illness. Baker et al. (2013) studied reactions of patients with a variety of cancers including lung, breast, and prostate. They found that patients early in the cancer trajectory, who had not yet started chemotherapy or radiation therapy, described emotional distress as a temporary and understandable reaction that did not warrant professional intervention.

For many, once a diagnosis is made, the focus shifts quickly to identifying treatment options. This may include going for a second, third, or multiple opinions; joining clinical trials; and researching on the Internet to find the right physician and treatment plan. Patients also need to make decisions about how to communicate the diagnosis to their families and friends. For some, this is a private matter. For others, reaching out for support personally and through social media are viable options. The patient's response to a new diagnosis can also include concealing the diagnosis from others. Gonzalez et al. (2015) found that some patients with lung cancer who concealed the initial diagnosis or recurrence related to more internalized shame regarding the etiology of the cancer.

Family Reactions

When cancer enters an individual's life, it also enters the lives of family members and close friends. These individuals are sometimes referred to as *informal caregivers*. How these caregivers react will also affect the patient (Rait, 2015). The diagnosis marks a major transition in the family's life (Zaider & Kissane, 2015). A sense of vulnerability and awareness of the inability to protect a loved one can lead to an intense feeling of helplessness. Because family members and patients often share common beliefs, the reactions of family members may parallel those of patients. Denial or blaming others for the diagnosis may occur in close family members. Family members may experience vulnerability with the realization that this could happen to them as well. New demands, role changes, disruption of future plans, and priorities contribute to stress in those close to the patient (Zaider & Kissane, 2015). In addition, family members often oversee the patient's transition into a medical culture, which can be confusing and disarming (Rait, 2015). Role changes can contribute to communication problems if someone is unsure of the usual care routines and 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 already on family members. They also may feel as though they need to conceal their own feelings and fears of what will be expected of them in the future if the disease progresses. Seeing a loved one vulnerable and fearful can create much distress, especially if this is a big change from the patient's personality.

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 and 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.

The family with cancer is a family in transition (Rait, 2015). Multiple challenges can affect all involved in different ways and at different times. Striving to maintain stability of the family system while adapting to the changing needs of the patient are important roles of family members.

Family members play a key role in the support system for 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. Caregiver stress can lead to changes in caregivers' physical health, immune function, and financial well-being (Northouse, Williams, Given, & McCorkle, 2012).

Life Span Considerations

A diagnosis of cancer in a child often causes profound shock and disruption among family members. A child's response to a cancer diagnosis of a family member depends on the child's developmental and cognitive levels as well as on how the parents respond (McFresh & Merck, 2011). Parents particularly are overwhelmed with the realization of their child's vulnerability to this disease and 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. During active medical treatment, parents of children and adolescents with cancer face many physical, emotional, and psychosocial challenges. These challenges often generate a need for information regarding medical treatments and a need for psychosocial support (Svavarsdottir & Sigurdardottir, 2013).

During the time of family disruption caused by the diagnosis, the child and siblings may exhibit behavioral and adjustment problems (e.g., problems with school attendance, sleep, aggression) in response to their anxiety. Children with cancer may require complex treatment regimens and multiple hospitalizations, as well as experience late complications, which may require long-term support.

Adolescents and young adults experience a separate set of challenges as a result of the disruptive impact that cancer and its treatment have on normal developmental transitions (Jacobsen et al., 2012). Young adults with cancer often are faced with challenges that put them in more dependent roles at a time when they are striking out on their own. Issues around establishing relationships, fertility, and delays in completing goals (e.g., school, career) are common (Katz, 2015). Individuals diagnosed with cancer during adolescence or young adulthood have the cognitive capacity to understand the severity of their illness and frequently demonstrate persistent distress and anxiety over death, cancer recurrence, or late effects (Zebrack & Isaacson, 2012).

Cancer is increasingly more likely to occur as one ages (Siegel, Miller, & Jemal, 2017). Thus, older adults are more at risk. The majority of cancer survivors are over age 65 (Institute of Medicine [IOM], 2013). In addition, the issues that survivors face can continue into advancing age. One of the major challenges for older adults with cancer is the presence of comorbidities that often complicate treatment and symptom management as well as contribute to more severe side effects (Given & Given, 2015). Other challenges include increasingly complex treatment regimen choices for frail patients. Older patients may have a limited support system, including caregivers that have the same level of limitation as the person with cancer (Meriggi et al., 2014). These concerns need to be incorporated in the decision-making process for cancer treatment. Age alone should not be the deciding factor. Newer treatments with fewer systemic side effects may present more options for the older patient.

Cancer Treatment

As the diagnostic phase is completed and treatment decisions are made, the patient and family face new experiences that will psychosocially affect them, including hospitalization, surgery, insertion of a central line, starting chemotherapy or other treatments, and frequent doctor visits. An urgency to begin treatment often exists, 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. Factors that can influence the patient's response to treatment include understanding the necessity of the treatment success rate, potential side effects, and discomforts of the treatment, as well as the relationship with the physician (Puts et al., 2015). Frailty is being recognized as an important factor to be considered in treatment decisions (Ethun et al., 2017).

Surgery

Surgery is the oldest form of cancer treatment (Mukherjee, 2010). 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 it is routinely performed for noncancerous conditions with positive outcomes. In early stages, surgery may be offered as curative. 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, Roth, & Holland, 1998). In women facing primary breast cancer surgery, Miller, Schnur, Weinberger-Litman, and Montgomery (2014) found poor body image was a factor in elevated distress in younger women.

For the individual who receives the news of a cancer diagnosis postoperatively, pain and weakness from the surgery will add to the distress and depression created by the new diagnosis. Psychosocial distress can be related to surgical healing time and the type of procedure (Lester et al., 2015). In the face of advanced cancer, palliative surgery may be chosen as treatment of physical symptoms (Williams, Ferrell, Juarez, & Borneman, 2015).

Chemotherapy and Targeted Therapies

Most individuals have preconceived ideas about chemotherapy and its side effects. While the patient is 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 intravenously to be effective. However, many new oral agents, including targeted therapies, with lower side effect profiles are now available. Screening for anxiety during initial chemotherapy is important because it is prevalent (Garcia, 2014). Attention to quality-of-life interventions has been shown to increase completion of chemotherapeutic regimens (Cheville et al., 2015). Because these drugs often have more complex dosing instructions and are managed at home, patients need to understand the importance of self-monitoring (Spoelstra et al., 2013).

Chemotherapy-induced nausea and vomiting is one of the most feared and severe side effects of cancer treatment (Lee et al., 2017). 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. Fatigue and risk for infection also contribute to psychosocial distress (see Chapter 6).

Chemotherapy forces the patient and family to adhere to medical appointments and hospitalization schedules and to reallocate family roles because the patient usually cannot meet obligations due to 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 negatively impact the family system.

Radiation Therapy

People are taught to fear and avoid radiation. However, the patient is also told that radiation is a treatment for 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. The patient may have heard myths concerning the side effects of this therapy and needs extensive education about what to expect. Radiation generally involves a longer time commitment of consecutive treatment sessions that can be disruptive in the patient's life, often requiring dependence on others for daily transportation to treatment (Haisfield-Wolfe, McGuire, & Krumm, 2012).

Palliative Care

Palliative care is a supportive treatment program that is generally for patients with advanced disease but can be appropriate from diagnosis. As defined by the Center to Advance Palliative Care (2015), it is specialized medical care for people with serious illnesses and focuses on providing patients with relief from the symptoms and stress of any serious illness. Palliative care can be provided at any stage of illness along with curative therapy. The goal is to improve quality of life for both the patient and family. The association of palliative care with hospice has led to the misunderstanding that palliative care is an end-of-life program. In 2012, a provisional clinical opinion from the American Society of Clinical Oncology (ASCO) stated that combined standard oncology care and palliative care should be considered early in the course of illness for any patient with metastatic cancer or high symptom burden (Smith et al., 2012). This standard supports bringing palliative care into the forefront of cancer treatment and can be brought in at diagnosis in some patients (IOM, 2015). In 2015, ASCO partnered with the American Academy of Hospice and Palliative Medicine to release a joint statement that established essential palliative care services and set achievable goals for medical oncologists. The established standards identify the basic skills medical oncologists need to provide primary palliative care, including symptom management, advance care planning, and communication and shared decision making.

Palliative care is generally provided by a team either in the hospital, outpatient clinic, or office, as well as in the home for symptom management, emotional support, advance care planning, and resource utilization. The vast majority of programs remain in the hospital, but growth in the other sectors is anticipated. Palliative care can be provided while the patient is still receiving aggressive treatment such as chemotherapy, total parenteral nutrition, and surgery. The presence of palliative care early in the disease trajectory can assist with complex symptom management and advance care planning. Later in the disease process, it can also assist with establishing treatment goals and helping with decision making as the patient is facing treatment choices about level of aggressiveness to pursue. Palliative care also can be a transition to hospice. An interprofessional team approach is generally a key part of palliative care.

The recent growth of the field has been fueled by studies demonstrating the positive impact of palliative care in symptom management, advance care planning, and emotional support (Bakitis, Lyons, Hegel, & Ahles, 2013; Dahlin, Kelley, Jackson, & Temel, 2010; Temel et al., 2010). Bakitis et al. (2013) found that palliative care for patients with cancer generally resulted in positive outcomes except when patients were not ready, lacked preparation for the referral, or equated palliative care with hospice. Temel et al. (2011) studied 151 patients newly diagnosed with non-small cell lung cancer. Those receiving early palliative care significantly improved understanding of their prognosis over time. This, in turn, may affect decision making about care near the end of life.

These patients also experienced improved quality of life and lived longer than the group without palliative care. Rabow et al. (2013) found evidence that palliative care contributed to improved patient satisfaction, symptom control, and quality of life; reduction in healthcare utilization; and longer survival in a population of patients with lung cancer.

Palliative care can provide access to expert symptom management as patients are pursuing curative therapy. If the focus changes to supportive care, then the palliative care team can take a larger role in providing support, managing symptoms, addressing goals, and assisting with plans for the future. Potentially, referral to palliative care will increase access to hospice care earlier in the course of the illness. Outcome measures for palliative care were developed by the National Consensus Project for Quality Palliative Care (2013) to include the following:

- Physical and emotional symptoms
- Support of function and autonomy
- Advance care planning
- Aggressive care near death
- Patient and family satisfaction with care
- Emphasis on quality of life
- Relief of family burden
- Provider continuity and ease of contact
- Bereavement assessment and care planning and support

The Oncology Nursing Society (2014) position statement on palliative care for people with cancer supports that all patients with cancer benefit from palliative care and that oncology nurses are critical participants in the delivery of this care. Pediatric palliative care programs are now available in many settings. The American Academy of Pediatrics (2000) has supported the introduction of palliative care for all children with life-threatening illness at diagnosis and throughout the disease course. Kaye et al. (2015) suggested that possible triggers for pediatric palliative care referrals at diagnosis include stage IV neuroblastoma, metastatic solid tumors, any new diagnosis with complex pain symptoms, and any disease where stem cell transplantation is part of the treatment plan.

With the growth of palliative care, the need for an adequate workforce of professionals to provide all levels of this care is a concern. Educating oncology professionals on the basics of palliative care will help to reach more patients (IOM, 2015). Advanced practice nurses play a key role in providing palliative care and leading many teams. Bedside nurses in many settings who care for patients with cancer will continue to incorporate palliative care principles in patient care (Coyle, 2015; Dahlin, 2015).

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

Adjusting to the demands of cancer treatment takes its toll on the patient and family. In addition, many adjustments must continue to be made as treatment continues (Williams & Jeanetta, 2015). For example, treatment side effects may develop, recovery times from procedures may be longer than expected, and outcomes from treatment may be disappointing. Some support needs during treatment include financial resources, information, and spiritual and emotional support (Smith, Hyde, & Stanford, 2014).

The emotional response to treatment has been extensively studied. Baker et al. (2013) found that newly diagnosed patients were less interested in emotional support resources prior to starting cancer treatment but more open to them once treatment had started. They postulated that this was because treatment increased exposure to vulnerability and potential suffering. A study by Sherman et al. (2012) on patients with breast cancer found that treatment challenged women's images of being healthy when looking at their surgical scars or hairless

heads. Treatment was associated with a reminder of the potential losses they face, such as loss of roles. During treatment, they were often on high alert to new symptoms that could signify a complication or recurrence of cancer.

The presence of treatment side effects will influence coping. Mortimer and Behrendt (2013) found that symptoms such as hot flashes, sleep disturbance, fatigue, and weight gain related to hormone treatment after breast cancer greatly affected quality of life for some time.

Family and friends are also affected by cancer treatment. With treatment increasingly occurring in the outpatient setting, family members and friends are being asked to take on greater responsibilities for patient care (Jacobsen et al., 2012; Latour, 2014). Cancer treatment leads to changes in responsibilities and roles in loved ones. Family members often assume the caregiving role with little or no preparation and without considering whether they have enough knowledge, resources, or skills (Northouse et al., 2012). These demands can cause changes in their psychological, physical, and financial well-being, especially if the patient or caregiver cannot return to work (Northouse et al., 2012). Duggleby et al. (2015) found that male spouses of patients with breast cancer took on a number of new roles and responsibilities, including as caregivers. They reported better quality of life when they had more hope and less guilt.

Family members need to adjust to the demands of long-term treatment. The patient and family often will transition from the crisis-oriented response of the initial diagnosis to a “new normal” as the treatment schedule and challenges become part of daily life. In long-term treatment, the loved ones need to establish a method of communication to stay informed on the patient’s condition without being too intrusive.

The Oncology Nurse’s Role in Cancer Treatment

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 hope and the development of a trusting relationship. Nurses should recognize that once hope is taken away, it is very difficult to recapture it. Helping patients to confront intense and confusing emotions is a key role for nurses and an important component of the nurse–patient relationship. Nurses can advise patients about ways to communicate so family and friends can keep abreast of changes without fatiguing the patient.

Recurrence

With longer survival rates comes the risk of recurrent disease. Because of the unpredictable nature of cancer, many individuals facing a diagnosis and initial treatment

eventually must face recurrence or advancing disease in the form of metastasis. Maintaining life balance in the face of new disease and managing pain, fatigue, and other physical and psychological symptoms are major challenges (Ganz & Stanton, 2015). *Recurrence* is 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.

Psychosocial Response to Recurrence

Individuals move from being short- or long-term survivors of cancer to being patients once more when the cancer returns, and this brings new stresses (Andersen, Shapiro, Farrar, Crespin, & Wells-DiGregorio, 2005; Vivar, Whyte, & McQueen, 2010). Families move from a state of fear of recurrence to one of uncertainty and distress as a result of the new crisis (Vivar, Canga, Canga, & Arantzamendi, 2009). Recurrence brings significant stress, which is not unlike that of the initial diagnosis (Yang, Brothers, & Andersen, 2008).

Research on psychosocial response to recurrence is limited and contradictory. 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 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. For these patients, the uncertainty can be more distressing than the actual return of disease. With recurrence comes many negative emotions, which are different in that they may be more intense than those after the first diagnosis of cancer. Survivors and their family members have to manage new psychological distress (Vivar et al., 2010). In a study by Schulman-Green et al. (2012), disease progression was as challenging as initial diagnosis of ovarian cancer. Warren (2010) found that diagnosis of metastatic (or secondary) breast cancer was frequently more distressing than the diagnosis of a primary tumor because it indicated the cancer was no longer curable.

Andersen et al. (2005) found that women's previous experiences with a cancer diagnosis may enable them to be emotionally resilient. In this study, patients had less distress with recurrence than with initial diagnosis.

A study by Yang et al. (2008) of women experiencing recurrence of breast cancer found that patients who coped with disengagement strategies such as avoidance, denial, and withdrawal had poorer quality of life. Those who had higher symptom distress experienced more difficulty coping.

Because these patients have already been through some type of cancer treatment, preparing for treatment again may be more difficult because they know what to expect. Patients who experienced severe side effects with the initial treatment may need more encouragement or more aggressive symptom management. These patients also may face decisions regarding more aggressive treatment, such as stem cell transplant, immunotherapy, and/or clinical trials. These treatments may not have been considered the first time around, thus creating more unknowns. In some 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.

The realization that treatment has failed can contribute to depression and a feeling of hopelessness. The patient's 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 the individual 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. Lamperti et al. (2012) found that depression was higher than anxiety in patients with recurrent brain tumors.

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, consideration of alternative therapies, or even 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 stressors 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. Recurrence creates great suffering in families (Northouse et al., 2002). In a study by Vivar et al. (2010), learning that the cancer had come back was, for most of the families, more devastating than hearing about the initial diagnosis. Signs of shock and suffering were experienced by families as an initial response to recurrence. The new diagnosis often entailed a change in family life. Survivorship period and age also seemed significant in the psychosocial experience of recurrence.

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 can be the response when the patient experiences multiple remissions and exacerbations. 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. In the past, spouses or siblings may have thought that they never could have coped with a loved one having cancer, and getting through the initial treatment may have given these individuals confidence in their ability to face whatever happens. At times, the patient may wish to have less contact with family members and friends because of depression or fatigue.

The Oncology Nurse'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 the patient 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. Healthcare professionals often describe it as the patient "failing treatment." In reality, the treatment has failed the patient. By avoiding the association with failure, the nurse can reduce the patient's sense of responsibility for outcomes. 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 make decisions. 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 hotlines, may be useful as patients seek more opinions about their options. Awareness of the patient's emotional state, including anxiety and depression, will affect learning; therefore, information needs to be repeated and provided in writing or to a family member or friend to reinforce the content.

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.

Terminal Illness

For some, awareness of a terminal illness may come as a gradual realization 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, when 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 concerning what will happen to family, life plans, life's work, and body are difficult to face, and they are also difficult questions for others, such as family members, to hear. Some of these thoughts can be acknowledged by talking about the concerns and preparing 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 (Breivik et al., 2009; Ng & von Gunten, 1998). Many individuals believe dying must mean terrible pain, loss of dignity, and uncontrollable suffering. Patients may have images of people they have known in the past screaming in torment while dying of cancer. The majority of people with terminal illness can obtain relief (Paice, 2015). Unfortunately, this fear becomes a reality for some when inadequate pain relief is provided. 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. Suffering can be caused by physical symptoms as well as a variety of emotional, social, and spiritual factors. See Chapters 8 and 10 for more information on the psychosocial impact of pain and suffering.

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 can often 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 their environment and what is happening to them. Because American society places strong value on 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 can inadvertently 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. Stopping aggressive treatment may represent a major loss of control as patients feel they are "giving in" to the cancer. This can lead to a fear of becoming a burden to the family (Steele & Davies, 2015). At some point in the dying process, patients may begin detaching from the outside world and becoming withdrawn. At this point, patients give up the struggle to stay invested in controlling aspects of life. This is a self-protective mechanism and is common in the dying process.

Encouraging the completion of advance 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 can enhance a sense of control and allow them to focus on the most important things.

Loss of identity: As individuals become weaker, more aspects of self can be lost as they 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). Because most people cannot truly understand what the patient is facing, terminal illness creates a sense of separation or disconnectedness from others (Borneman & Brown-Saltzman, 2015).

Opportunities 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 can be therapeutic to some 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. This can provide an opportunity for healing and possible reconciliation. Ferrell (2012) described forgiveness as assisting the person to acknowledge the harm they have done, to feel worthy of being forgiven, and to fully embrace the experience of the other who was involved. Byock (2004) condensed supportive responses to loved ones in four phrases: “Please forgive me,” “I forgive you as well,” “Thank you,” and “I love you.”

Loss of hope: Hope is a natural part of human existence. Although it is often challenged in the face of terminal illness, hope can also thrive, even with the realization that cure is no longer possible (Cotter & Foxwell, 2015). When hope for a cure is no longer realistic, individuals often are able to alter wishes for the future. The nature of hope can adjust as patients may begin to hope for an easy death, to resolve a conflict with an estranged relative, leave a legacy, or to believe one’s spouse will be prepared to face life alone. Reframing hope can be supported by focusing on the present and specifics rather than vague uncertainties in the future. See Chapter 7 for more information about hope and the psychosocial experience.

The Family’s Fears

Loss of the relationship: Anticipating the loss of a family member 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 can be more intense. During the dying process, family members begin to realize what life will be like as the patient weakens, sleeps 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. 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., a man who anticipates losing his lifelong friend and confidant). Corless (2015) described the process of letting go of the relationship as part of the grieving process, but it does not mean cutting off memories of the lost person.

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. Chapter 19 discusses the grieving process and ways to manage grief.

Loss of control: As with the patient, family members must face a loss of control with the realization that 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, this can be a particularly difficult experience because the sense of loss of control can be overwhelming. Helping family members to face this loss, 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 caring for a dying loved one. Giving family members some control in making decisions about care routines or activities can help to reduce the sense of loss of control. See Chapter 21 for more information on loss of control and powerlessness.

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.

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 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. Wright et al. (2008) found that aggressive medical treatment at the end of life was associated with a higher risk of depressive disorder in bereaved caregivers.

The Oncology Nurse's Role in End-of-Life Care

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 interprofessional team, the oncology nurse often is a leader in identifying palliative interventions and support needs. Acknowledging emotions, providing a supportive environment, and promoting access to resources of palliative care and hospice are some of the important nursing interventions. Nurses often are the ones who see the patients and family members' raw emotions as they cope with approaching death. Chapter 26 gives more information on end-of-life care.

An additional nursing role is providing information to the patient and family about what to expect in the dying process (Goldsmith, Ferrell, Wittenberg-Lyles, & Ragan, 2013). Information often reduces uncertainty and provides comfort. Family members often model their care of the patient on what they observe from the nurses (Ferrell & Coyle, 2008).

Incorporating discussions about end-of-life wishes is an important role for oncology nurses. Patients who have conversations about their wishes for end-of-life care are more likely to receive care consistent with their preferences (Mack, Weeks, Wright, Block, & Prigerson, 2010).

Survivorship

Survivorship has become an important area of study for oncology professionals (Hahn & Ganz, 2015). A cancer survivor is any individual who has been diagnosed with cancer, from

the time of discovery and for the balance of life, and includes family, friends, and caregivers (National Coalition for Cancer Survivorship, 2013).

Survivors comprise a significant segment of society, especially in light of the advances in early detection and treatment as well as the growth of the aging population (Miller et al., 2016). Survivorship, however, is still a relatively new concept to oncology. Until the 1990s, relatively little research examined this period for patients with cancer, particularly regarding the psychosocial sequelae. This may be because of the assumption that the quality of life of survivors returns to normal after treatment. 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). The National Cancer Institute created the Office of Cancer Survivorship in 1996. With advances in treatment, people with a cancer diagnosis are now living longer, and because of the aggressiveness of treatment approaches, physical and psychological after-effects are common. In 2005, IOM recommended the development of a survivorship care plan and treatment summary to address ongoing needs. Chapter 2 provides more information on survivorship.

Survivorship is a dynamic, lifelong process 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 with cancers controlled by treatment but that periodically progress. Along with the long-term effects from the cancer and its treatment, the challenges of survivorship affect many areas of the person's life, including personal relationships, employment, financial security, sexuality, childbearing, and coping style (IOM, 2005).

Fear of Recurrence

Fear of cancer recurrence remains an ongoing theme for most survivors (Butow, Fardell, & Smith, 2015; Dahl, Wittrup, Væggemose, Petersen, & Blaakaer, 2013; Koch, Jansen, Brenner, & Arndt, 2013). Cancer recurrence is defined as the fear that cancer could return in survivors who have had treatment with a goal of cure (Butow et al., 2015). It has been found that this fear does not necessarily decrease over time for some (Stanton et al., 2002). This chronic uncertainty of health status during and after cancer treatment can be a significant psychological burden (Simard, Savard, & Ivers, 2010; Thewes et al., 2012). Fear of progression (or fear of recurrence) is an appropriate, rational response to the real threat of cancer and cancer treatments. However, elevated levels of fear of progression can become dysfunction, leading to altered well-being, quality of life, and social functioning (Herschbach & Dinkel, 2014). Addressing worry over return of the cancer is the most prevalent unmet supportive care need (Butow et al., 2015; van den Beuken-van Everdingen et al., 2008).

Fear of recurrence often is thought solely as a patient concern, 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. They found that family caregivers reported significantly higher fears 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 fears addressed.

The Oncology Nurse's Role in Survivorship

In whatever nursing setting, cancer survivors will be part of the patient population. In addition to being educators about survivorship issues, oncology nurses need to consider sharing knowledge about the impact of survivorship with non-oncology nurse colleagues—the nurses most likely to see survivors after treatment.

Cancer survivors need information about the psychological changes that will occur, the long-term physical effects of treatment, the challenges of reentering the work world, the financial impact of the disease, and the effect of the disease on the family. Preparing survivors for the anxiety associated with follow-up medical appointments, self-monitoring of symptoms, end of treatment, reactions when returning to work, and anniversary-related emotions can provide important support and reassurance. Providing encouragement to continue medical follow-up and support group involvement is another important nursing role. 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 after treatment. Nurses need to encourage them to recognize that the individual's ongoing need to share memories or feelings can be important to recovery.

Recognizing the uniqueness of the cancer experience is an important element to remember when assessing survivors. Each individual will respond differently to this process. Some may easily talk about it. Some 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 their perception of the world.

Conclusion

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. The oncology nurse 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 psychosocial care. From diagnosis, throughout treatment, and into survivorship, along with the possibility of end-of-life care, the challenges of cancer provide opportunities for oncology nurses to offer support, leadership, and care.

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