The phenomenon of distress in patients with cancer is underassessed, underdiagnosed, and undertreated. The National Comprehensive Cancer Network ([NCCN], 2005) defined distress as “a multifactorial unpleasant emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment.” The continuum of distress ranges from feelings of vulnerability, grief, and worry to issues such as “depression, anxiety, panic, social isolation, and existential and spiritual crisis” (NCCN). This article will focus on the symptoms of anxiety and depression. Excessive worries, fear, sadness, unclear thinking, despair, severe family problems, spiritual crisis, and severe financial problems can trigger distress (NCCN).

Despite the fact that being diagnosed with cancer is a traumatic event for most patients, oncology healthcare professionals, including nurses, traditionally tend to focus primarily on the physical aspects of their patients’ care. As a result, patients with cancer often experience distress without sufficient support from their oncology nurses.

Distress in patients with cancer is not uncommon. The American Cancer Society (2006) estimated that, based on clinical data, more than 25% of patients with cancer undergoing treatment become clinically depressed. The depression, often reactive in type, can be distinguished from depression as a normal stage of grieving. Reactive depression, also known as adjustment disorder, often is situational and is characterized by depression that occurs after an event or situation. It lasts for as long as six months and is characterized by feelings of hopelessness and helplessness, anxiety, shaking or twitching, and palpitations (Medline Plus Medical Encyclopedia, 2005a, 2005b). Patients with a history of depression are at increased risk for depressive episodes, as are patients with other significant comorbidities, those with a family history of depression, and those with a history of alcohol or drug abuse (American Cancer Society).

Sadness, grief, and anxiety are normal reactive emotions to the crisis faced during the cancer trajectory. Because such feelings are common, oncology nurses must be able to distinguish between normal degrees of sadness or anxiety and depressive or anxiety disorders. A critical part of oncology nursing care is the assessment of the level of patients’ potential distress, as well as the appropriate level of nursing interventions (McCorkle, 2004).

Distress is a significant issue for patients with cancer in terms of their quality of life (QOL). Distress can influence treatment outcomes and survival rates of women with breast cancer. Women with prior diagnoses of depression are less likely to receive cancer treatment that generally is recognized as appropriate. They also

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have poorer survival rates than women without a diagnosis of depression. Depressed individuals may be less likely to receive cancer screenings, less likely to seek treatment when they suspect illness, and less likely to adhere to their oncologists’ treatment recommendations (Goodwin, Zhang, & Ostir, 2004).

Distress also affects patients with cancer in terms of their psychological QOL, on a short-term and long-term basis. Sarna et al. (2002) concluded that risk factors for poorer QOL are linked strongly to depression, a potential target for intervention. The National Cancer Institute (2006) identified cancer-related risk factors for depression as depressed mood at the time of diagnosis, poor pain management, advanced disease, increased physical symptoms, pancreatic cancer, being single, head and neck cancer, and treatment with certain antineoplastic agents. The Sarna et al. study of cancer survivors, all of whom were at least five years from diagnosis, indicated that depression is a factor that continues to affect patients with cancer long after cancer diagnosis.

Betsy Patterson, RN, MSN, AOCN®, former oncology nurse practitioner and nurse educator for Oncology Education Services, Inc., has lived with anxiety and depression during her 20-year experience with non-Hodgkin lymphoma. Patterson, commenting on the effects of her depression on QOL, stated, “When you’re depressed, everything is gray. When the depression is lifting, the grayness lifts, and the oranges in the grocery store are a brighter orange” (Betsy Patterson, personal communication, July 24, 2005).

Distress tends to increase in patients with poorer performance status (Bodurka-Bevers et al., 2000) and as the cancer disease process becomes more advanced. In the absence of a prior psychiatric history, severe psychiatric symptoms are rare and far less common in patients with early-stage breast cancer than in patients with more advanced disease (Antoni et al., 2001). As the disease progresses to end-stage metastatic breast cancer, patients’ psychological distress tends to increase considerably. Oncology nurses need to be particularly aware of the need for psychological assessment and treatment among patients with end-stage disease (Butler et al., 2003).

Etiology and Risk Factors for Distress

Distress can be complicated by several factors. From a physiologic perspective, patients at later stages of disease or with more physical symptoms are at increased risk for distress. Patients with a shorter time perspective about survival have a greater chance of being distressed, as do those with any kind of functional impairment. Psychologically, patients with a history of psychiatric problems are at higher risk for distress, as are overly anxious patients and those with low ego strength (i.e., a person’s capacity to maintain his or her own identity despite psychological pain, distress, and conflict). Patients who have had difficulty coping with stressors in the past may be more apt to become distressed, as may those with a history of substance abuse.

Certain periods of time in the cancer trajectory can increase the risk of emotional distress. Finding a suspicious symptom, being diagnosed, and beginning treatment are stressful times for patients with cancer, as are finishing treatment, dealing with recurrence, and coping with end-of-life issues (NCCN, 2005). Lastly, social issues may be a factor as well. Patients with lower socioeconomic status are at increased risk for distress, as are those with marital problems or other life stressors. Patients who expect support from others but do not receive it are at increased risk for distress, as are patients with little or no church attendance (Weisman & Worden, 1976–1977).

Differing types of cancer can affect patients’ chances of being distressed. A study by Zabora, BrintzenhofeSzoc, Curbow, Hooker, and Piantadosi (2001) found that the overall incidence of distress was 35% among their sample of patients; patients with pancreatic cancer had the highest mean scores for anxiety and depression combined, followed by those with lung cancer, liver cancer, Hodgkin disease, and head and neck cancer.

Barriers to Assessment: Why Nurses Are Not Assessing for Distress

The Oncology Nursing Society’s Statement on the Scope and Standards of Oncology Nursing Practice recommended that oncology nurses assess patients for coping and comfort, which includes assessment of psychosocial issues such as distress (Brant & Wickham, 2004). McCorkle (2004) suggested that oncology nurses do not assess for distress regularly because of time constraints, lack of knowledge, and lack of emotional ability. Oncology nurses may not have extensive psychological training, but they can learn when patients need to be referred to a psychologist or require pharmacologic support for emotional distress. Oncology nurses may not be comfortable inquiring about their patients’ worries and sadness. That may reflect some of their own inner concerns, or they may be reluctant to raise potentially upsetting issues with patients. Conversations about distress can be emotionally taxing, in addition to time consuming. Those barriers to patients’ psychological assessment can be overcome through continuing education about psychosocial issues, discussions with peers about why nurses are reluctant to assess for distress, and an honest look inward.

Healthcare providers may fail to ask how patients are coping, adopting a “don’t ask, don’t tell” policy. They also may assume that patients will tell them if they are feeling depressed. They may feel that psychosocial concerns are secondary and unimportant compared to treating cancer. However, failing to assess and treat increased levels of distress can jeopardize the outcomes of cancer therapies, decrease patients’ overall QOL, and increase healthcare costs in the long run (Zabora et al., 2001).

Patients are concerned about the stigma of mental illness, as well as the stigma of having a cancer diagnosis. Also, institutions may have a primary goal of treating the cancer itself and may not provide psychosocial care. Psychology is a “soft” science, with outcomes that are difficult to measure, which may cause institutions to shy away from treating patients’ psychological needs. Third-party reimbursement for psychological care to treat distress also may not be available (Clark, 2001).

Screening and Diagnosis

NCCN guidelines suggest that nurses, as well as other members of multidisciplinary healthcare teams, assess all patients for distress. Distress can be assessed initially in a number of ways. Informal questions such as, “You seem worried today. Have you been feeling more anxious lately?” or “Are you still...
feeling those feelings of hopelessness and helplessness we discussed last week?" can begin discussions. Unfortunately, terms such as anxiety and depression can carry some stigma. Informal questions, however, allow for no standardization of assessment.

Another option is the use of an established depression or anxiety scale. The three most common self-rating scales for depression in the literature are the Hospital Anxiety and Depression Scale (Snaith, 2003), a 14-item questionnaire; the Beck Depression Inventory® (Beck, Steer, & Brown, 2006), a 21-item questionnaire; and the Zung Self-Rating Depression Scale (World Health Organization, 2006), a 20-item questionnaire. Two common self-rating anxiety scales also found in the literature are the Hamilton Anxiety Scale (Healthcare Technology Systems, 2006), a 14-item scale; and the Beck Anxiety Inventory® (Harcourt Assessment, 2006), a 21-item scale. Unfortunately, the scales require that patients complete two separate forms to assess for anxiety and depression. The Brief Patient Health Questionnaire, a 34-question tool, assesses patients for anxiety and depression, but it is a longer tool and can be difficult for many oncology nurses to administer on a regular basis.

Another option is the Distress Management Assessment Tool (see Figure 1). The Distress Thermometer allows for rapid assessment of patients’ anxiety and depression. Use of the word distress in the description of the tool avoids some of the stigma associated with depression and anxiety. The Distress Thermometer is a visual analog scale, measuring distress from 0 (none) to 10 (extreme). Oncology nurses who assess their patients for pain and fatigue are familiar with the use of such scales. The tool takes approximately three or four minutes to complete. Canadian oncology nurses said that patients tended to report more concerns in writing than they did verbally to nurses (Larouche & Edgar, 2004), so the use of a distress assessment tool such as the Distress Thermometer can be part of any oncology institution’s initial assessment of patients. Alternatively, nurses with more limited time or resources can use a verbal version of the Distress Thermometer, although no data exist to suggest that it is as effective a means of assessing for distress as using the Distress Thermometer itself.

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The true extent of anxiety and depression can be diagnosed more accurately, if necessary, with the use of the Diagnostic and Statistical Manual for Mental Disorders, 4th edition (DSM-IV). The resource, used mostly by psychiatric nurse practitioners and other mental healthcare professionals, helps diagnose and determine the standardized type of depression or anxiety that is occurring. Oncology nurses assessing for distress using the Distress Thermometer may refer some patients to psychological or psychiatric healthcare professionals, who, in turn, will use the DSM-IV to provide standardized diagnoses of anxiety and depression. This allows treatment for distress to be more systematic.

Caregivers’ Response to Distress

Distress affects not only patients with cancer but also their caregivers. Caregivers become stressed when trying to cope with a loved one’s illness and distress and often cannot manage patients at home because of their own untreated psychosocial problems (Clark, 2001). Kurtz, Kurtz, Given, and Given (1995) found that the level of caregivers’ depression could be predicted by the level of their loved ones’ depression. Improving patients’ mood states, then, would improve their caregivers’ mood states, which would improve QOL for both.

Caregivers can be stressed for other reasons as well, according to McCorkle (2004). Patients have increasingly complex needs, so caregivers assume difficult tasks and have a high proportion of unmet needs themselves. Factors associated with increased caregiver distress include patient disease state and subsequent emotional adjustment, age, socioeconomic status, and other life stressors. Patients’ and caregivers’ personality traits may predict their levels of distress, as may their ability to cope and their degree of social support (Toseland, Blanchard, & McCallion, 1995).

Nursing Interventions

Many intervention options exist for patients with distress who have been assessed and diagnosed appropriately. First, oncology nurses play an important role in educating and reassuring patients that distress can be treated and is not a situation that must be endured. Providing patients with educational information about what to expect can help reduce their anxiety about upcoming treatments. Patients who are informed that distress is not uncommon in people with cancer are less likely to feel that their experiences are unusual or abnormal, and they may be more likely to talk about their distress.

Nurses can mobilize resources for patients, educate regarding side effects of medications, and assist in monitoring distressing symptoms. They also can suggest therapies such as meditation or music therapy, which can help to reduce stress. Providing support for physical symptoms alone is not sufficient; oncology nurses must be sensitive to psychological QOL issues as well.

Treatment Options

For many patients with mild distress, support groups may offer a way to ease their emotional suffering. Involvement with other cancer survivors can be a wonderfully empowering experience and can ease mild distress. Oncology nurses can help patients with mild distress by making information about area support groups readily and easily available. For other patients, one-on-one psychological counseling, whether with a priest or minister, psychiatric nurse practitioner, licensed clinical social worker, or psychologist, can provide needed support to help them cope with the cancer experience. Oncology nurses can refer patients to other members of the healthcare team as necessary.

Advanced practice nurses can play a role in the assessment, diagnosis, and treatment of patients with cancer and distress. They initiate appropriate actions to facilitate the implementation of psychologically therapeutic plans that are consistent with the continuing mental and physical healthcare needs of patients.

Patients may benefit from pharmacotherapy, either with short-term use to assist them with adjustment disorder or with long-term use to treat more severe depressive or anxiety symptoms. Patients with moderate to severe distress can be referred to a psychologist or psychiatrist for evaluation; such professionals can evaluate for dementia, mood disorders, adjustment disorders, personality disorders, and other psychiatric diagnoses (NCCN, 2005). Treatment for more severe distress can include counseling and pharmacotherapy with antidepressants and antianxiety agents, as mentioned previously, as well as education about problem-solving and coping skills (McCorkle, 2004). Some patients may require hospitalization.

Conclusion

Distress is a common psychosocial issue and can radically affect the QOL of patients with cancer. Patients must be monitored closely to determine who may require ongoing care. Oncology nurses can become proficient in assessing for distress using the Distress Thermometer, thus assisting patients in resolving their symptoms of distress, allowing them to enjoy better QOL. Once patients with cancer have been assessed, oncology nurses can provide interventions to help with their practical and psychosocial issues. In this manner, nurses can help ensure that patients’ symptoms of distress are managed, giving them the best care for all aspects of their cancer experience.
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