Cancer Survivorship: Meeting Psychosocial Needs

Marcelle Kaplan, RN, MS, AOCN®

Attention to issues unique to cancer survivorship has increased in recent years as the number of cancer survivors has grown. In 2004, the latest year with complete statistics in the United States, an estimated 10.8 million cancer survivors represented approximately 3.7% of the population (Ries et al., 2007). The cancer sites with the highest frequency of survivors were breast (22%), prostate (19%), colorectal (10%), and gynecologic (9%) (Ries et al.). An individual is defined as a cancer survivor from initial diagnosis until the end of life. Family members, friends, and caregivers also are considered survivors because they share the impact of the experience (National Cancer Institute [NCI], 2006a). Cancer survivorship has been conceptualized as consisting of three phases of survival, each with its own dimensions. Phase 1, acute survival, is devoted to coping with the diagnosis and the initial treatments and side effects. Phase 2, extended survival, refers to the period when the individual may be in remission or receiving consolidation therapy but is returning to a normal life while being followed regularly. Phase 3, permanent survival, relates to long-term adjustment and adaptation to life beyond cancer (Mullan, 1985) (see Figure 1).

Acute Survival
- Extends from diagnosis to completion of initial treatment
- Dominated by cancer treatment and coping with effects of therapy
- Confronting one's mortality
- Fear and anxiety are constant elements.
- Family and community support are important; needs of family often overlooked.

Extended Survival
- Beginning to return to normal life after treatment completion
- Period of “watchful waiting,” regular follow-up examinations, intermittent therapy as needed, dealing with physical limitations secondary to treatment (e.g., fatigue, hair loss, altered body image, cognitive dysfunction)
- Psychosocial support services important
- Dominated by fear of recurrence

Permanent Survival
- Evolves from extended disease-free survival and low likelihood of disease recurrence
- Adjustment to the “new normal”
- Long-term physiologic effects of treatment
- Employment and health insurance concerns
- Health promotion strategies

Figure 1. Phases of Survival
Note. Based on information from Mullan, 1985.

Meeting Psychosocial Needs of Patients With Cancer

Great strides have been made in identifying the biology of malignancy and in advancing the state-of-the-art of cancer therapy; however, a widespread failure to recognize and address the psychosocial needs of cancer survivors because of a variety of barriers has occurred (see Figure 2). A landmark report from the Institute of Medicine ([IOM], 2008), Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs, proposed that identifying and addressing the psychosocial needs of cancer survivors should become a new standard of care. Components of the standard include screening patients for distress and other problems, connecting patients and families to healthcare providers and services that possess the expertise and resources to handle these issues, coordinating care, and monitoring the effectiveness of the services provided. The Oncology Nursing Society (2008) also
advocated support for the standard in a recent position statement. The American Psychosocial Oncology Society (APOS), an organization of psycho-oncology professionals dedicated “to advance the science and practice of psychosocial care for people with cancer,” devoted its 2008 conference to integrating psychosocial services in quality cancer care (APOS, 2008).

Cancer and Distress

Cancer survivors experience varying degrees of distress throughout the cancer continuum. The National Comprehensive Cancer Network ([NCCN], 2008) 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” (p. DIS-2). Distress can range from feelings of vulnerability and sadness to disabling problems, such as depression, panic, and social isolation. NCCN has produced comprehensive practice guidelines for distress management that include a simple screening tool to measure distress (see Figure 3). According to the guidelines, patients should be referred for assessment if they have clinical evidence of moderate to severe distress or a score of 4 or more a 0–10 scale on the distress thermometer screening tool.

NCI (2006b) supports survivorship research, including examining the psychosocial effects of cancer on the survivor. Studies have revealed that periods of highest distress for women with breast cancer are associated with transition points in treatment: at the time of diagnosis, beginning and end of treatment, follow-up visits, and disease recurrence. Although completion of treatment may be met with feelings of joy and relief, often it is a time of increased anxiety and emotional distress. Feelings of abandon-

Figure 3. Distress Management Screening Tools

To view the most recent and complete version of the guideline, go online to www.nccn.org and see page DIS-A, the distress thermometer.
ment by the medical establishment, fear of recurrence, intrusive thoughts about illness, feelings of vulnerability, and fear of death may create persistent anxiety (IOM, 2004). Although breast cancer has been used as a model to examine psychosocial issues related to the cancer experience, similar feelings can be expected in men and women with a variety of cancer diagnoses (IOM, 2004).

Cancer Survivorship Care Plans

An earlier IOM (2005) report, From Cancer Patient to Cancer Survivor: Lost in Transition, was a call to action to provide comprehensive, coordinated follow-up care to cancer survivors. The key recommendation was the creation of a Cancer Survivorship Care Plan, a post-treatment tool that would serve as a road map for long-term follow-up care and provide a concise, detailed summary of the patient’s diagnosis and treatment history. The patient and primary care providers would receive the plan from the oncologist(s) coordinating the patient’s care as guidance in the transition from acute oncology care to general health care. Elements of the plan include schedules of the type and frequency of follow-up examinations, recommendations for prevention practices, and information about available psychosocial services, employment counseling, and access to health insurance (IOM, 2005). A variety of modifiable cancer treatment summary templates that can be filled out online or in writing are available on the American Society of Clinical Oncology (2008) Web site (www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries). In addition, the American Cancer Society has valuable content that can be used for creating a care plan (www.cancer.org/docroot/MH/MH_0.asp?sitearea=).

Case Study

L.M. is a 52-year-old widow who was diagnosed 18 months ago with stage IIA cancer of the left breast. Surgery included lumpectomy and sentinel lymph node biopsy that was found positive for cancer cells and was extended to a low-level axillary lymph node dissection. Pathologic evaluation of the surgical specimen revealed invasive ductal carcinoma (1.2 cm) with clear margins, two positive axillary lymph nodes, and lack of receptors for estrogen and progesterone (estrogen receptor negative and progesterone receptor negative). The HER2 tumor status was 3+ based on fluorescence in situ hybridization (FISH) testing (HER2+). At present, L.M. has completed dose-dense chemotherapy with doxorubicin, cyclophosphamide and paclitaxel, followed by 28 fractions of radiation therapy. She now is completing one year of HER2-targeted therapy with trastuzumab. L.M. has come to the chemotherapy center for her last trastuzumab infusion and begins to cry. She tells the nurse that she is fearful of going it alone now that all her treatments are finished.

Nursing Intervention

Oncology nurses are the ideal health professionals to provide emotional support to patients (see Figure 4). The oncology nurse takes L.M. to a quiet spot in the treatment center where they can sit and talk uninterrupted for at least 15 minutes. The nurse holds L.M.‘s hand and asks what is bothering her. L.M. says she is “afraid that my cancer will come back once treatment stops. I can’t sleep at night because all these thoughts are running around in my head. I feel hopeless.” The nurse reassures L.M. that, based on the latest research, she has received the most effective treatment for her type of breast cancer and that her team will not be deserting her; the oncology nurse practitioner will quickly get back to her if she calls, and her oncologist will be seeing her for follow-up visits on a regular basis. In addition, L.M. will receive a comprehensive breast cancer survivorship care plan in the following week, as will her primary care physician and cardiologist. The plan includes detailed information that she might not remember in the future—results of the pathology reports and imaging tests, dates and dosages of her treatments, description of side effects and their management, physician contact information, and a recommended schedule for future follow-up visits and examinations.

To elicit more information about her emotional state, the nurse asks L.M., “Tell me more about what you’re feeling right now.” “What types of things bring you pleasure?” “Do you see friends after work?” From her negative responses the nurse determines that professional psychological assessment is indicated for L.M. With her consent, the oncology nurse calls the psychiatric social worker to set up an appointment for L.M. The nurse then goes to the patient education files and returns to L.M. with lists of phone numbers and Web site addresses for local and national psychosocial and financial aid support resources and hotlines. The nurse asks L.M. for her home and work phone numbers to contact her later in the week to check on the status of her appointments and their outcomes. As L.M. is getting ready to leave, the nurse asks, “Is there is anything else on your mind that you’d like to talk about, anything at all?” and is gratified by L.M.’s response, “Oh no, I feel so much better already, now that I’ve been able to talk to someone who understands.”

Figure 4. The Role of the Nurse in Providing Emotional Support

Note. Based on information from Buckman & Gilewski, 2008; Duhamel & Dupuis, 2004; McCorkle, 2008.

Conclusion

By providing a supportive, unhurried atmosphere and creating a bond of trust, oncology nurses are the ideal healthcare professionals to assess patients and families for signs of distress, create opportunities for sharing psychosocial concerns, and provide emotional support and...
referrals to appropriate mental health and financial aid specialists. Oncology nurses should be particularly sensitive to psychosocial needs of patients during the critical junctures along the cancer continuum and help them during these transitions with anticipatory counseling. Oncology nurses should become aware of free and low-cost behavioral and psychosocial health resources available in their communities and nationally and develop lists of these services to provide to patients and families and should follow up with patients to assess use of and effectiveness of these services.

Author Contact: Marcelle Kaplan, RN, MS, AOCN®, can be reached at mkaplan@nyp.org, with copy to editor at CJONEditor@ons.org.

References


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