

# Concerns Across the Survivorship Trajectory: Results From a Survey of Cancer Survivors

Sheryl Ness, RN, MA, OCN®, Janine Kokal, RN, MS, OCN®, Kelliann Fee-Schroeder, RN, BSN, OCN®, Paul Novotny, MS, Daniel Satele, BS, and Debra Barton, RN, PhD, AOCN®, FAAN

The National Cancer Institute (NCI, 2011) estimated that more than 12 million cancer survivors live in the United States. The number of cancer survivors is growing because of advances in early detection, diagnosis, treatment, and care. The five-year relative survival rate for adults with cancer is greater than 67%, an increase from 49% in 1975–1977 (American Cancer Society, 2012). In addition, the number of people diagnosed with cancer is expected to almost double by the year 2050 because of an aging population (Edwards et al., 2002).

The National Coalition for Cancer Survivorship (NCCS, 1996) was the first organization to introduce the term *cancer survivor* and define it as an individual from the time of cancer diagnosis through the balance of his or her life. The NCI's (2004) Office of Cancer Survivorship added that family members, friends, and caregivers are included in this definition as secondary survivors. Cancer survivorship is a dynamic process of living with, through, and beyond a diagnosis of cancer, regardless of the outcome (Centers for Disease Control and Prevention, 2004).

Current literature documents that cancer survivors deal with a myriad of acute, chronic, and late effects of cancer and treatment. They face a host of physical, psychological, emotional, social, spiritual, and economic effects. Therefore, research is needed to better understand the complex needs of survivors.

As many as 75% of cancer survivors have health deficits related to their treatment (Haylock, 2006). Baker, Denniston, Smith, and West (2005) investigated concerns of 752 survivors one year after diagnosis and reported that 57%–68% expressed fears related to disease recurrence and concerns about their future. Sixty-seven percent of the survivors surveyed were dealing with physical effects such as fatigue, loss of strength, sleep difficulties, and sexual dysfunction. Studies have shown that patients with cancer have an elevated risk for psychosocial distress and other problems based on disease factors, gender, age, marital status, ethnicity, and household income (Baker et al., 2005; Vachon, 2006). Harrington, Hansen, Moskowitz, Todd, and

**Purpose/Objectives:** To evaluate the most prevalent physical, social, emotional, and spiritual concerns of cancer survivors.

**Design:** Descriptive, cross-sectional study.

**Setting:** A matrix (multisite) cancer center in three urban centers in the United States.

**Sample:** 337 cancer survivors representing nine diagnostic groups in a broad spectrum of time since diagnosis.

**Methods:** Participants completed a survey designed to evaluate the self-reported concerns of cancer survivors. Demographic information and questions using Likert scales were used to measure concerns and quality of life. Descriptive statistics and regression analyses were used to evaluate data.

**Main Research Variables:** Cancer diagnosis; time since diagnosis; and physical, social, emotional, and spiritual concerns.

**Findings:** Overall, quality of life was reported as a mean of 8.44 on a scale of 0–10. The top five concerns identified were fear of recurrence, fatigue, living with uncertainty, managing stress, and sleep disturbance. Prevalence and severity of concerns differed by cancer diagnosis and time since diagnosis. Patients reporting extreme concerns related to fatigue were associated with lower quality-of-life scores.

**Conclusions:** The research indicated that fatigue and fear of recurrence are lasting concerns across the survivorship trajectory and that age, cancer diagnosis, and time since diagnosis will have an effect on the survivor's experience.

**Implications for Nursing:** Nurses should take a proactive role in assessing the physical, social, emotional, and spiritual needs of all cancer survivors, regardless of cancer type and time since diagnosis. Future research and support programs for cancer survivors should focus on the major concerns of fatigue and fear of recurrence.

**Knowledge Translation:** The results of this research confirmed the importance of designing programs to support cancer survivors in an integrative manner from initial diagnosis into the period of long-term survivorship. Specific attention should be placed on the concerns related to fear of recurrence, fatigue, financial burden, and the long-term effects of cancer treatment.

Feuerstein (2010) conducted a review of the evidence of symptom burden following primary cancer treatment and found that cancer survivors can experience symptoms for more than 10 years following treatment.