

# 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

**T**he 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.

### Physical Domain

Pain; fatigue; sleep disturbance; memory and concentration; nausea and vomiting; poor appetite; trouble swallowing; dental or mouth problems; weight changes; balance, walking, and mobility; loss of strength; peripheral neuropathy; lymphedema; osteoporosis and bone health; hair and skin care issues; body changes; bowel or bladder changes; hot flashes; sexual issues; and fertility issues

### Social Domain

Managing household activities, caring for family members, talking about cancer with family and friends, returning to work, health insurance, financial concerns, and debt from medical bills

### Spiritual Domain

Religious or spiritual support, religious or spiritual distress, loss of faith, and end-of-life concerns

### Emotional Domain

Defining a new sense of normal; managing difficult emotions such as anger, fear, sadness, depression, guilt, and anxiety; coping with grief and loss; living with uncertainty; fear of recurrence; managing stress; isolation and feeling alone; intimacy issues; looking for the bright side with gratitude, forgiveness, love, happiness, and contentment; having a sense of well-being; changing relationships with spouse, family, and others; finding support resources; connecting to counseling services; and genetic counseling (fear about your children getting cancer)

### Other

Staying connected with the medical system, knowing who to call for medical problems, keeping your primary care physician informed of your cancer treatment and risk of recurrence, use of complementary and alternative therapies, and concern about long-term effects of treatment

**Figure 1. Survivorship Concerns Survey Content**

The Institute of Medicine ([IOM], 2006) has recommended that cancer centers place a priority on conducting research to understand and address the continuum of needs of cancer survivors. The recommendations, along with the results from previous cancer survivorship studies, provided the impetus to assess the needs and concerns of cancer survivors at Mayo Clinic Cancer Center sites in Rochester, MN, Jacksonville, FL, and Phoenix, AZ. A cross-sectional survey was developed to evaluate the most prevalent physical, social, emotional, and spiritual concerns of cancer survivors.

## Methods

### Participants and Settings

For the current study, cancer survivor was defined using the NCCS (1996) and the NCI (2004) definitions. Participants were aged 18 years and older and able to read and write English. The survey was distributed at the three Mayo Clinic campuses. All cancer survivors, regardless of diagnosis or time since diagnosis, were included. This project was reviewed and approved as a minimal risk study by the Mayo Clinic Cancer Center's institutional review board. Participation in the survey was voluntary and completion indicated consent to participate in the study.

### Instruments

A survey tool was developed by the investigators with support from the Mayo Survey Research Center (consultation and feedback on instrument development, pilot sampling, and data analysis). Additional review of the survey tool was provided by medical, educational,

and behavioral researchers. Survey questions were chosen based on current literature recommendations (Baker et al., 2005; IOM, 2006; Vachon, 2006). The researchers sought to build on and add strength to current research

**Table 1. Sample Characteristics (N = 337)**

| Characteristic                                 | $\bar{X}$ | SD    |
|--|-----------|-------|
| Age (years)                                    | 62.2      | 12.82 |
| Characteristic                                 | n         | %     |
| <b>Gender (N = 334)</b>                        |           |       |
| Female   | 251       | 75    |
| <b>Ethnicity (N = 335)</b>                     |           |       |
| Caucasian                                      | 321       | 96    |
| African American                               | 6         | 2     |
| Other  | 8         | 2     |
| <b>Currently receiving treatment (N = 302)</b> | 126       | 42    |
| <b>Prior treatment modality</b>                |           |       |
| Surgery  | 252       | 75    |
| Chemotherapy                                   | 197       | 59    |
| Radiation                                      | 164       | 49    |
| Hormonal therapy                               | 40        | 12    |
| <b>Cancer type (N = 334)</b>                   |           |       |
| Breast   | 146       | 44    |
| Hematologic                                    | 40        | 12    |
| Gastrointestinal                               | 32        | 10    |
| Prostate                                       | 30        | 9     |
| Gynecologic                                    | 30        | 9     |
| Other cancer type                              | 22        | 7     |
| Melanoma or skin                               | 15        | 5     |
| Urinary  | 10        | 3     |
| Lung   | 9         | 3     |
| <b>Years since diagnosis (N = 332)</b>         |           |       |
| 1  | 86        | 26    |
| 2–5  | 105       | 32    |
| 6–20   | 112       | 34    |
| More than 20                                   | 29        | 9     |

Note. Because of rounding, not all percentages total 100.

on short- and long-term cancer survivorship. A total of 50 survey questions covered five domains: physical, emotional, social, spiritual, and other (i.e., medical system interaction, complementary therapy use, and long-term effects). Within each of these five domains, participants rated specific items using a six-point Likert rating scale from 0 (no level of concern) to 5 (extreme level of concern). In addition, one question included in the survey tool was designed and studied to measure overall quality of life (QOL) using an 11-point Likert scale from 0 (as bad as it can be) to 10 (as good as it can be). Single-item linear analog scales, including Likert scales, have been validated as general measures of global QOL dimensional constructs in numerous settings (Grunberg, Groshen, Steingass, & Zaretsky, 1996; Gudex, Dolan, Kind, & Williams, 1996; Hyland & Sodergren, 1996; Locke et al., 2007; Sriwatanakul et al., 1983; Wewers & Lowe, 1990). Completion of the survey took about 15 minutes. Figure 1 lists the specific content areas of the survey.

## Study Procedures

Survey distribution and collection was completed from June to December 2008. To facilitate survey collection, participants were invited to take part in the survey during American Cancer Society– or Mayo Clinic Cancer Center–sponsored survivor day events and local support group activities. In addition, participants were recruited at all three Mayo Clinic Cancer Center campuses in a variety of treatment and support service locations. Individuals were invited to participate by cancer center nurses or American Cancer Society patient navigators.

## Data Analysis

Descriptive statistics were compiled to identify the mean level of concern as well as prevalence of concerns. Mean severity concern

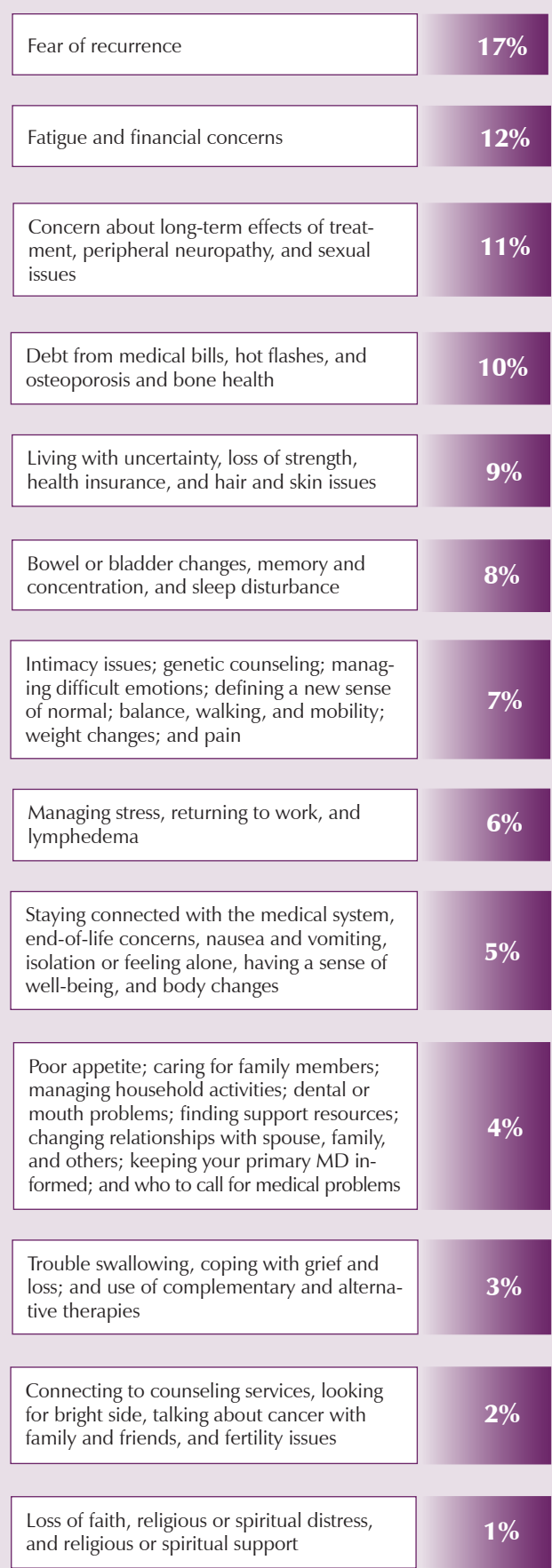
**Table 2. Mean Severity Scores and Prevalence of Concerns (N = 337)**

| Domain and Concern                           | Severity <sup>a</sup> |      | Severity <sup>b</sup> |     | Concern <sup>c</sup> |
|--|-----------------------|------|-----------------------|-----|----------------------|
|  | $\bar{X}$             | SD   | $\bar{X}$             | SD  | %                    |
| <b>Physical</b>                              |                       |      |                       |     |                      |
| Fatigue                                      | 1.5                   | 1.51 | 2.5                   | 1.2 | 60                   |
| Sleep disturbance                            | 1.3                   | 1.5  | 2.4                   | 1.2 | 50                   |
| Memory and concentration                     | 1.2                   | 1.43 | 2.2                   | 1.2 | 53                   |
| Loss of strength                             | 1.2                   | 1.42 | 2.3                   | 1.2 | 51                   |
| Sexual issues                                | 1.1                   | 1.61 | 2.8                   | 1.4 | 35                   |
| Peripheral neuropathy                        | 1.1                   | 1.57 | 2.6                   | 1.3 | 42                   |
| Osteoporosis and bone health                 | 1.1                   | 1.52 | 2.5                   | 1.3 | 41                   |
| Hot flashes                                  | 1.1                   | 1.52 | 2.5                   | 1.3 | 40                   |
| Bowel or bladder changes                     | 1.1                   | 1.46 | 2.3                   | 1.3 | 45                   |
| Hair and skin issues                         | 1                     | 1.52 | 2.6                   | 1.3 | 37                   |
| Pain   | 1                     | 1.37 | 2.2                   | 1.3 | 42                   |
| Body changes                                 | 1                     | 1.35 | 2.2                   | 1.2 | 42                   |
| Weight changes                               | 0.9                   | 1.37 | 2.3                   | 1.3 | 36                   |
| Balance, walking, and mobility               | 0.9                   | 1.37 | 2.3                   | 1.3 | 39                   |
| Lymphedema                                   | 0.8                   | 1.31 | 2.3                   | 1.3 | 34                   |
| Dental or mouth problems                     | 0.6                   | 1.19 | 2.4                   | 1.3 | 24                   |
| Poor appetite                                | 0.5                   | 1.15 | 2.4                   | 1.3 | 21                   |
| Nausea and vomiting                          | 0.4                   | 1.06 | 2.5                   | 1.5 | 15                   |
| Trouble swallowing                           | 0.3                   | 0.92 | 2                     | 1.4 | 15                   |
| Fertility issues                             | 0.2                   | 0.73 | 2.6                   | 1.6 | 6                    |
| <b>Social</b>                                |                       |      |                       |     |                      |
| Financial concerns                           | 1                     | 1.58 | 2.7                   | 1.4 | 36                   |
| Debt from medical bills                      | 0.9                   | 1.51 | 2.8                   | 1.4 | 30                   |
| Health insurance                             | 0.8                   | 1.47 | 2.7                   | 1.4 | 29                   |
| Managing household activities                | 0.8                   | 1.23 | 2.2                   | 1.1 | 32                   |
| Caring for family members                    | 0.6                   | 1.16 | 2.2                   | 1.2 | 25                   |
| Returning to work                            | 0.5                   | 1.25 | 2.8                   | 1.4 | 18                   |
| Talking about cancer with family and friends | 0.5                   | 0.96 | 2                     | 1   | 22                   |
| <b>Emotional</b>                             |                       |      |                       |     |                      |
| Fear of recurrence                           | 1.8                   | 1.67 | 2.7                   | 1.3 | 63                   |
| Living with uncertainty                      | 1.3                   | 1.45 | 2.3                   | 1.2 | 55                   |
| Defining a new sense of normal               | 1.2                   | 1.4  | 2.4                   | 1.1 | 47                   |
| Managing stress                              | 1.2                   | 1.34 | 2.1                   | 1.1 | 55                   |
| Managing difficult emotions                  | 1.1                   | 1.36 | 2.2                   | 1.1 | 47                   |
| Genetic counseling                           | 1                     | 1.42 | 2.5                   | 1.2 | 36                   |
| Having a sense of well-being                 | 0.9                   | 1.29 | 2.2                   | 1.1 | 39                   |
| Intimacy issues                              | 0.8                   | 1.38 | 2.5                   | 1.4 | 29                   |
| Isolation and feeling alone                  | 0.8                   | 1.25 | 2.1                   | 1.2 | 35                   |
| Coping with grief and loss                   | 0.8                   | 1.17 | 1.9                   | 1.1 | 39                   |
| Relationships with spouse, family, others    | 0.7                   | 1.19 | 2.1                   | 1.2 | 29                   |
| Looking for the bright side                  | 0.7                   | 1.14 | 2                     | 1   | 34                   |
| Finding support resources                    | 0.5                   | 1.07 | 2.1                   | 1.2 | 22                   |
| Connecting to counseling services            | 0.4                   | 0.96 | 2.1                   | 1.1 | 18                   |
| <b>Spiritual</b>                             |                       |      |                       |     |                      |
| End-of-life concerns                         | 0.6                   | 1.19 | 2.2                   | 1.3 | 26                   |
| Religious and spiritual support              | 0.4                   | 0.9  | 2                     | 1   | 17                   |
| Religious and spiritual distress             | 0.3                   | 0.81 | 1.9                   | 1   | 16                   |
| Loss of faith                                | 0.2                   | 0.67 | 1.8                   | 1   | 12                   |
| <b>Other</b>                                 |                       |      |                       |     |                      |
| Concern about long-term effects              | 1.2                   | 1.58 | 2.6                   | 1.3 | 46                   |
| Staying connected with medical system        | 0.6                   | 1.17 | 2.1                   | 1.3 | 26                   |
| Who to call for medical problems             | 0.5                   | 1.14 | 2.1                   | 1.3 | 24                   |
| Keeping your primary physician informed      | 0.5                   | 1.11 | 2.1                   | 1.2 | 24                   |
| Complementary and alternative therapies      | 0.5                   | 1.1  | 2.2                   | 1.2 | 22                   |

<sup>a</sup> Range = 0–5

<sup>b</sup> Excludes participants who selected 0 responses (range = 1–5)

<sup>c</sup> Prevalence reporting any level of concern (range = 1–5)



**Figure 2. Extreme Concerns for Cancer Survivors**

scores were calculated using the entire sample, as well as a subset of the sample excluding those who rated their level of concern on a given domain item as 0 (no concern). In addition, the data were organized in three broad categories: the sample as a whole, by cancer diagnosis, and by time since diagnosis. The individual severity scores of all 50 concern items were categorized into low (0–1), moderate (2–3), or extreme (4–5) groups. In evaluating severity of concerns, comparisons between cancer diagnostic groups and time since diagnosis were evaluated by chi square or Kruskal-Wallis tests. All tests were two-sided with type 1 error rates of 0.05. Multivariate logistic regression models were performed to evaluate the relationship between independent participant characteristics and severity of concerns. Stepwise forward and backward selections were used to identify significant variables to predict any extreme concerns. The independent variables used in the modeling process were gender, age, ethnicity, cancer type, treatment modality, current treatment status, and time since diagnosis. The dependent variable was extreme concern, defined as a rating of 4 or 5. Multivariate linear models were created to evaluate the relationship between overall QOL scores and having an extreme concern.

**Results**

**Demographics and Characteristics**

The survey was completed in a nonrandomized fashion by 337 participants. The median age was 63 years. The sample was predominantly Caucasian and female. Participants with a diagnosis of breast cancer represented 44% of the survey respondents; no other individual cancer diagnosis represented greater than 12% of the overall sample (see Table 1). The sample was consistent with the general cancer survivor population in the United States, where 54% of survivors are female and breast cancer survivors are the single largest survivor group (NCI, 2011).

**Concerns Identified by the Sample as a Whole**

For the sample as a whole, severity of concern scores within each domain are listed in Table 2 in descending order. Fear of recurrence was the most prevalent concern reported across all domains, with a mean of 1.8 for the sample as a whole and 2.7 when including only those reporting the concern with a score of 1–5. That indicated that the concern is most prevalent and one of the most severe concerns reported from the group.

Within the physical domain, the highest mean scores overall (rating 0–5) were fatigue, sleep disturbance, memory and concentration, and loss of strength. However, when excluding those who rated a score of 0, and only reporting on items rated 1–5 as a concern, the most prevalent items were sexual issues, peripheral



**Table 3. Most Prevalent Extreme Concerns: Breast (N = 145)**

| Concern                                      | n  | %    |
|--|----|------|
| <b>0–1 year since diagnosis (n = 40)</b>     |    |      |
| Hair and skin issues                         | 10 | 25   |
| Hot flashes                                  | 7  | 18   |
| Fear of recurrence                           | 7  | 18   |
| Fatigue                                      | 6  | 15   |
| Defining a new sense of normal               | 6  | 15   |
| Sleep disturbance                            | 5  | 13   |
| Peripheral neuropathy                        | 5  | 13   |
| Religious and spiritual distress             | 5  | 13   |
| Concern about long-term effects of treatment | 5  | 13   |
| <b>2–5 years since diagnosis (n = 47)</b>    |    |      |
| Hot flashes                                  | 11 | 23   |
| Peripheral neuropathy                        | 10 | 21   |
| Fear of recurrence                           | 10 | 21   |
| Financial concerns                           | 8  | 17   |
| Debt from medical bills                      | 8  | 17   |
| Concern about long-term effects of treatment | 8  | 17   |
| Health insurance                             | 7  | 15   |
| Genetic counseling                           | 7  | 15   |
| Living with uncertainty                      | 6  | 13   |
| Weight changes                               | 5  | 11   |
| Hair and skin issues                         | 5  | 11   |
| Sexual issues                                | 5  | 11   |
| <b>6–20 years since diagnosis (n = 58)</b>   |    |      |
| All concerns                                 | –  | < 10 |

neuropathy (numbness and tingling), hair and skin care, and fertility.

In the social domain, the most prevalent concern (highest mean score) was financial issues. Participants who reported concerns in this area rated debt, returning to work, financial concerns, and health insurance the highest. Along with fear of recurrence (n = 212), other concerns within the emotional domain with the highest means overall are living with uncertainty (n = 185), defining a new sense of normal (n = 157), and managing stress (n = 186), with more than 50% of participants reporting concerns in all but one of these areas.

Spiritual concerns were not prevalent and did not score high in the sample overall. However, for those who did rate some level of concern (rating 1–5), end-of-life concerns were reported by 87 participants (26%), with a mean concern of 2.2. In the other domain, only concerns about long-term effects of treatment were prevalent, with an overall mean of 1.2; however, for the 154 respondents (46%) who rated this as a concern, the mean was 2.6.

### Extreme Concerns by Cancer Diagnosis

Figure 2 shows the percentage of reported extreme concern items (rated as 4–5). When extreme concerns were separated by diagnosis and time since diagnosis, different patterns emerged. The large number of respon-

dents with breast cancer allowed their data to be divided into three time frames based on time since diagnosis: 0–1 year, 2–5 years, and 6–20 years. Participants with hematologic cancers also used those same time frames. For other cancer types, time since diagnosis was split into two time frames: 0–5 years and 6–20 years.

Within the first year after a breast cancer diagnosis, 10 respondents (25%) reported extreme concerns regarding hair and skin care (see Table 3). Hot flashes and fear of recurrence were the next most prevalent extreme concerns. For those 2–5 years after breast cancer diagnosis, 11 (23%) reported extreme concerns about hot flashes and 10 (21%) about peripheral neuropathy and fear of recurrence.

Five prostate cancer survivors (42%) reported extreme concerns regarding sexual issues within the first five years of diagnosis (see Table 4). Sexual concerns continued to be reported by 4 (29%) in the 6–20 years postdiagnosis. For those with gastrointestinal cancer and within the first five years from diagnosis, the most prevalent extreme concern was fear of recurrence at 44% (n = 8) (see Table 5).

In the group with hematologic cancers within the first year of diagnosis, fatigue, fear of recurrence, return to work, and financial concerns were the most prevalent reported areas of extreme concerns (n = 3, 30%) (see Table 6). In the period 2–5 years after diagnosis, concern about the long-term effects of treatment was the most prevalent extreme concern (n = 3, 21%). Five of the longer-term survivors (6–20 years) (35%) reported extreme concerns related to fear of recurrence, and 21% (n = 3) reported sleep disturbance.

Forty percent of respondents with gynecologic cancer (n = 6) within the first five years reported extreme concerns related to fear of recurrence and managing stress,

**Table 4. Most Prevalent Extreme Concerns: Prostate (N = 26)**

| Concern                                    | n | %  |
|--|---|----|
| <b>0–5 years since diagnosis (n = 12)</b>  |   |    |
| Sexual issues                              | 5 | 42 |
| Balance, walking, and mobility             | 3 | 25 |
| Pain                                       | 2 | 17 |
| Fatigue                                    | 2 | 17 |
| Sleep disturbance                          | 2 | 17 |
| Weight changes                             | 2 | 17 |
| Peripheral neuropathy                      | 2 | 17 |
| Hair and skin issues                       | 2 | 17 |
| Bowel or bladder changes                   | 2 | 17 |
| Hot flashes                                | 2 | 17 |
| Managing household activities              | 2 | 17 |
| Returning to work                          | 2 | 17 |
| <b>6–20 years since diagnosis (n = 14)</b> |   |    |
| Sexual issues                              | 4 | 29 |
| Hot flashes                                | 2 | 14 |

and 33% (n = 5) reported fatigue and debt from medical bills as an extreme concern (see Table 7). Twenty percent of survivors (n = 3) 6–20 years postdiagnosis reported extreme concerns related to health insurance.

## Predictors

Predictors of at least one extreme concern overall and in each domain are listed in Table 8. Participants reporting at least one extreme concern overall were more likely to be young, currently receiving treatment, within 2–5 years of diagnosis, and had a diagnosis of breast cancer. Of note, no significant predictors of physical concerns were noted in this sample.

## Relationship to Quality of Life

Reported concerns were compared with overall QOL scores using Kruskal-Wallis tests and multivariate linear models. Patients expressing any concerns tended to have lower levels of overall QOL ( $\bar{X}$  = 8.4 versus 9.5,  $p$  = 0.0008). If patients reported extreme concerns, overall QOL was even lower ( $\bar{X}$  = 7.7) (Sloan et al., 2003). These can be considered clinically significant differences in overall QOL. Linear regression modeling showed that extreme fatigue concerns had the largest impact on overall QOL. Patients with extreme fatigue concerns reported QOL scores that were almost two points lower on a 10-point scale. Addressing patient concerns, particularly the extreme concerns, could improve the patient's overall QOL.

**Table 5. Most Prevalent Extreme Concerns: Gastrointestinal (N = 32)**

| Concern                                      | n | %  |
|--|---|----|
| <b>0–5 years since diagnosis (n = 18)</b>    |   |    |
| Fear of recurrence                           | 8 | 44 |
| Pain   | 4 | 22 |
| Fatigue                                      | 4 | 22 |
| Sexual issues                                | 4 | 22 |
| Financial concerns                           | 4 | 22 |
| Debt from medical bills                      | 4 | 22 |
| Loss of strength                             | 3 | 17 |
| Peripheral neuropathy                        | 3 | 17 |
| Health insurance                             | 3 | 17 |
| Living with uncertainty                      | 3 | 17 |
| Concern about long-term effects of treatment | 3 | 17 |
| Balance, walking, and mobility               | 2 | 11 |
| Isolation and feeling alone                  | 2 | 11 |
| <b>6–20 years since diagnosis (n = 14)</b>   |   |    |
| Sleep disturbance                            | 3 | 21 |
| Balance, walking, and mobility               | 2 | 14 |
| Loss of strength                             | 2 | 14 |
| Peripheral neuropathy                        | 2 | 14 |
| Health insurance                             | 2 | 14 |
| Fear of recurrence                           | 2 | 14 |
| Isolation and feeling alone                  | 2 | 14 |

**Table 6. Most Prevalent Extreme Concerns: Hematologic (N = 38)**

| Concern  | n | %  |
|--|---|----|
| <b>0–1 year since diagnosis (n = 10)</b>           |   |    |
| Fatigue  | 3 | 30 |
| Returning to work                                  | 3 | 30 |
| Financial concerns                                 | 3 | 30 |
| Fear of recurrence                                 | 3 | 30 |
| Sexual issues (n = 9)                              | 2 | 22 |
| Sleep disturbance                                  | 2 | 20 |
| <b>2–5 years since diagnosis (n = 14)</b>          |   |    |
| Concern about long-term effects of treatment       | 3 | 21 |
| Hair and skin issues (n = 12)                      | 2 | 17 |
| Loss of strength (n = 13)                          | 2 | 15 |
| Financial concerns (n = 13)                        | 2 | 15 |
| Fear of recurrence (n = 13)                        | 2 | 15 |
| Poor appetite                                      | 2 | 14 |
| <b>6–20 or more years since diagnosis (n = 14)</b> |   |    |
| Fear of recurrence                                 | 5 | 35 |
| Sleep disturbance                                  | 3 | 21 |
| Bowel and bladder changes (n = 13)                 | 2 | 15 |
| Health insurance                                   | 2 | 14 |
| Defining a new sense of normal                     | 2 | 14 |
| Managing difficult emotions                        | 2 | 14 |
| Intimacy issues                                    | 2 | 14 |
| Concern about long-term effects of treatment       | 2 | 14 |

## Discussion

Based on mean severity scores of the sample as a whole, concerns generally were rated as low to moderate. However, when evaluating extreme concerns by specific diagnostic group and/or time since diagnosis, respondents did identify a number of areas that may represent priorities that should be addressed for cancer survivors.

The diagnostic group that had the most overall number of extreme concerns was the group with gynecologic cancer. They had more physical, emotional, and social concerns than any other diagnostic group. The prostate cancer group reported the fewest concerns, and long-term survivors (6–20 years) of breast cancer had no prevalent extreme concerns.

Fear of recurrence was a more prevalent extreme concern than any physical concern. Fear of recurrence also was prevalent in all cancer diagnoses except prostate cancer and long-term survivors of breast cancer. More long-term survivors with hematologic cancer reported fear of recurrence as an extreme concern than those within five years of diagnosis. Therefore, survivorship programs should include strategies to manage this issue. Survivorship programs should be designed and tailored to guide and support the patient and family needs on what to expect as they transition from active treatment to long-term survivorship. Ideas might include psychosocial programs, such as cognitive restructuring,

addressing and reframing fears, mind/body techniques, building resilience, and defining a new sense of self.

Not surprisingly, fatigue was reported as an extreme concern in all diagnoses early in the disease trajectory and is a lasting concern on some level across time. Cancer-related fatigue has been studied and is known to be a significant and long-lasting concern for cancer survivors (Baker et al., 2005; IOM, 2006; Kirshbaum, 2010). Cancer survivor programs must continue to address this issue across a survivor's lifetime, incorporating resources and strategies for energy conservation, nutrition, exercise, sleep hygiene, and stress management.

Sexual issues are more salient in prostate cancer survivors, even in respondents far from diagnosis. However, respondents with all types of cancer noted sexual or intimacy concerns at some time from diagnosis. Survivorship programs should be designed to address ongoing sexuality issues regardless of cancer diagnosis, particularly prostate cancer.

Overall, physical and emotional concerns were most prevalent and spiritual issues were the least concerning. That may indicate that survivors are able to find resources on their own to meet spiritual needs, but may need more assistance with physical and emotional issues. The exception to this is with prostate cancer survivors, who did not report extreme concerns in the emotional domain. Almost all of their issues reported were physical, with only two social concerns: returning to work and managing household activities.

Financial concerns were reported across diagnostic groups. Addressing the hidden costs of cancer care, including transportation, lodging, loss of income, treatment costs, copays, and deductibles with support and resources is vital to address the financial burden for survivors. Findings from the regression models support current literature in that increased age is associated with less extreme concerns and receiving treatment is associated with more extreme concerns.

## Limitations and Strengths

The survey was created for the purpose of this study and has not been formally validated. Participants included a self-selected sample of individuals attending public cancer-related events, support groups, or were actively seeking information from cancer center resource locations. That sample may be a reflection of more highly functioning individuals, contributing to better scores. They may not be representative of survivors who are ill, isolated, or not functionally able to access these opportunities. Therefore, the data are not widely generalizable. In addition, survivors with various types of cancer were not equally represented, with breast cancer being the most prevalent group.

This study also had some unique strengths. The survey captured data from survivors who spanned the

**Table 7. Most Prevalent Extreme Concerns: Gynecologic (N = 30)**

| Concern                                      | n | %  |
|--|---|----|
| <b>0–5 years since diagnosis (n = 15)</b>    |   |    |
| Fear of recurrence                           | 6 | 40 |
| Managing stress                              | 6 | 40 |
| Fatigue                                      | 5 | 33 |
| Debt from medical bills                      | 5 | 33 |
| Pain   | 4 | 27 |
| Nausea and vomiting                          | 4 | 27 |
| Osteoporosis and bone health                 | 4 | 27 |
| Body changes                                 | 4 | 27 |
| Bowel or bladder changes                     | 4 | 27 |
| Caring for family members                    | 4 | 27 |
| Returning to work                            | 4 | 27 |
| Financial concerns                           | 4 | 27 |
| Managing difficult emotions                  | 4 | 27 |
| Living with uncertainty                      | 4 | 27 |
| Having a sense of well-being                 | 4 | 27 |
| Health insurance                             | 3 | 20 |
| Defining new sense of normal                 | 3 | 20 |
| Finding support services                     | 3 | 20 |
| End-of-life concerns                         | 3 | 20 |
| Concern about long-term effects of treatment | 3 | 20 |
| Weight changes                               | 2 | 13 |
| Loss of strength                             | 2 | 13 |
| Intimacy issues                              | 2 | 13 |
| <b>6–20 years since diagnosis (n = 15)</b>   |   |    |
| Health insurance                             | 3 | 20 |
| Weight changes                               | 2 | 13 |
| Loss of strength                             | 2 | 13 |
| Defining new sense of normal                 | 2 | 13 |
| Managing difficult emotions                  | 2 | 13 |
| Fear of recurrence                           | 2 | 13 |
| Intimacy issues                              | 2 | 13 |

trajectory from initial cancer diagnosis to more than 20 years postdiagnosis. In addition, although breast cancer survivors represented 44% of the sample, 56% of the respondents had other types of cancers, which provides some insight into the needs and concerns of cancer survivors as a whole.

## Conclusion

The results of this survey will be used to address the ongoing educational, informational, and resource needs of cancer survivors throughout the continuum of care. Programs should address a broad range of needs and not assume that all survivors' needs are the same. According to the IOM (2006), "Healthcare providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care" (p. 150).

Information provided by participants in this survey can support and influence survivorship care. Important areas to address include symptom management and

**Table 8. Multivariate Logistic Regression Models for Reporting Extreme Concerns**

| Dependent Variable                                 | Independent Variable            | OR    | p        |
|--|---------------------------------|-------|----------|
| At least one extreme concern overall               | Age                             | 0.955 | 0.0002   |
|  | Currently receiving treatment   | 3.643 | < 0.0001 |
|  | 2–5 years since diagnosis       | 2.406 | 0.0042   |
|  | Diagnosis of breast cancer      | 0.532 | 0.0432   |
| Presence of at least one extreme physical concern  | No significant predictors       | –     | –        |
| Presence of at least one extreme social concern    | Age                             | 0.944 | 0.0002   |
|  | Currently receiving treatment   | 5.546 | 0.0016   |
|  | Prior surgical treatment        | 3.509 | 0.0223   |
|  | Prior radiation treatment       | 0.3   | 0.0136   |
| Presence of at least one extreme emotional concern | 2–5 years since diagnosis       | 3.368 | 0.0057   |
| Presence of at least one extreme spiritual concern | Currently receiving treatment   | 8.061 | 0.001    |
|  | Diagnosis of gynecologic cancer | 5.61  | 0.0045   |
| Presence of at least one extreme other concern     | 2–5 years since diagnosis       | 2.397 | 0.0171   |
|  | Currently receiving treatment   | 4.41  | < 0.0001 |
| OR—odds ratio                                      |                                 |       |          |

psychological needs using resources to help manage fatigue, stress, emotions, and recurrence fears across diagnoses and the survivorship trajectory. Patients will benefit from cancer centers having formal survivorship programs that help proactively identify and address survivors' ongoing needs. Additional research is needed to study and understand the unique needs of cancer survivors.

## Implications for Nursing

The results of this research indicate that cancer survivors continue to face challenges and symptoms long after treatment is completed. Nurses working with cancer survivors should develop tools and strategies to assess and address individual needs on an ongoing basis. New educational, self-care, and psychosocial interventions should be developed with a focus on health and wellness, sleep habits, and stress and anxiety management strategies specific to the cancer survivor population.

Sheryl Ness, RN, MA, OCN®, is an assistant professor of oncology in the Mayo Clinic College of Medicine and an educator at the Mayo Clinic Cancer Center, both in Rochester, MN; Janine Kokal, RN, MS, OCN®, is an educator, Kelliann Fee-Schroeder, RN, BSN, OCN®, is an oncology research coordinator, Paul Novotny, MS, is a biostatistician, and Daniel Satele, BS, is an analyst in biostatistics, all at the Mayo Clinic Cancer Center; and Debra Barton, RN, PhD, AOCN®, FAAN, is an associate professor of oncology at the Mayo Clinic College of Medicine and an administrator in the Department of Nursing Research at the Mayo Clinic Cancer Center. No financial relationships to disclose. Ness can be reached at [ness.sheryl@mayo.edu](mailto:ness.sheryl@mayo.edu), with copy to editor at [ONFEditor@ons.org](mailto:ONFEditor@ons.org). (Submitted January 2012. Accepted for publication March 15, 2012.)

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