

Challenges and Opportunities in Cancer Survivorship Research

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Presenting the keynote address for the Seventh National Conference on Cancer Nursing Research was a distinct honor and pleasure. My focus was on the challenges and opportunities facing us in cancer survivorship research. We have witnessed major changes in cancer survival during the past three decades, with an increase in survival of all cancers combined. At the same time, we are at a unique juncture in our current scientific knowledge of late effects among childhood, adolescent, and adult cancer survivors. Accumulating evidence documents the existence of late physical and psychosocial morbidity from cancer and its treatment that challenges some of our prevailing notions, approaches, and paradigms. In addition, our lack of knowledge in other arenas presents tremendous opportunities for new and exciting research directions. This article focuses on four specific questions for which we have some answers.

1. Who are cancer survivors?
2. What is cancer survivorship research?
3. What do we know about cancer survivors?
4. How do we meet the challenges in cancer survivorship research?

It also will focus on some yet-to-be-answered questions.

Who Are Cancer Survivors?

Leigh (2001) suggested that differences exist in the culture of cancer survivorship. The population of cancer survivors and the concept of survivorship mean different things to different people. Answers to the question "Who are cancer survivors?" may differ depending on the perspective of the individuals—whether from the point of view of research, practice, personal experience, or family experience. Despite the differences in semantics, the National Coalition for Cancer Survivorship continues to define a cancer survivor as a person who is diagnosed with cancer (Clark & Stovall, 1996).

In the United States, cancer survivors total about 8.9 million people, representing 3.3% of the population (American Cancer Society, 2003). The population of long-term cancer survivors is increasing, with 60% of adults and 77% of children surviving beyond five years after diagnosis. As seen in Figure 1, 14% of all survivors were diagnosed more than 20 years ago. Of the 24,040 households in the 1992 National Health Interview Survey, 63% of respondents had received a cancer diagnosis more than five years previously and 10% had received a cancer diagnosis more than 25 years previously (Hewitt, Breen, & Devesa, 1999). Changes in the fundamental understanding of genetics, rapid translation of basic science to practice, modification of dose-limiting toxicities, an increase in screening and early detection activities, enhanced rehabilitation and support interventions, and changes in sociocultural factors have contributed to the increase in cancer survivors (Rowland, Aziz, Tesauero, & Feuer, 2001).

We have reason to be optimistic: a decline in the cancer death rate from all cancers combined and from each of the four major cancer sites (Simmonds, 2003). Yet, tempered against the optimism of survival is that the burden of cancer in the United States is expected to climb. Two key trends—aging and diversifying population—are expected to increase the cancer burden. First, cancer rates increase with aging. Currently, about 60% of cancer survivors are 65 or older, and the current median age of male and female cancer survivors at time of diagnosis is 68 and 67, respectively (Rowland et al., 2001). However, the number of people with cancer in the United States is expected to double from 1.3 million to 2.6 million from 2000–2050. Thus, cancer in the elderly also is expected to double (Simmonds). Cancer in the elderly presents a challenge for several reasons. The elderly may have comorbid illnesses, making diagnosis, treatment, and survival greater challenges. In addition, caregivers of the elderly with cancer may be frail, which can increase the demand for additional supportive services.

At the same time, the population is diversifying. By 2050, Latinos and Hispanics are expected to comprise 25% of the U.S. population; African Americans, Asian Americans, and Native Americans are projected to constitute an additional 25% of the population. However, few studies have focused on the many multicultural needs of cancer survivors (Aziz & Rowland, 2002).

Figure 2 examines the different groups of cancer survivors by disease (National Cancer Institute [NCI], 2003). The largest group of survivors has breast, prostate, and colorectal cancers. When the data are broken down by gender, about 71% of the female survivors have histories of breast (40%), gynecologic (20%), or colorectal cancer (11%). Almost two-thirds (63%) of male cancer survivors have a history of prostate (38%), other genitourinary (e.g., testicular, kidney) (12%), or colorectal cancer (13%).

What Is Cancer Survivorship Research?

Cancer survivorship research encompasses the "physical, psychosocial, and economic sequelae of cancer diagnosis and its treatment among both pediatric and adult survivors of cancer" (NCI, 2003). Cancer survivorship research focuses on (a)



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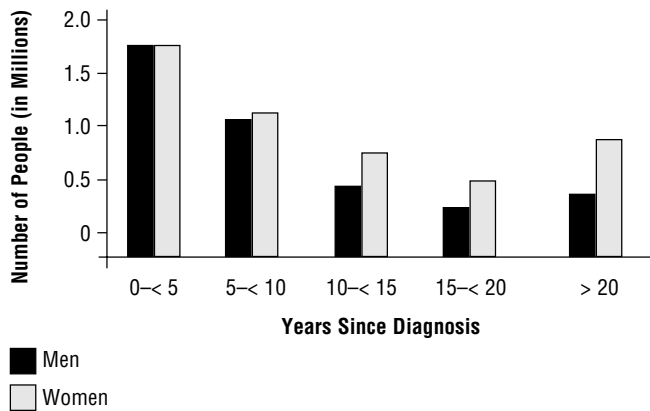


Figure 1. Years Since Diagnosis

Note. Based on information from American Cancer Society, 2003; Rowland et al., 2001; Simmonds, 2003.

health beyond acute diagnosis and treatment, (b) prevention and control of adverse outcomes, late effects, second cancers, and poor quality of life (QOL), and (c) optimizing follow-up, surveillance, and health after treatment. The ultimate goal of cancer survivorship research is to identify adverse effects and develop effective prevention or intervention strategies so that, ultimately, cancer survivors have the best chance for long and healthy lives (Meadows et al., 1998; Vaughn & Meadows, 2002).

The National Cancer Institute

The NCI cancer survivorship research portfolio focuses on studies about the health and lives of people with histories of cancer *beyond* the acute diagnosis and treatment phase. Studies that examine newly diagnosed survivors or those in active treatment are included in the survivorship portfolio if follow-up extended at least two months or longer post-treatment. Studies addressing recurrence or end-of-life research are not included in the current portfolio. Figure 3 shows the distribution of federal cancer survivorship research funding. In fiscal year (FY) 2001, 125 of the 142 research grants focusing on cancer survivorship were funded by or jointly with NCI. The remaining 17 were funded or cofunded through other National Institutes of Health (NIH) centers.

Figure 4 shows the comparison between FY 2000 and FY 2001 with respect to the focus of survivorship by cancer site (NCI, n.d.). About 33% of NIH survivorship research grants had a primary focus on female breast cancer survivors in 2000. This compares with FY 2001, when 63% of the NIH and U.S. Department of Defense survivorship research grants focused on breast cancer survivors. Lung, colorectal, and prostate cancer survivors comprised about 15% of survivorship research. Thus, efforts to describe or address outcomes for survivors of these and other cancers, including gynecologic and hematologic cancers, are needed greatly.

Table 1 shows the distribution of FY 2001 survivorship research grants by focus and funding levels. Of the 58 intervention studies examining the efficacy of a physiologic, psychosocial, or health behavior interventions, more than half (51%, $n = 24$) studied breast cancer survivors. This information continues to point to the dire need for intervention studies targeting survivors of cancers other than breast. Table 2

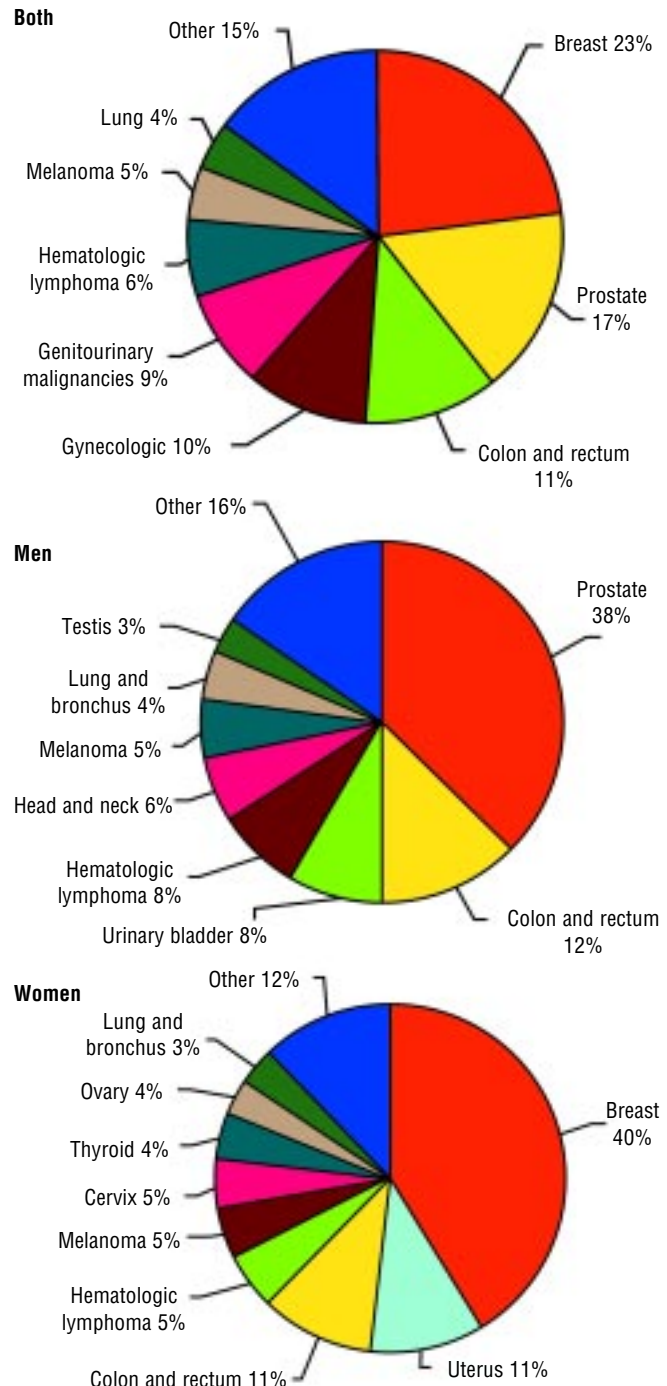


Figure 2. Cancer Survival by Disease

Note. Based on information from National Cancer Institute, 2003.

shows the distribution of FY 2001 survivorship research grants emphasizing family members of cancer survivors. Seven grants focused on parents of children younger than 21.

A very small proportion of NCI-funded research focused on the effects of cancer on the poor, elderly, those with low education, people living in rural areas, or those from ethnically diverse backgrounds. Thus, opportunities exist for research to address issues of survivorship for specific cancers and for underrepresented populations. This becomes

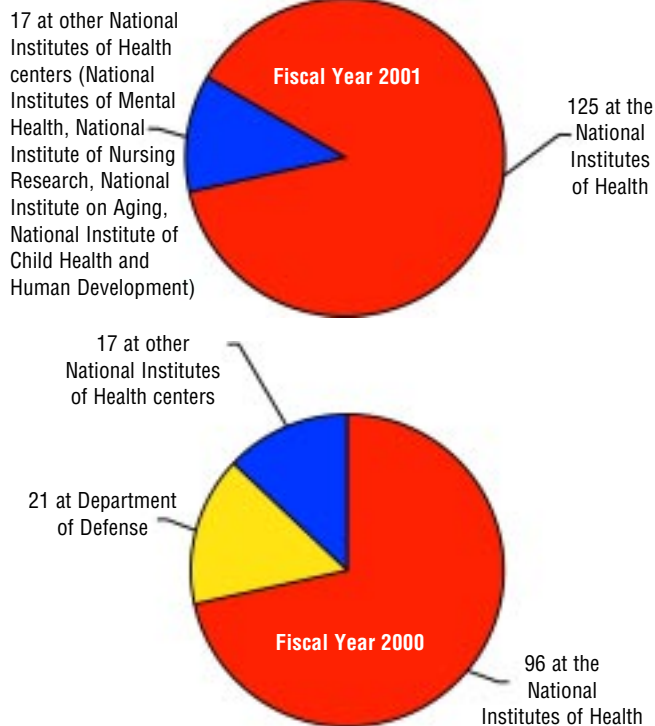


Figure 3. Distribution of Federal Cancer Survivorship Research Funding

particularly important as the proportion of ethnic diversification continues to increase.

Cancer survivorship research was designated by NCI as a new extraordinary opportunity for FY 2004. The goals of cancer survivorship research are to reduce the adverse effects of cancer and its treatment and optimize outcomes for cancer survivors. The major emphasis will be the expansion of research efforts targeting long-term survivors beyond five years (N. Aziz, personal communication, February 2003).

The National Institute of Nursing Research

The National Institute of Nursing Research (NINR) does not target cancer survivorship research specifically. However, its broad scientific goals and areas of research opportunity can encompass survivorship research. The FY 2001 NINR extramural grants program included 77 grants in the immune response and cancer portfolio, and, of this number, 31 were related to cancer (NINR, 2003). Table 3 lists the NINR funds by category, including nine relating to breast cancer, three to prostate cancer, and two to screening for breast, cervical, and prostate cancers. A total of six cancer symptom-management grants were directed at interventions for symptoms including fatigue, pain, oral pain and mucositis, and sleep problems. Four grants examined family and children issues, and one grant was devoted to genetics.

One exciting area of research at NINR is its strategic plan to reduce health disparities among racial and ethnic minorities (Phillips & Grady, 2002), which can be accessed at the NINR Web site (www.nih.gov/ninr). In FY 2001, NINR devoted 22% of its overall research budget to support research in minority health. Thus, the emphasis on health disparities may further present new research options in cancer survivorship outcomes among minorities.

The Oncology Nursing Society

Data from the Oncology Nursing Society (ONS) showed a limited portfolio focusing on cancer survivorship research. Ropka et al. (2002) recently published ONS research priorities based on a stratified sample of 2,000 members. They evaluated 113 diverse topics arranged under eight major categories. The top 10 research priorities are summarized in Figure 5. With the exception of cognitive impairment and QOL, the major research priorities do not focus specifically on cancer survivors. Cancer survivorship, as a topic, did not rank in the top 10 priorities with either ONS members or researcher groups; one research priority item, recurrence, was ranked 20 among the ONS members surveyed.

Table 4 lists selected priority items that are specific to cancer survivors. The second column shows the priority rank by ONS members compared with the third column, which shows the priority rank by researcher group. For example,

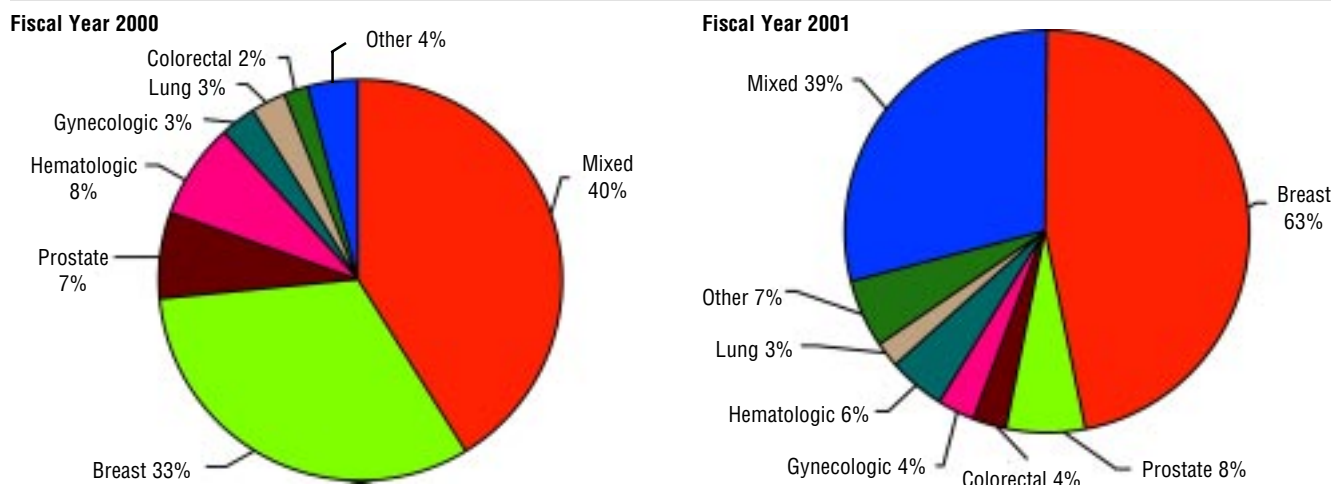


Figure 4. Fiscal Years 2000 and 2001 Comparison

Note. Based on information from National Cancer Institute, n.d.

Table 1. National Institutes of Health Distribution of Survivorship Research Grants in Fiscal Year 2001

Focus of Survivorship	Grants
Physiologic, psychosocial, or health behavior interventions	58
Psychosocial or quality of life	29
Patterns and quality of care	20
Physiologic sequelae	15
Conference grants	9
Surveillance	6
Physiologic and social late effects	5

N = 142
Note. Based on information from National Cancer Institute, 2003.

cancer survivors, as a specific priority topic, ranked 66 of 113 for ONS members (Ropka et al., 2002) and 32 for the group of researchers (G. Mallory, personal communication, February 2003). In the major category of symptom management, items specific to cancer survivors included neurologic impairment, impaired cardiac function, cognitive impairment, weight changes, insomnia, and sleep difficulty. With the exception of neurologic impairment and impaired cardiac function, these cancer survivor-specific items were ranked in the lower half. In another major category, behavioral aspects, items such as QOL, depression, and stress-coping adaptation showed more consistent rankings between groups.

More recently, Given, Berger, et al. (2001) identified additional areas of research focusing on late effects of long-term survivorship and research in psychosocial and behavioral areas, including communications, ethics, and decision making. Research into family caregiving and vulnerable populations was of high interest. The top priority research areas for 2002–2005 are research in cancer symptoms and side effects to include new knowledge regarding successful relief strategies and identification of symptom clusters and their associated outcomes.

Since 1982, the ONS Foundation has awarded more than \$4.7 million dollars in 298 research grants (ONS Foundation, 2003). A review of the 2002 ONS-funded small grants awards (n = 23) showed one project focusing on older cancer survivors. The data did not indicate that cancer survivorship research is *not* a top priority area, but rather that the majority of ONS members are in clinical practice providing direct care for patients across the continuum of cancer.

Table 2. Fiscal Year 2001 National Institutes of Health Survivorship Research Grants Focused on the Family

Topic	Grants
Parents of children younger than 21 years	7 (3 of mothers alone)
Family member self-identified as caregiver	4
Couples	4
Offspring younger than 21 years	3
Family unit	2

N = 20
Note. Based on information from National Cancer Institute, 2003.

Table 3. National Institute of Nursing Research-Funded Grants in Fiscal Year 2001: Immune Response and Cancer Portfolio

Type	n
Breast cancer	9
Prostate cancer	3
Screening for breast, cervical, and prostate cancer	2
Non-Hodgkin's lymphoma	1
Family	2
Children	2
Genetics	1
Symptom management (general)	1
Fatigue, pain, and sleep	3
Oral pain and mucositis	1
Psychoimmune response (breast cancer)	1

N = 26

Cancer survivorship research is a major area of opportunity identified at NCI. The majority of NCI cancer survivorship grants focus on breast cancer, with a limited proportion focusing on other high-incidence cancers such as prostate, colorectal, lung, and gynecologic. A small but very important part of the NCI survivorship portfolio targets family research. NINR does not have a specific thrust in cancer survivorship; however, the broad areas of research priority and emphasis on reducing health disparities fit with cancer survivorship research. The 2000 ONS research priorities show a potential growth in high-priority topics relating to cancer survivorship research.

What Do We Know About Cancer Survivors?

Although children and adults with histories of cancer are living longer, a growing body of evidence demonstrates long-term and late effects such as secondary cancers, cognitive changes, cardiorespiratory dysfunction, infertility, fatigue, menopausal symptoms, and psychosocial late effects (Ferrell & Dow, 1997; Ganz, 2001; Hancock & Hoppe, 1996; Harpham, 1998; Loeschner, Clark, Atwood, Leigh, & Lamb, 1990; Loeschner, Welch-McCaffrey, Leigh, Hoffman, & Meyskens, 1989; Mertens et al., 2001; Moller et al., 2001). Late effects differ from acute side effects and symptoms at the

ONS Members	Research Group
Pain	Evidence-based practice
Quality of life	Pain
Early detection	Quality of life
Prevention and risk reduction	Outcomes of cancer care
Neutropenia and immunosuppression	Caregiver burden
Hospice and end of life	Family caregiving
Oncologic emergencies	Fatigue
Suffering	Access to cancer care
Fatigue	Family communications
Ethical issues	Early detection of cancer
	Cognitive impairment

Figure 5. Comparison of Research Priorities
Note. Based on information from Ropka et al., 2002

Table 4. Oncology Nursing Society (ONS) Research Item Priority Rank in 2000

Item	Priority Number by ONS Members	Priority Number by Researchers
Cancer symptom management		
Neurologic impairment	47	
Impaired cardiac function	49	
Cognitive impairment	70	11
Weight changes	83	
Insomnia and sleep difficulties	94	
Altered mobility	98	
Sexual dysfunction	102	
Hot flashes and sweats	108	
Behavioral aspects		
Quality of life	2	3
Depression	13	15
Stress-coping adaptation	14	
Family communications and relationships	21	9
Body image and sexuality	75	
Cancer care delivery systems		
Family caregiving and communications	36	9
Cancer health services		
Outcomes of cancer care	51	4

Items = 113

end of life. Acute side effects include nausea, vomiting, diarrhea, hair loss, taste changes, oral mucositis, and postoperative pain syndromes, among others. Symptoms most prevalent at the end of life include dyspnea, pain, and cachexia. Although pain most often is thought of as an end-of-life issue, several post-treatment chronic pain conditions, such as proctitis, obstruction, plexopathy, and neuropathy, affect cancer survivors (Lyne, Coyne, & Watson, 2002).

Because detailed descriptions of each of these late physical and psychosocial effects are beyond the scope of this article, the major effects will be described briefly. The main consideration is to examine the current evidence and describe new areas for targeted research and intervention in the future.

Mortality and Late Effects Among Childhood and Adolescent Cancer Survivors

Childhood and adolescent cancer cure rates have risen dramatically during the past few decades, creating a growing body of adult survivors who face long-term health risks (Hudson et al., 1998; Neglia et al., 2001). The Childhood Cancer Survivor Study (CCSS), a large-scale, multi-institutional, retrospective cohort study started in 1994, was designed to study late effects among long-term survivors of childhood cancer (Mertens et al., 2001). Among the cohort of 20,227 five-year childhood cancer survivors, the study found a 10.8 excess mortality (standard mortality ratio [SMR]). Recurrent disease accounted for 67% of deaths. Survivors were 8.8 times more likely to die from cardiac-related events and 9.2 times more likely to die from pulmonary toxicity. Relative mortality was highest five to nine years after diagnosis but stabilized about 15 years later. Differences in survival existed based on type of diagnosis. Children with histories of leukemia or central nervous system (CNS) tumors had the highest mortality. Children with

Wilms's tumor and neuroblastoma had the best overall survival. Death rates from second cancers increased more rapidly 15–25 years after diagnosis.

Findings from a population-based Scandinavian study including a cohort of 13,711 pediatric cancer survivors also demonstrated a remarkably similar SMR of 10.8 (Moller et al., 2001). Recurrence of the primary cancer was the major cause of death. At least 50% of patients survived at least five years after diagnosis. Both studies showed that excess mortality for patients continued for the rest of their lives into adulthood (Simone, 2001).

Secondary Cancers

The risk of secondary cancer after treatment for Hodgkin's disease is 6.4 times greater than the risk for the general population (Donaldson, Hancock, & Hoppe, 1999; Hancock & Hoppe, 1996; Metayer et al. 2000; Tucker, Coleman, Cox, Varghese, & Rosenberg, 1988; van Leeuwen et al., 2000). A higher incidence of leukemia, non-Hodgkin's lymphoma, lung cancer, breast cancer, gastric cancer, melanoma, thyroid cancer, and sarcomas of the bone and soft tissue exists among Hodgkin's disease survivors (Donaldson et al.; Hudson et al., 1998; Linch, Gosden, Tulandi, Tan, & Hancock, 2000; Ng et al., 2002).

Lung cancer is the most common secondary solid tumor, with a relative risk of 10.3 (Linch et al., 2000). Cigarette smoking is implicated as a cofactor in lung cancer risk (van Leeuwen et al., 1995). Among patients who received a radiation dose of 5 Gy or more and who had less than one pack-year smoking history, the relative risk (RR) of lung cancer was 2.5. With more than one pack-year smoking history, the RR increased dramatically to 9.1 (van Leeuwen et al., 1995).

Secondary breast cancer also is a major concern for Hodgkin's disease survivors (Tucker et al., 1988; Hancock, Tucker, & Hoppe, 1993; van Leeuwen et al., 2000). Young women exposed to mantle radiation before age 20 have a higher risk of breast cancer and screening mammography is recommended at an earlier age. However, Diller et al. (2002) found in a prospective study of 90 long-term female survivors of Hodgkin's disease that 40% did not know that they were at higher risk for breast cancer and that wide variations existed in follow-up cancer surveillance, particularly mammography.

Cognitive Dysfunction

An emerging area of interest is cognitive dysfunction in pediatric, adolescent, and adult cancer survivors (Ahles & Saykin, 2002a; Challinor, Miaskowski, Moore, Slaughter, & Franck, 2000; Meyers, Geara, Wong, & Morrison, 2000; Palmer et al., 2001; van Dam et al., 1998). Among pediatric and adolescent cancer survivors, radiation dose and younger patient age are risk factors for cognitive dysfunction (Palmer et al.). Over time, patterns of cognitive functioning decline. Palmer et al. found that although survivors continued to acquire new knowledge, they acquired information and skills at 49%–62% of the rate among healthy, same-age peers. At five years post-treatment, children were two or more years behind their same-age peers academically and 26% attended special schools because of inability to follow normal curriculum.

Challinor et al. (2000) evaluated the impact of childhood cancer treatment on neurocognition and behavioral and social

competency. The studies indicated that negative effects were associated with childhood cancer treatment in all three areas. Data were conflicting, however, with some studies finding no differences between childhood cancer survivors compared to normative data or healthy controls.

Silberfarb (1983) described one of the first reports of the effects of chemotherapy on cognition in adults. Cognitive changes have been documented in patients with cancers of the breast and lung, lymphoma, and melanoma (Ahles et al., 1998; Ahles & Saykin, 2002a, 2002b; Bender et al., 2000; Meyers, 2000; Meyers et al., 2000). In adults, cognitive changes more often are related to chemotherapy dose, with greater dysfunction related to high-dose chemotherapy (van Dam et al., 1998) and duration of chemotherapy. Neurocognitive effects have been observed two years after last chemotherapy, suggesting long-term cognitive deficits (Schagen et al., 1999). Brezden, Phillips, Abdoell, Bunston, & Tannock (2000) found that adjuvant chemotherapy was a factor in the development of cognitive changes and that the residual effects continued after completion of treatment. Cimprich and Ronis (2001) reported that older women newly diagnosed with breast cancer had cognitive function changes persisting as long as three months postsurgery. Although some investigators have found an association between cognitive changes and mood disturbances such as depression and fatigue (Valentine & Meyers, 2001), others have not demonstrated an association (Brezden et al.).

Brezden et al. (2000) identified some methodologic challenges in assessing the effects on cognitive function in women receiving adjuvant chemotherapy. Subclinical CNS metastasis, paraneoplastic syndromes, and metabolic abnormalities are uncommon in this population. However, the identification of subtle cognitive impairment and how it may differ from effects on mood alterations, fatigue, and stress is difficult to separate (Servaes, Verhagen, & Bleijenberg, 2002; Vollmer-Conna et al., 1997).

Methodologic challenges also are evident in the nursing literature, where cognitive symptoms often are embedded in other broad and related symptoms such as fatigue (Berger & Higginbotham, 2000; Woo, Dibble, Piper, Keating, & Weiss, 1998), attentional fatigue (Cimprich, 1992, 1993), and menopause (Carpenter & Elam, 2003; Carpenter & Andrykowski, 1999; Knobf, 1998) rather than evaluated as specific late effects. Bender et al. (2000) have begun to focus research on assessment and interventions for cognitive changes. More work in this area is needed in the future.

Barton and Loprinzi (2002) theorized that cognitive changes may result from indirect chemical toxicity and oxidative damage, direct injury to neurons, inflammation, or autoimmune response; thus, novel approaches such as hormonal interventions, antioxidants, monoamine oxidase inhibitors, growth factors, dopamine agonists, and behavioral interventions may need to be developed to prevent or reduce cognitive dysfunction.

Cardiac Toxicity

Cardiac toxicity contributes to major morbidity and mortality among childhood and adolescent cancer survivors (Chronowski et al., 2003; Donaldson et al., 1999; Meinardi et al., 2000; Mertens et al., 2001; Moller et al., 2001). Chemotherapy agents most commonly associated with cardiac toxic-

ity are anthracyclines (Lipshultz et al., 1995). Anthracycline-induced congestive heart failure (CHF) usually is caused by permanent changes in the myocardium such as contractile failure resulting from cardiomyopathy. Free radical-mediated myocyte damage may be the likely mechanism of this cardiac damage (Iarussi, Indolfi, Galderisi, & Bossone, 2000). Radiation also has been associated with increased risk (Chronowski et al.). When mediastinal radiation is combined with anthracyclines, cardiac toxicity may occur at even lower radiation doses.

Childhood and adolescent cancer survivors may have marginal cardiac reserve in later life. They may develop late-onset CHF when they start vigorous exercise programs or may experience CHF during pregnancy. Treatment changes such as limited cycles of multiagent chemotherapy and focused radiation treatment fields have been instituted to reduce late cardiac complications. However, education programs and intervention studies to help cancer survivors better understand and monitor cardiac toxicity are needed.

In adults, cardiac toxicity has been observed in patients receiving high-dose chemotherapy for breast cancer and lymphoma (Brockstein, Smiley, Al-Sadir, & Williams, 2000) and in women with advanced breast cancer receiving combination doxorubicin and trastuzumab, a monoclonal antibody against HER2-neu (Nabholtz, Reese, Lindsay, & Riva, 2002; Nabholtz & Slamon, 2001; Sparano, 2001), and bolus doxorubicin and paclitaxel (Giordano et al., 2002). The incidence of cardiac dysfunction is associated strongly with prior or concurrent doxorubicin exposure, ranging from 1% in patients with minimal exposure to anthracyclines to 29% among patients receiving concurrent doxorubicin. Although the etiology of trastuzumab-associated cardiac dysfunction is unknown, its occurrence with either prior or concurrent doxorubicin suggests a common pathophysiologic basis with anthracycline-induced myocardial injury (Sparano).

Cardiac imaging studies (e.g., echocardiogram, multiple gated acquisition scans) may identify subclinical evidence of myocardial dysfunction, but current practice does not support routine use for monitoring asymptomatic patients (Sparano, Brown, & Wolff, 2002). Other modalities such as nuclear medicine scintigraphy and endomyocardial biopsy may be useful, but routine use is limited by feasibility and cost. Circulating markers such as troponins and natriuretic peptides are being investigated as methods to identify patients at risk for myocardial damage. Descriptive and other studies assessing, evaluating, and examining cancer survivors' experiences with late cardiac effects represent a largely unexplored area of research.

Infertility and Reproductive Outcomes

Premature ovarian failure and infertility pose concerns among childhood, adolescent, and young adult cancer survivors (Linch et al., 2000). Alkylating agents, some antineoplastic agents, anthracyclines, procarbazine, and abdominal radiation contribute to premature ovarian failure. Risk is age-related. Chemotherapy in premenopausal women older than 30 creates the highest risk of amenorrhea and menopause. Chemotherapy and radiation destroy germ cells in men. Treatment causes low estrogen levels and onset of menopause in women. Sperm cryopreservation has been used routinely for male patients. However, newer assistive

reproductive technologies such as testis sperm extraction and intracytoplasmic sperm injection have been used for male cancer survivors who become azoospermic after treatment (Damani et al., 2002).

Oocyte cryopreservation is the female equivalent to sperm cryopreservation but is not used routinely because it is a time-consuming process producing a limited number of oocytes (Oktay, Newton, Aubard, Salha, & Gosden, 1998; Opsahl, Fugger, Sherins, & Schulman, 1997). Although Linch et al. (2000) reported that no children have been born to cancer survivors using this method, Atkinson, Apperley, Dawson, Goldman, and Winston (1994) described one successful pregnancy using embryo cryopreservation after bone marrow transplantation for leukemia. Gonadotropin-releasing hormone (GnRH) agonists are another assistive reproductive option for female cancer survivors. Limited clinical and experimental evidence has shown that follicle inhibition produced by GnRH agonists will downregulate pituitary gonadotrophins and produce gonadal protection from cancer treatment. Blumenfeld et al. (1996) reported a protective effect on ovarian function in patients with lymphoma who were given a GnRH agonist during chemotherapy. They found that 94% of patients who received a GnRH agonist resumed normal menses and ovulation after treatment compared with 39% in the nonrandomized control group.

Data on pregnancy outcomes are derived primarily from female childhood cancer survivors (Green et al., 2002) and breast cancer survivors (Dow, Harris, & Roy, 1994; Gelber et al., 2001). Green et al. reviewed pregnancy outcomes in more than 1,000 female participants in the CCSS who were younger than 21 at the time of diagnosis and survived more than five years. They found no adverse pregnancy outcomes for female cancer survivors treated with chemotherapy. Risk of low birth weight was seen in those who received pelvic radiation.

The impact of treatment on fertility for childhood, adolescent, and young adult cancer survivors and the effects on QOL of these survivors is not well documented and represents another area of research in long-term cancer survivors.

Late Effects After Breast Cancer

A benefit of having the majority of cancer survivorship research focused on breast cancer is that tremendous strides have been made in understanding and developing interventions for major symptoms such as fatigue (Barsevick, Whitmer, Sweeney, & Nail, 2002; Mock et al., 1997, 2001; Schwartz et al., 2000), menopausal symptoms (Knobf, 1998, 2002) including hot flashes (Barton & Loprinzi, 2002; Carpenter et al., 1998; Carpenter & Andrykowski, 1999; Finck, Barton, Loprinzi, Quella, & Sloan, 1998), and osteoporosis (Shapiro, Manola, & Leboff, 2001).

Research to improve understanding of other symptoms such as lymphedema (Armer, Heppner, & Mallinkrodt, 2002; Coward, 1999) and sleep problems (Berger et al., 2002; Owen, Parker, & McGuire, 1999; Savard & Morin, 2001) and interventions to improve these symptoms is ongoing through productive programs of research.

Less-Studied Cancers

Very few studies have examined the needs and concerns of long-term survivors of lung, prostate, gynecologic, and colorectal cancers. Cancer survivorship studies focusing on lung

cancer survivors are rare; a few studies included lung cancer survivors in a mixed cancer group (Carter & Chang, 2000; Given, Given, Azzouz, Kozachik, & Stommel, 2001; Rawl et al., 2002), and one article focused on QOL (Cooley, 1998). Sarna et al. (2002) reported on the first study of QOL in long-term survivors of non-small cell lung cancer. Using tumor registry data, the authors identified 995 patients who survived more than five years. They had a response of 16% ($n = 142$) with a mean age of 70 years. Eighty percent were older than 65. More than 50% of survivors lived more than 10 years. Anxiety and depression were factors that significantly affected QOL.

In prostate cancer, the majority of studies have targeted screening and early detection (Weinrich, Weinrich, Boyd, & Atkinson, 1998), decision making (O'Rourke, 1999), and active treatment (Maliski, Heilemann, & McCorkle, 2002; O'Rourke & Germino, 1998; Phillips et al., 2000) rather than post-treatment survivorship. Because prostate cancer is a disease for which treatments and surveillance are available, the needs, issues, and QOL of long-term prostate cancer survivors represent another research opportunity.

In ovarian cancer, the few studies available focused on symptoms and concerns during treatment (Fitch, Gray, & Franssen, 2001; Payne, 2002). Ersek, Ferrell, Dow, and Melancon (1997) reported on the first study of long-term ovarian cancer survivors and found that women reported good QOL despite physical symptoms. Mahon, Williams, and Spies (2001) described a program for screening for second cancers and osteoporosis in a mixed sample of patients with breast, colorectal, and gynecologic cancers.

Studies of colorectal cancer survivors are needed. Many patients are elderly at the time of diagnosis and face many physical and psychosocial effects, including depression. Kurtz, Kurtz, Stommel, Given, & Given (2002) found that gender, race, comorbid conditions, physical functioning, social functioning, and symptoms were significant predictors of depression over time. Female patients, African Americans, and patients having two or more comorbid conditions had more depressive symptoms. Patients with more symptoms and more restricted physical and social functioning had higher levels of depression. In another study using a mixed cancer group, investigators examined pain and fatigue among elderly cancer survivors in the year after treatment and found that patients with lung cancer and those with more comorbidity continued to experience pain and fatigue (Given, Given, et al., 2001).

Ramfelt, Severinsson, and Lutzen (2002) conducted a qualitative study of 52 Swedish patients with colorectal cancer at 3 and 12 months after diagnosis and explored attempts to find meaning in colorectal cancer. Results showed that participants attempted to find meaning in illness to achieve emotional coherence. Subthemes included gratefulness, confidence in self and others, and looking forward to creating a new future. Other subthemes included altered self-value, loss of temporality, and infringement of body integrity.

Although breast, lung, prostate, and colorectal cancers comprise almost 50% of all adult cancers, relatively few studies examining long-term survivorship needs and concerns have been conducted. Thus, research about long-term survivors of these cancers and the ways in which they manage or face adverse outcomes is needed.

Family Research

Family research is a vital target of cancer survivorship research, but additional studies of the effects of long-term survival on families are needed. The 1992 National Health Interview Survey suggested that 20%–27% of adult cancer survivors have a child 18 years old or younger in the home (Hewitt et al., 1999). Sometimes referred to as “secondary survivors,” families face long-term costs of cancer survivorship. To date, family research has shown that many families of cancer survivors experience adverse physical and psychosocial distress, including a sense of isolation and loneliness, employment and insurance concerns, caregiver burden, uncertainty, relationship difficulties, sleep problems, and depression (Carter & Chang, 2000; Given, Given, Helms, Stommel, & DeVoss, 1997; Jepson, McCorkle, Adler, Nuamah, & Lusk, 1999). An additional area of concern is that families of cancer survivors may be at risk for cancer because of inherited susceptibility, shared lifestyle, or toxic exposures (Eisen, Rebbeck, Wood, & Weber, 2000).

Family Caregivers

The chronic and consuming nature of caregiving often leads to changes in QOL (Ferrell, Ervin, Smith, Marek, & Melancon, 2002; Mellon, 2002; Mellon & Northouse, 2001). Mellon and Northouse examined QOL from a family framework and tested a family model of factors that influenced family QOL one to five years post-treatment. The Family Survivorship Model included illness survival stressors (family stressors, fear of recurrence, and patient somatic concerns), resources (family hardiness and family social support), and appraisal (family meaning of the illness). The researchers found that the strongest predictors of QOL were concurrent family stressors, family social support, family member fear of recurrence, family meaning of the illness, and patient employment status.

Caregivers of patients with lung cancer often require assistance in providing emotional support, behavioral management, symptom management, and transportation (Bakas, Lewis, & Parsons, 2001). An important role for nurses is educating caregivers about effective communication strategies and cognitive therapy techniques. Caregivers of patients with advanced ovarian cancer often struggle to maintain their individual QOL throughout their loved ones' experiences (Ferrell et al., 2002). Couples vary in their adjustment to colon cancer (Northouse, Mood, Templin, Mellon, & George, 2000). These researchers found gender differences, with women reporting more distress, more role problems, and less marital satisfaction, regardless of whether they were the patients or spouses. Both patients and spouses reported decreases in family functioning and social support, but also decreases in emotional distress over time.

Two studies evaluated families' and couples' experiences with recurrent breast cancer. Lewis and Deal (1995) interviewed married couples and examined their experiences with breast cancer recurrence. Median length of time since recurrence was 10 months. The core category of “balancing” explained how couples lived with recurrence. Couples actively worked to balance their lives by keeping the breast cancer in the background. Although couples talked about managing the daily realities of recurrence, they did not dwell, but rather moved ahead to heal themselves.

Northouse et al. (2002) reported on FOCUS (family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management), a family-based program of care for women with recurrent breast cancer. The FOCUS program consisted of five components: family involvement, optimistic attitude, coping effectiveness, uncertainty reduction, and symptom management. The program was delivered in three home visits and two follow-up phone calls over a five-month period of time. Results showed that patients with recurrent breast cancer and their family members reported high satisfaction with the intervention program.

Children of Cancer Survivors

Foley (2001) considered children of cancer survivors as the forgotten survivors. Lewis and her colleagues have informed the understanding of the needs of spouses and children of long-term breast cancer survivors. Their program of research was viewed from the parental perspective of the impact of cancer on their children (Issel, Ersek, & Lewis, 1990; Lewis, Zahlis, Shands, Sinsheimer, & Hammond, 1996; Shands, Lewis, & Zahlis, 2000) and the nature of mother-child interactions (Davis Kirsch, Brandt, & Lewis, 2003; Shands et al.).

Other researchers have focused on children's or adolescents' perspectives of parental cancer (Birenbaum, Yancey, Phillips, Chand, & Huster, 1999; Hilton & Elfert, 1996; Hymovich, 1993). Hilton and Gustavson (2002) examined children's perspectives on coping with their mothers' cancer during chemotherapy. Children worried about parents' cancer, whether their loved ones would die, and whether they would manage (Zahlis, 2001). Awareness is another theme where children's developmental level greatly influenced the level of information about cancer shared by parents (Hilton & Elfert).

Psychosocial Late Effects

Quality of Life in Cancer Survivorship Research

QOL issues in long-term cancer survivors differ from the problems faced at the time of diagnosis and treatment (Dow, Ferrell, Haberman, & Eaton, 1999; Ferrell & Dow, 1997; Ferrell, Dow, Leigh, Ly, & Gulasekaram, 1995; Gotay & Muraoka, 1998; Harpham, 1998). Zebrack (2000) provided a comprehensive overview of the literature on QOL and cancer survivors. Differences in the meaning of QOL have changed in the past 30 years. In the 1970s, research focusing on how people survive was as important as length of survival. The 1980s focused on the psychosocial aspects of cancer (e.g., psychological, behavioral, environmental factors) in relationship to causes of cancer. The stress-coping paradigm served as the basic framework in which cancer was a major identifiable stressor having persistent negative outcomes. High-risk factors for poor psychosocial adjustment were identified with implications for buffering or preventive interventions. In the 1990s, studies focused on problems of adjustment and psychological distress, with less attention to personal growth and well-being (Zebrack, 2002). By the mid-1990s, QOL studies with varying definitions, methods, and approaches became the dominant construct, leading some to suggest the need for a new paradigm (Aaronson et al., 1991; Zebrack, 2000).

Gotay and Muraoka (1998) reviewed research on the QOL in long-term cancer survivors as identified by five or more years of survival and suggested additional areas of QOL. The research areas are outlined in Figure 6.

Improve understanding of long-term impact of different treatments on quality of life.
Assess quality of life in survivors experiencing second cancers.
Assess more diverse populations.
Examine the impact of long-term survival on the family.
Ask survivors what they need and want.

Figure 6. Issues for Quality-of-Life Research

Note. Based on information from Gotay & Muraoka, 1998.

Nail (2001) challenged the prevailing notions about psychosocial adjustment to cancer that prescribe correct and incorrect ways to cope. Although no single way to cope fits all cancer survivors, perceived “negative” coping measures such as denial, anger, hostility, and repressed emotions often are labeled as maladaptive by healthcare providers. Nail suggested that any range of strategies is important as long as the strategies are not harmful to patients or others.

Clinical experience has suggested that other outcomes such as function and health are reflective of the positive life changes seen as part of the response to life-threatening illness. In addition, better understanding of the phased nature of the cancer experience and the coping issues at each phase is important in clinical practice and research. Integrating the cancer experience into self-concept is vital to improve QOL for long-term survivors (Zebrack, 2002). Interventions should promote opportunities for individuals to make meaning or reappraise their cancer experience as a way of achieving better QOL. In the pediatric cancer survivorship literature, resilience is a concept most often associated with positive appraisal, flexibility, and adaptation (Dyer & McGuinness, 1996; Hunter & Chandler, 1999; Haase, 1997; Haase, Heiney, Ruccione, & Stutzer, 1999).

Multicultural Issues and Advocacy

Studies to ascertain the multicultural issues facing long-term cancer survivors are very rare. Phillips and Weekes (2002) identified 27 studies with a multicultural focus, but only a few were related to cancer survivorship in culturally diverse groups. Phillips (1999) described fear and fatalistic attitudes of African American women. Wilmoth and Sanders (2001) described survivorship concerns of African American women that differed from Caucasian women in the survivorship period. Wyatt et al. (1998) provided a descriptive comparison between African American and Caucasian breast cancer survivors.

Braun, Mokuau, Hunt, Kaanoi, and Gotay (2002) conducted focus groups to examine rural and urban perspectives of Native Hawaiian survivors’ concerns in survivorship. Obstacles to survival included lack of insurance, out-of-pocket costs, delayed diagnosis, and transportation issues. Personal advocacy supported survival. Two excellent publications have addressed multicultural perspectives: the Proceedings of the Summit Meeting on Breast Cancer in African American Women (Lythcott, Green, & Kramer Brown, 2003) and the June 2002 issue of the *Oncology Nursing Forum*, which focused on multicultural issues.

Clustering of Health Behaviors

The concept of clustering of health behaviors to improve well-being among early-stage cancer survivors was proposed

by Demark-Wahnefried, Peterson, McBride, Lipkus, and Clipp (2000). Patients with early-stage breast and prostate cancer were surveyed to identify information about healthy behaviors relating to smoking cessation, physical activity, and healthy dietary choices. Results showed that cancer survivors had a strong interest in health-promotion programs. Respondents preferred a program that could be delivered via mailed brochure and initiated at the time of diagnosis or within six months. This population may have been an ideal group to target for health behavior change because they believed they were in good to excellent health. Two areas of high research interest focus on management of weight gain among breast cancer survivors and smoking prevention and cessation among childhood and adult cancer survivors.

Weight Gain

Twenty-five years ago, Dixon, Moritz, and Baker (1978) first reported the phenomenon of weight gain in premenopausal women receiving chemotherapy. Despite the co-occurrence with nausea, vomiting, and mucositis, weight gain has been reported consistently during the past 20 years. The early assumption was that weight gain was the result of an energy imbalance from overeating, but studies involving intensive diet counseling and energy-restricted diets did not support this assertion (Demark-Wahnefried et al., 2001). The underlying basis for weight gain still is poorly understood but is of clinical concern for several reasons. Weight gain may negatively affect QOL (Knobf, Mullen, Xistris, & Moritz, 1983) and may predispose women to other weight-related disorders such as hypertension, cardiovascular disease, and diabetes. Camoriano et al. (1990) first reported that premenopausal women who gained more than a median amount of weight were 1.5 times more likely to experience recurrence and die of their disease than those who gained less weight. This finding was not conclusive, and ongoing studies continue to evaluate the role of weight gain and risk of recurrence (Demark-Wahnefried et al., 2001; Rock & Demark-Wahnefried, 2002a, 2002b).

Intervention studies to control weight gain are in progress (Chlebowski, Aiello, & McTiernan, 2002; Goodwin, 2001; Goodwin et al., 1998; McTiernan et al., 1998). Demark-Wahnefried et al. (2001) suggested that weight gain during breast cancer treatment might be related to sarcopenic obesity (i.e., weight gain in the presence of lean tissue loss or absence of lean tissue gain). The development of sarcopenic obesity with evidence of reduced physical activity supports the need for exercise and resistance training in the lower extremities. Weight control that emphasizes exercise to preserve or increase lean muscle mass and a diet rich in vegetables, fruit, whole grains, and low-fat dairy foods may, in turn, help to lower disease risk in this population.

Two large, multicenter, randomized, controlled trials evaluated whether diet modification can influence the risk for recurrence after early-stage breast cancer. The Women’s Intervention Nutrition Study involved 2,500 postmenopausal women randomized within 12 months of surgery with the goal of reduction in dietary fat intake (Chlebowski et al., 1992). The second study, the Women’s Healthy Eating and Living study, evaluated premenopausal and postmenopausal women with the primary emphasis on increased fruit and vegetable intake, dietary goals of five fruits and vegetables, 15%–20% energy from fat, and 30 grams of dietary fiber daily (Pierce et al., 2002).

Smoking Prevention and Cessation

Lifestyle choices of cancer survivors may influence their risk of late cardiac and pulmonary damage. Smoking prevention or cessation to reduce tobacco-related cardiac and pulmonary disease is another important area of healthcare intervention research for cancer survivors. Emmons et al. (2002) examined smoking behavior among five-year survivors in the CCSS cohort. They found that 28% of patients reported ever smoking and 17% reported current smoking. Although these smoking figures are lower than rates compared to the general population, they occur within a high-risk group. Factors that were related to smoking initiation included older age at cancer diagnosis, lower household income, less education, not having a pulmonary-related cancer treatment, and not having brain radiation.

In a follow-up study, some of the same investigators described baseline data collection for Partnership for Health, a smoking-cessation intervention for smokers in the CCSS (Emmons et al., 2003). Initial results showed that smokers had 14 cigarettes on average per day, 53% were nicotine-dependent, and 58% had made at least one attempt to quit. Smoking behaviors were related to age at cancer diagnosis and perceived vulnerability to smoking-related illnesses. Preliminary findings also showed that cancer survivors were receptive to smoking-cessation interventions.

Hecht et al. (1994) identified strategies for oncology nurses to assist patients with cancer in modifying their smoking behaviors by assessing smoking status and readiness to quit. These included providing brief, supportive messages consistently over time, offering or referring patients to appropriate resources, and providing continued follow-up.

Two smoking-cessation intervention programs were identified in the nursing literature. Griebel, Wewers, and Baker (1998) evaluated the effectiveness of a nurse-managed minimal smoking-cessation intervention among 28 hospitalized patients with cancer. Although 64% of the intervention group and 71% of the usual care group reported intention to quit smoking, only 21% and 14% of the intervention and usual care groups, respectively, reported abstinence from smoking. More than 90% of the intervention group members who resumed smoking did so within the first week after discharge.

Browning, Ahijevych, Ross, & Wewers (2000) evaluated the effectiveness of a nurse-managed smoking-cessation intervention based on the Agency for Health Care Policy and Research (AHCPR) Smoking Cessation Guidelines in a lung cancer surgery clinic. Participants in the intervention group received a nurse-delivered, AHCPR-based smoking-cessation intervention that included face-to-face and phone follow-up contact beginning with the first preoperative clinic consultation. Results showed that smokers diagnosed with lung cancer wanted to quit smoking and benefited from an intensive smoking-cessation intervention at the time of diagnosis.

Cancer Screening and Follow-Up of Post-Treatment Cancer Survivors

No evidence-based guidelines exists for cancer screening or surveillance for survivors (Diller et al., 2002; Oeffinger, Eshelman, Tomlinson, & Buchanan, 1998). Also, no clearly defined system for monitoring and managing long-term and delayed side effects or secondary cancers exists (Pelusi,

2001). Hobbie and Ogle (2001) identified four transitional care models: disease-specific, generic, primary care, and single-site models. Each model has benefits and drawbacks. Problems identified in the clinical setting include inability to locate adult survivors of childhood cancer, patient unwillingness to seek follow-up care, lack of insurance, distance to clinic, lack of funding, lack of dedicated provider time, financial problems, and lack of institutional support. Thus, research also is needed to determine the most appropriate roles of oncology specialists, primary care providers, and survivors in cancer surveillance and follow-up care.

How Do We Meet the Challenges in Cancer Survivorship Research?

Both challenges and gaps in the knowledge exist and present exciting opportunities in cancer survivorship research. The following discussion highlights a few areas to consider. They are by no means exhaustive.

1. Consider conducting research in unexplored or underexplored late effects.

Although researchers have learned a great deal about breast cancer, a vital need exists for research across all types of cancers, particularly lung, prostate, colorectal, and gynecologic cancers. Multidisciplinary research teams have a unique opportunity to examine both physiologic and psychosocial late effects of cancer and its treatment on childhood, adolescent, and adult cancer survivors. Multidisciplinary efforts are needed to develop specific interventions for long-term cancer survivors beyond five years. Adverse sequelae contribute to the burden of illness and QOL for families of survivors, the elderly, and underrepresented groups. With an aging and diversifying population, developing knowledge in these underdeveloped areas is critical.

2. Reexamine preexisting assumptions and challenge prevailing paradigms.

Cancer survivorship research demands that researchers move beyond the current knowledge of symptom management of acute effects and develop effective strategies for long-term survival and recurrence. Stress-coping and QOL models have been the predominant paradigms. Researchers may need to consider developing and expanding health-promotion models within chronic illness. In addition, what researchers are learning about family-centered research and current multicultural perspectives challenges preexisting notions and provides a new view of changing paradigms for the future.

3. Develop new or modify existing theoretical or conceptual models.

Symptom clusters, the occurrence of three or more symptoms that are related to each another but may not share the same etiology, first were reported by Dodd, Miaskowski, and Paul in 2001. Symptoms may be pain, fatigue, and sleep problems. The strength of the relationship among the symptoms has not yet been specified, nor has the amount of time that all of the symptoms need to be present (Dodd et al.). These symptom clusters may have adverse effects on patient outcomes and may act synergistically. This conceptual model offers interesting perspective on cancer survivors. For example, what symptom clusters, if any, occur in survivors beyond 1, 5, 10, or 20 years post-treatment?

New instruments focusing on the themes consistent with long-term survivorship are yet to be developed. Researchers

should consider developing other conceptual approaches, in addition to QOL frameworks, that may guide thinking in new directions.

4. Access cancer survivors in new ways.

Novel methods for accessing cancer survivors and delivering interventions are of interest. The Internet has transformed the way that cancer survivors receive psychosocial support (Sharp, 2000) and increasingly is being evaluated for use in research (Duffy, 2002). Web-based research provides many advantages, such as access to specific, difficult-to-reach populations; speed of data access; and decreased cost for data collection and entry. However, methodologic problems such as the nature and representativeness of samples, privacy and confidentiality issues, and response rates need to be considered carefully (Treadwell, Soetikno, & Lenert, 1999). The shift from single institutional samples to population-based samples and methods for cancer survivorship research also is increasing (Pakilit et al., 2001).

5. Be consistent in use of research terms and language.

Consider aligning the language of research to be consistent with cancer survivorship research. Using titles, keywords, or phrases that contain "cancer survivors" provides specificity and focus. Delineating what aspect of cancer survivorship is the focus of the study or article also is important. For example, the phrase "cancer survivors five years after treatment" provides more specificity than the phrases "after therapy" and "after treatment."

6. Increase publication about cancer survivorship clinical topics and research.

Ferrell, Virani, Smith, and Juarez (2003) reviewed the three leading oncology nursing journals in 2001 and found that the most common themes about survivorship focused on primary care, quality of care, and QOL issues. Although researchers are making great strides, literature reviews, clinical insights and experiences, descriptive studies of survivorship beyond five years, interventions relating to psychosocial management of cancer recurrence, new delivery models focusing on access

to care for long-term survivors, and management of long-term effects are needed.

7. Support and mentor new and midcareer investigators.

Supporting and mentoring new and midcareer, doctorally prepared oncology nurse researchers is vital. Researchers have had the benefit of senior investigators with established programs of research. Senior researchers have used creative ways of nurturing junior investigators within their programs. Given (2001) noted that a consistent strategy and deliberate action in external funded research must be consistent with training and experience. Tremendous training opportunities are available through the research and training awards at the national level, but new and midcareer investigators need mentoring in the writing and submission of these applications.

Conclusion

We are at a tremendous crossroads in cancer survivorship research. This is a time when exciting opportunities in research are available at the national level, with interest in cancer survivorship research representing an extraordinary opportunity. Researchers have learned a great deal about childhood, adolescent, and cancer survivors. At the same time, tremendous gaps exist in other areas of research, such as late physiologic and psychological effects and less frequently studied cancers affecting a large proportion of cancer survivors. New interventions are needed to manage late effects; at the same time, researchers must challenge prevailing assumptions. Oncology nurse researchers are uniquely poised to take on the challenges of cancer survivorship research. We can continue to work together, collaborate, persevere, and enjoy the opportunities before us.

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