

This material is protected by U.S. copyright law. Unauthorized reproduction is prohibited. To purchase quantity reprints, please e-mail reprints@ons.org or to request permission to reproduce multiple copies, please e-mail pubpermissions@ons.org.

Cancer Survivorship: History, Quality-of-Life Issues, and the Evolving Multidisciplinary Approach to Implementation of Cancer Survivorship Care Plans

Mary Ann Morgan, PhD, ARNP

Cancer survivorship is complex and involves many aspects of care, from prevention, screening, and rehabilitation to end-of-life care (Ferrell, Virani, Smith, & Juarez, 2003; Mellon, 2002; Mullan, 1985). The National Cancer Institute (NCI, 2008c) estimated that 10.8 million cancer survivors are living in the United States, which represents about 3.7% of the population, and 14% were diagnosed more than 20 years ago. Projections indicate that 75% of contemporary American families have a relative who is or will be diagnosed with cancer. Sixty-five percent of adults who are diagnosed with cancer will be alive after five years, and 75% of childhood cancer survivors will be alive after 10 years; however, childhood cancer survivors are at increased risk for secondary cancers (Ganz, 2005; Hewitt, Greenfield, & Stovall, 2006; NCI, 2008a).

Survivors have many unique needs that are not well understood. To acknowledge the considerable number of long-term cancer survivors, NCI established the Office of Cancer Survivorship in 1996. The Office of Cancer Survivorship supports research that will help to clarify and promote understanding of the physical, psychological, and economic outcomes patients with cancer experience. It attempts to prevent or reduce potential adverse effects of cancer and its treatment on quality of life (QOL) and to provide education to healthcare professionals and survivors about the issues that promote optimal well-being (NCI, 2008b; Rowland, Aziz, Tesaro, & Feuer, 2001).

The Oncology Nursing Society (IONS, 2008b) Research Agenda includes caring for long-term survivors as a priority for nursing research. The Institute of Medicine (IOM) published a report, *From Cancer Patient to Cancer Survivor: Lost in Transition* (Hewitt et al., 2006), highlighting medical, functional, and psychosocial consequences of cancer and its treatment. IOM has defined high-quality health

Purpose/Objectives: To discuss the history of cancer survivorship, related quality-of-life issues, and cancer survivorship care plans (CSCPs).

Data Sources: CINAHL®, PubMed, published articles, and Web sites.

Data Synthesis: A cancer survivor is an individual who has been diagnosed with cancer, regardless of when that diagnosis was received, who is still living. Cancer survivorship is complex and involves many aspects of care. Major areas of concern for survivors are recurrence, secondary malignancies, and long-term treatment sequelae that affect quality of life. Four essential components of survivorship care are prevention, surveillance, intervention, and coordination. A CSCP should address the survivor's long-term care, such as type of cancer, treatments received, potential side effects, and recommendations for follow-up. It should include preventive practices, how to maintain health and well-being, information on legal protections regarding employment and health insurance, and psychosocial services in the community.

Conclusions: Survivorship care for patients with cancer requires a multidisciplinary effort and team approach. Enhanced knowledge of long-term complications of survivorship is needed for healthcare providers. Further research on evidence-based practice for cancer survivorship care also is necessary.

Implications for Nursing: Nurses can review CSCPs with patients, instruct them when to seek treatment, promote recommended surveillance protocols, and encourage behaviors that lead to cancer prevention and promote well-being for cancer survivors.

care for cancer survivors and is developing strategies to improve survivors' lives (Hewitt et al.).

This review will address the history of cancer survivorship, discuss the role of uncertainty as an issue related to QOL, and describe the current status of cancer survivorship care plans (CSCPs). Because cancer survivorship care still is developing as a specialty, further education for healthcare professionals is recommended.

Survivorship

A cancer survivor is an individual who has been diagnosed with cancer, regardless of when that diagnosis was received, who is still living (Centers for Disease Control and Prevention, 2008; Decker, Haase, & Bell, 2007; Mullan, 1985). Survivorship is a three-stage process: acute, extended, and permanent. No specific timeframes exist for the stages, nor do all patients experience all stages (Decker et al.; Mullan).

The acute stage of survivorship is the time surrounding the initial diagnosis when decisions are made about staging and treatment are initiated. Patients may be facing acute and potential losses as a result of disruptions in family and social roles. They may experience challenges in managing their finances, acute side effects from treatment, and fear of the possibility of death (Itano & Taoka, 2005).

The extended stage follows completion of intense treatment and possible remission. Survivors may have periodic examinations or intermittent therapy during this stage, or their condition may be terminal. Cancer survivors may have ambiguous feelings about being alive while dealing with the uncertainty of treatment outcomes, fear of recurrence, or possibly impending death. They may be negotiating physical and psychosocial compromises (Itano & Taoka, 2005).

The permanent stage is defined as the achievement of cure or extended or long-term survival and is presumed to be permanent (Decker et al., 2007; Mullan, 1985; Pedro, 2001). Diminished probability for recurrence exists, and survivors in this stage may face long-term or late effects of the disease and therapy. They may be confronted with workplace discrimination and insurance issues (Itano & Taoka, 2005).

A survey of members of the American Society of Clinical Oncology (ASCO) indicated that 74% of oncologists believed they should provide continuing care to cancer survivors. The focus of continuing care remains unresolved but could include surveillance for recurrence, health promotion, disease prevention, and monitoring or preventing late treatment-related effects and the subsequent effects on QOL (Ganz, 2005).

History of Survivorship Advocacy

In 1986, representatives from 20 organizations founded the National Coalition for Cancer Survivorship (NCCS); the founders sought to change the perception of cancer victim to survivor. Those pioneers envisioned an organization that would address survivorship issues and include family, friends, and caregivers. In 1996, the coalition published *Imperatives for Quality Cancer Care: Access, Advocacy, Action, and Accountability*, which was the first report to examine quality cancer care from the perspective of patient/survivor and was the impetus

that led to the creation of the NCI's Office of Cancer Survivorship (NCCS, 2008).

Some cancer survivors and their families have established private foundations to support cancer research and survivorship issues. Lance Armstrong, one of the world's best cyclists, has won numerous international cycling competitions. However, at age 25, he was diagnosed with testicular cancer that had metastasized to his abdomen, lung, and brain. Armstrong took an active role in his treatment, visualizing himself as a survivor, not a victim. With aggressive medical treatment and a holistic approach that included diet and physical conditioning, he defeated his cancer (Lance Armstrong Foundation, 2008a). In 1997, he founded the Lance Armstrong Foundation and is one of the leading advocates in educating the public and improving the outlook for cancer survivors (Lance Armstrong Foundation, 2008c). The foundation developed an online resource for the public—LIVESTRONG.org—which is based on the belief that strength exists in unity, that knowledge is power, and that attitude is everything (Lance Armstrong Foundation, 2008b).

Another foundation that has an active network of breast cancer survivors is Susan G. Komen for the Cure, which was founded in 1982 by Nancy G. Brinker, whose sister, Susan, died of breast cancer. Brinker promised her sister that she would do everything possible to eradicate breast cancer. Events such as the Komen Race for the Cure have become the largest source of nonprofit funds worldwide in the fight against breast cancer. The organization has facilitated the empowerment of patients and their families and financially supported cancer research. The organization's Web site also works to educate the public about breast cancer (Susan G. Komen for the Cure, 2009).

The 2004 President's Cancer Panel addressed survivorship issues in *Living Beyond Cancer: Finding a New Balance*, which recognized that long-term and late effects of cancer or its treatment can occur many years after treatment ends (Reuben, 2004). The report was based on a series of meetings focusing on survivorship issues across the life span. The panel listened to testimony on the extensiveness of survivorship issues from about 200 American and European survivors, caregivers, community advocates, healthcare professionals, researchers, health systems specialists, and representatives from the insurance industry. The forums included cancer survivors diagnosed as children, adolescents, young adults, adults, and older adults. The President's Cancer Panel supported the need to continue research and inquiry into the needs and concerns of the growing U.S. population of cancer survivors. The panel made recommendations for legislators, policy makers, scientific and medical communities, employers, insurers, advocates, and others whose decisions and activities affect the QOL of people with cancer and their loved ones.

In 2005, ASCO and the NCCS collaborated to develop the Cancer Quality Alliance (Hoffman & Stovall, 2006).

The alliance is designed to foster collaboration among representatives from government agencies, oncology-related organizations, other healthcare-related associations, and third-party payers or insurers with the goal of addressing the challenges of defining, measuring, and implementing high-quality care and its translation by practitioners in oncology ("Organizations Collaborate to Improve the Quality of Cancer Care," 2006).

In July 2005, an invitational symposium addressing survivorship issues for patients with cancer was convened by the *American Journal of Nursing* (Haylock, Mitchell, Cox, Temple, & Curtiss, 2007) and supported by the Centers for Disease Control and Prevention, NCCS, the American Cancer Society, the Lance Armstrong Foundation, and several pharmaceutical companies. Eleven peer-reviewed papers by nurse scientists were presented during the symposium, and participants were charged with creating an action plan to promote cancer survivor care (Haylock & Curtiss, 2007). The collaboration called for a "prescription for living," or a CSCP, and mandated that the plan should be interdisciplinary and nurses should participate in its development. In November 2006, a follow-up symposium was held as a nursing response to the 2005 IOM report on cancer survivorship. Nursing goals established from the symposium included educating nurses, caregivers, patients, and the public about cancer survivorship issues and creating an evidence-based wellness plan as part of a CSCP (Houldin, Curtiss, & Haylock, 2006).

Institute of Medicine Recommendations

IOM has published several recommendations and initiatives, including interdisciplinary research, guidelines for disease screening for patients with cancer, and comprehensive cancer control plans for launching high-quality survivorship care (Hewitt et al., 2006; Hewitt & Ganz, 2007). Recommendations from the 2005 IOM report include the following.¹

- Healthcare providers should work to raise awareness of needs of cancer survivors, establish cancer survivorship as a distinct stage of cancer care, and provide appropriate care.
- Patients should be provided with a survivorship care plan written by the principal providers who coordinated the oncology treatment, and this should be reimbursed by third-party payers of health care.
- Healthcare providers should use, develop, and refine evidence-based clinical practice guidelines, including assessment tools and screening instruments, to help

¹ From "Fact Sheet: *From Cancer Patient to Cancer Survivor: Lost in Transition: Report Recommendations*," by Institute of Medicine, 2005. Retrieved July 20, 2008, from <http://www.iom.edu/CMS/28312/4931/30869/30879.aspx>. Copyright by National Academy of Sciences. Adapted with permission.

identify and manage late effects of cancer and its treatment. These guidelines should be developed through public and private-sector efforts.

- Quality assurance programs should be established to ensure appropriate cancer survivorship care.
- Qualified organizations should support demonstration programs to test models for interdisciplinary survivorship care for diverse communities and across varied systems of care delivery.
- Congress should support the Centers for Disease Control and Prevention and encourage collaboration with other institutions and state legislatures in developing comprehensive cancer control plans that include survivorship care.
- NCI, professional associations, and voluntary organizations should expand and coordinate efforts to provide education to healthcare providers to enable them to give quality care to cancer survivors.
- Employers, legal advocates, healthcare providers, supporting services, and government agencies should act to eliminate discrimination in employment of cancer survivors and support allowances for short- and long-term limitations in ability to work resulting from the adverse effects of cancer.
- Federal and state policy makers should act to ensure that cancer survivors have access to affordable and sufficient health insurance recognizing survivorship care is essential. Reimbursement mechanisms should be designed to facilitate coverage for evidence-based aspects of care.
- New research initiatives focused on cancer survivorship care are urgently needed.

Cancer Survivorship Care Plan

Cancer survivors face many serious issues: physical late effects, lack of consistent long-term medical follow-up, psychosocial concerns, employment and insurance problems, and discrimination (Hewitt & Ganz, 2007). One of the key components in the IOM report (Hewitt et al., 2006) was a recommendation that a CSCP be developed by primary providers. The CSCP would summarize five types of information recommended by the President's Cancer Panel in 2004 and address the issues that cancer survivors face across the life span as children, adolescents or young adults, adults, and older adults (Reuben, 2004).

The plan is envisioned as a summary of the patient's treatment and a comprehensive path for the follow-up care addressing long-term effects of cancer and its treatment. Specifically, the plan needs to address the survivor's long-term care: type of cancer, treatments received, potential side effects, and recommendations for follow-up supported by evidence-based guidelines. In addition, preventive practices, how to maintain health and well-being, information on legal protections regarding employment

and health insurance, and psychosocial support services that are available in the community should be included (Hewitt & Ganz, 2007). The plan should offer a systematic way for healthcare providers to share essential information with others involved in the care of cancer survivors ("Building a Bridge of Continued Care for Cancer Survivors," 2006; Ganz, 2005; Hoffman & Stovall, 2006). The plan should be provided to the patient and his or her primary care providers (Hewitt & Ganz, 2007). Much of the work or design of care plans was based on guidelines developed by the Children's Oncology Group Nursing Discipline (Hewitt & Ganz) for survivors of childhood, adolescent, and young adult cancers.

ASCO (2008) developed a generic template for a CSCP. Breast and colorectal cancer templates have been available since 2007. Other diagnoses and treatment plans are under development. The goal of all of the cancer treatment plans and summaries is to ensure high quality in patient treatment across healthcare settings by improving communication among oncologists, patients, and other healthcare providers. The core elements of every treatment plan and summary are provided in Figure 1 (ASCO, 2008).

Uncertainty

A major area of concern for cancer survivors is the issue of uncertainty (Decker et al., 2007; McKinley, 2000; Wonghongkul, Moore, Musil, Schneider, & Deimling, 2000), which is linked closely to QOL (Ferrell, Dow, & Grant, 1995; Lockwood-Rayermann, 2006; Pedro, 2001). Uncertainty is part of the illness process, particularly for patients with cancer, and is derived from Lazarus and Folkman's (1984) stress and coping theory that was used by Mishel (1981) to develop the midrange theory of uncertainty in illness. Uncertainty is characterized by the inability to determine the meaning of illness-related events and includes ambiguity regarding the significance of the illness and symptoms. Many areas of daily life are involved, and uncertainty can result in anxiety and an appraisal of harm or danger to oneself. As a result, coping activities can be positive or negative (Barron, 2000; Decker et al.; Mishel, 1981). The patient becomes immersed in a complex system of care and treatment that includes unpredictability regarding the course of the disease process and its prognosis. Uncertainty involves many areas of daily life and can cause anxiety, which influences normal routines and activities. Mishel's (1990) further refinement of her Uncertainty in Chronic Illness Theory explains how patients cognitively process illness-related stimuli. The theory applies to cancer survivors as they attempt to structure or ascertain value in life after diagnosis of this chronic illness. Uncertainty is a major theme for survivors and a given part of their existence (Mellon, 2002; Wonghongkul et al.). After intense involvement with healthcare providers during treatment, the end of treatment transition for cancer survivors can

Patient's name: _____
Diagnosis: _____
 Date at diagnosis: _____
 Age at diagnosis: _____
 Medical oncologist: _____
 Surgical oncologist: _____
 Radiation oncologist: _____
 Primary care provider: _____
 Family history: _____
 Predisposing factors: _____

Cancer site/type: _____

Surgery: _____

Procedures and dates: _____

Lymph nodes

• Number examined: _____

• Number positive: _____

Hormone status, if applicable: (ER, PR, HER2-neu)

Stage: _____

Tumor, node, metastasis: _____

Adverse events: _____

Chemotherapy: _____

Start and end dates: _____

Drug, dose, and total dose for anthracyclines: _____

Adverse events: _____

Clinical trials: _____

Hormonal therapy: _____

Targeted therapy: _____

Radiation therapy: _____

Start and end dates: _____

Dose, type, site, and total dose: _____

Adverse events: _____

Follow-Up Care^a

Referrals: _____

Providers: _____

Community resources: _____

Potential long-term effects: _____

Health maintenance recommendations: _____

^a Provide evidence-based survivorship and surveillance guidelines from specialty societies such as the American Society of Clinical Oncology, the National Comprehensive Cancer Network, and the American Urological Association.

ER—estrogen receptor; PR—progesterone receptor

Figure 1. Core Elements of Treatment Summary and Cancer Survivorship Care Plan

Note. Based on information from the American Society of Clinical Oncology, 2008.

be marked by grief, anxiety, and uncertainty. Cancer survivors have reported feeling like warriors without a war when treatment ended and they no longer regularly saw healthcare providers (Hewitt et al., 2006; McKinley).

Clayton, Mishel, and Belyea (2006) used structural equation modeling to test a model of symptom bother (i.e., distress associated with how much the symptom intrudes on daily awareness), communication with healthcare providers, uncertainty, and well-being in breast cancer survivors older than 50 years. Women with lower education who were younger than 60 years had more symptom bother, greater uncertainty, and a poorer sense of well-being. The study included Caucasian and African

American women, and no difference was found between races. The participants received their first cancer diagnosis more than five years before the study. A surprising finding that the authors could not explain was that increased communication (amount, not quality or content) with healthcare providers increased uncertainty and thoughts of recurrence. Fifty-two percent of the patients saw an oncologist, 35% saw a family physician, 2% saw a nurse practitioner, and 11% were designated as other. The authors proposed that additional research should target symptoms, uncertainty, and healthcare provider communication. Perhaps as breast cancer survivors move away from the initial diagnosis, their personal complex needs may not be the same as the traditional focus of longevity embraced by medicine and society, but rather that of QOL (Clayton et al.).

QOL is important for cancer survivors and their families (Ganz, 2005; Mellon, 2002). Surviving cancer can have positive effects, such as greater appreciation of life, improved interpersonal relationships, enhanced spirituality, and healthier lifestyle choices. Health-promotion behaviors may be particularly important for childhood cancer survivors and may help to prevent or minimize some late effects and potential second malignancies (Decker et al., 2007). Negative influences of survivorship include fear of the future, recurrence, and lingering long-term effects of cancer treatment from surgery, chemotherapy, and radiation (e.g., physical or psychological changes) (Decker et al.; Ferrell et al., 1995; Ganz; Lockwood-Rayermann, 2006; Mellon) (see Figure 2). ASCO is developing guidelines to address those components, having published "Follow-Up Care Guidelines for Breast and Colon Cancer Patients" thus far, but limited evidence is available, which has been a common problem with survivorship questions ("Building a Bridge of Continued Care for Cancer Survivors," 2006; Cancer.net, 2008).

Wonghongkul et al. (2000) conducted a study of 71 breast cancer survivors with no recurrence using three instruments: the Mishel Uncertainty in Illness Scale–Community; an Appraisal Index measuring threat, harm or loss, and challenge; and the Herth Hope Index. The participants demonstrated low levels of uncertainty ($\bar{X} = 43.96$, $SD \pm 12.21$; range = 23–115) and high levels of hope ($\bar{X} = 41.62$, $SD \pm 5.36$; range = 12–48). Significant variation was not demonstrated with any of eight coping strategies by analysis of variance.

Decker et al. (2007) measured uncertainty using the Mishel Uncertainty in Illness Scale in 193 adolescents with a wide range of cancer diagnoses. Subjects were divided into three groups: newly diagnosed, one to four years since diagnosis, and five or more years since diagnosis. Analysis of variance indicated that survivors had similar levels of uncertainty overall and reported ambiguity and complexity no matter how long they were from diagnosis.

Kasper, Geiger, Freiburger, and Schmidt (2008) used qualitative techniques and grounded theory to explore

uncertainty in relation to physician-patient communication issues and discussed shared decision making. They found that patients experienced uncertainty in eight areas: social integration, diagnosis and prognosis, deciphering information, mastering of requirements, causal attribution, preferred degree of involvement, physician's trustworthiness, and treatment. Though the goal today is to base practice on evidence-based medicine, when it comes to individual patients, there are elements of uncertainty. The authors recommend that patients would benefit from open discussions and negotiating various uncertainties with their healthcare providers, and that this would empower patients' decision making.

Quality of Life

Ganz (2005) explained that pretreatment considerations should include time to discuss potential risks and complications that affect the individual prior to selecting the most appropriate treatments with the fewest toxicities. Issues of fertility, genetic counseling, and testing for hereditary cancer predisposition genes may affect primary treatment choices. Survivors who are informed about their options and believe they have some personal control over decision making generally have higher QOL (Hoffman & Stovall, 2006).

Ferrell et al. (1995) developed and tested the Quality of Life for Cancer Survivors instrument, which included distress from treatment, fear of recurrence, and fertility issues. The variables that accounted for the greatest overall effect on QOL were perception of control, aches and pain, uncertainty, satisfaction, future appearance, and fatigue. The top predictor of QOL was control and accounted for 46% of the variance. Many predictors of QOL are related to psychological well-being. Two physical items—aches and pain and fatigue—also were among top predictors of QOL. Patient groups ranged from those with active disease to those in remission. QOL scores were higher in those surviving more than five years after the initial diagnosis of cancer and those with family incomes of more

Physical Changes

Altered body/self-image
Cardiac damage secondary to anthracycline treatment
Impaired sexuality
Osteoporosis
Pain
Peripheral neuropathies
Premature menopause
Secondary cancers
Stress incontinence

Psychological Changes

Changes in family structure
Cognitive changes
Fear of genetic inheritance for families
Fear of recurrence
Financial concerns
Loss of ability to work
Pain
Social support

Figure 2. Negative Outcomes of Cancer Survivorship

Note. Based on information from Decker et al., 2007; Ferrell et al., 1995; Ganz, 2005; Lockwood-Rayermann, 2006; Mellon, 2002.

than \$40,000. Participants who lived alone demonstrated significantly decreased QOL across all domains.

Wenzel et al. (2002) characterized 49 early-stage (I, II) ovarian cancer survivors (greater than 5–10 years after diagnosis) with multiple scales assessing long-term side effects from cancer treatment and open-ended questions with a qualitative analysis to elucidate survivorship concerns not covered in the questionnaires. The predominant physical symptom patients experienced that impacted their QOL was loss of bowel control for 18% of the participants. Thirty-six percent reported significant distress related to fear of a second malignancy. The frequency of fear of recurrence was 20%, and fear regarding future tests was 30%. Forty-three percent of the sample had no current survivorship concerns. According to the investigators, the most notable component of the study was that the participants exhibited evidence of resilience and post-traumatic growth as a result of the ovarian cancer experience.

Using two open-ended questions to explore the meaning of illness and QOL, a qualitative study of 123 family dyads examined comparisons between family members and cancer survivors (with diagnoses of stage I–III breast, colon, prostate, or uterine cancer who had no recurrence and were not undergoing treatment) (Mellon, 2002). The authors identified four terms that evolved regarding similarities between the meaning of cancer illness for survivors and for the family members: devastation or shock at time of diagnosis, taking care of the cancer “action,” not thinking or talking about it too much, and reliance on faith. Family QOL shared four themes: valuing and living life to the fullest, no lasting effect on QOL, increased family closeness, and living with other stressors, such as insurance problems, concern for cancer in the family, and changes in financial status.

Nursing Perspectives of Survivorship Care

A qualitative research study with three focus groups of oncology nurses at ONS Congress in 2006 explored perspectives on survivorship care of patients and nurses’ role in implementation of a CSCP (Hewitt & Ganz, 2007). Thirty-four oncology nurses and nurse practitioners participated, representing various practice settings, including academic, hospital-based, and private practice. The focus group leaders (Hewitt & Ganz) reviewed current practices, nurses’ perceptions of survivors’ needs, nurses’ roles in survivorship, and the components of the proposed CSCP, including barriers. Nurses agreed that a transition to survivorship care was needed for patients at completion of treatment. They expressed concerns about the time required to implement a care plan, need for collaboration between physicians and nurses, and reimbursement issues.

H.R. 5585, “Assuring and Improving Cancer Treatment Education and Cancer Symptom Management Act

of 2008,” was introduced by Steve Israel (D-NY) into the U.S. House of Representatives. The bill is an amendment to Medicare that would provide coverage of comprehensive treatment education services for patients with cancer. The bill was reintroduced in the 111th Congress as H.R. 1927 on April 2, 2009, and has been referred to the House Ways and Means Committee (Govtrack.us, 2009). Education services are defined as one hour of patient education delivered by an RN who educates the patient and any caregivers about all aspects of the care to be provided to the individual, including potential side effects, symptoms, or adverse events. The passage of the bill might allow nurses to review the cancer treatment summary with patients, including potential long-term side effects and health maintenance plans as part of a CSCP, and permit subsequent reimbursement of those services. For nurse practitioners, reimbursement will be based on cancer diagnosis code (National Center for Health Statistics, 2009). Services performed are billed using current procedural terminology codes that use strict criteria to define the complexity of care delivered, including time spent reviewing treatment, referrals, physical examinations, consultations, and documentation (Children’s Oncology Group, 2007).

Healthcare Practitioner Education

Survivorship care for patients with cancer requires an interdisciplinary approach to develop and implement a CSCP (Ferrell & Winn, 2006). Healthcare providers need to enhance their knowledge of long-term complications, monitor for sequelae of treatment, and be knowledgeable in interpretation of the risk for complications and other survivorship issues. Ferrell and Winn reviewed curricula for nursing and medicine, continuing education programs, textbooks, and journals for cancer survivorship content. They concluded that representation in medical school curricula has been limited, but attempts are being made to include cancer survivors so that students are educated about those experiences. Educational materials are available in an online repository being developed by the Association of American Medical Colleges (AAMC) (Ferrell & Winn). Thus far, AAMC provides a blueprint aimed at medical education with five case scenarios that have been developed in conjunction with the Cancer Quality Alliance and NCCS for healthcare practitioners (Rose, Stovall, Ganz, Desch, & Hewitt, 2008). No tutorials are available for nonmembers through the AAMC MedEd Portal for Cancer Survivors (AAMC, 2009). However, members may be able to access new tutorials through their universities. The content needs to be addressed in nursing and medical schools, but a concerted effort must be conducted to educate practicing clinicians who encounter survivors (IOM, 2005). NCI, professional associations, and voluntary organizations should expand and coordinate efforts

to provide educational opportunities for healthcare providers to equip them to care for survivors ("Building a Bridge of Continued Care for Cancer Survivors," 2006; Ferrell et al., 2003; Ferrell & Winn; Hewitt & Ganz, 2007; Hoffman & Stovall, 2006).

In response to awareness of survivorship issues, Charles R. Drew University of Medicine and Science in Los Angeles, CA, is establishing a core competencies curriculum for medical students that focuses on epidemiology of survival, risk assessment, treatment of late effects, psychosocial concerns, prevention strategies, and resources for patients that is projected to be used by other medical schools (Ferrell & Winn, 2006). ASCO is creating a competence curriculum for the medical oncology subspecialty that includes supportive care and survivorship (Ferrell & Winn; Ganz, 2005; Hoffman & Stovall, 2006). The original core curriculum from ASCO was completed in 1998, and in 2005, the second edition was completed, which includes survivorship (ASCO, 2009c). Primary care and internal medicine curricula do not mention cancer survivorship (Ferrell & Winn). Subsequent to the IOM (2005) report, the ASCO Survivorship Task Force planned to issue clinical practice guidelines addressing cardiovascular disease, hormone replacement therapy, osteoporosis, sexual dysfunction, secondary malignancies, neurocognitive dysfunction, and psychological problems (Ferrell & Winn). Thus far, ASCO has issued practice guidelines for survivorship issues for surveillance and monitoring of patients with breast cancer, surveillance of colon and rectal cancer, and fertility issues (ASCO, 2009b). It has provided online generic treatment summary templates and disease-specific summary templates for breast and colorectal cancers that are easily downloaded and are modifiable (ASCO, 2009a).

Undergraduate nurses receive limited training in cancer care related to chronic disease (Ferrell & Winn, 2006). ONS (2008a) has 285 members in its Survivorship, Quality of Life, and Rehabilitation Special Interest Group, so that group and ONS itself can be important resources for nurses in this evolving area.

Conclusions and Summary

Development of treatment and care programs for cancer survivors is a relatively new and ongoing process. Many areas of potential research for cancer survivors exist, including the long-term effects on physical challenges; workplace, marital and relationship, and financial issues; and social aspects. Literature about lifestyle interventions

(e.g., diet, exercise, smoking cessation, sun protection) for cancer survivors after completion of treatment is growing. Through the efforts of patient advocacy, including the American Cancer Society, Cancer Quality Alliance, NCCS, Lance Armstrong Foundation, and Susan G. Komen for the Cure, cancer survivors' special needs are being recognized and addressed. Through those organizations, survivors receive support in seeking ways to prevent a cancer recurrence, assistance in formulating questions to ask their healthcare providers, and ways to enhance the quality and length of their lives.

Discussion continues as to who should provide or take responsibility for monitoring and follow-up care of cancer survivors: oncologists or primary healthcare providers (Ganz, 2005; NCI, 2009). An interdisciplinary approach will be necessary to develop and implement a CSCP, and oncology nurses and nurse practitioners are an essential part of that team. Oncology nurses should be integrally involved in CSCP development and implementation with patients and families, including provision of resources for nutrition, health maintenance, sunscreen protection, and Web sites that provide accurate information from legitimate authorities. Healthcare providers should provide lists of resources, including advocacy Web sites, support groups, and national and local organizations that serve survivors of specific types of cancer (Hoffman & Stovall, 2006). The overall goal of cancer survivorship is to empower survivors and their families. This is an area of opportunity for nurses and nurse practitioners to provide and ensure quality care for patients.

The IOM report identified four essential components of survivorship care: prevention, surveillance, intervention, and coordination (Hewitt et al., 2006). Those components should be addressed in the CSCP, thus summarizing the five types of information that were recommended by the President's Cancer Panel in 2004 (Reuben). The overall goal of cancer survivorship is to empower survivors and their families. A CSCP will enable cancer survivors to receive better care because follow-up will be enhanced by the ready availability of past diagnosis and treatment history, surveillance guidelines, and potential long-term effects (Ganz, 2005; Hoffman & Stovall, 2006).

Mary Ann Morgan, PhD, ARNP, is a nurse practitioner in the Survivorship Program at the Moffitt Cancer Center and Research Institute in Tampa, FL. Funding for this research was provided by a nursing doctoral scholarship from the American Cancer Society. Morgan can be reached at mary.morgan@moffitt.org, with copy to editor at ONFEditor@ons.org. (Submitted May 2008. Accepted for publication December 11, 2008.)

Digital Object Identifier: 10.1188/09.ONF.429-436

References

American Society of Clinical Oncology. (2008). ASCO launches new template to document chemotherapy treatment and survivor care for cancer patients. Retrieved May 6, 2009, from <http://www.asco.org/ASCOv2/Press+Center/Latest+News+Releases/ASCO+Lau>

nches+New+Template+to+Document+Chemotherapy+Treatment+and+Survivor+Care+for+Cancer+Patients
American Society of Clinical Oncology. (2009a). Cancer treatment plan and summary resources. Retrieved May 23, 2009, from <http://www.asco>

- .org/ASCOv2/Practice+&+Guidelines/Quality+Care/Quality+Measurement+&+Improvement/Chemotherapy+Treatment+Plan+and+Summary/Cancer+Treatment+Plan+and+Summary+Resources
- American Society of Clinical Oncology. (2009b). Clinical practice guidelines. Retrieved May 23, 2009, from <http://www.asco.org/guidelines>
- American Society of Clinical Oncology. (2009b). Curriculum for medical oncology. Retrieved June 17, 2009, from <http://www.asco.org/ASCOv2/Education+&+Training/ASCO+Program+Guidelines>
- Association of American Medical Colleges. (2009). MedED portal. Retrieved May 23, 2009, from <http://services.aamc.org/30/mededportal/servlet/segment/mededportal/information>
- Barron, C. (2000). Stress, uncertainty, and health. In V.H. Rice (Ed.), *Handbook of stress, coping, and health: Implications for nursing research, theory, and practice* (pp. 517–539). Thousand Oaks, CA: Sage Publications.
- Building a bridge of continued care for cancer survivors. (2006). *Journal of Oncology Practice*, 2(2), 77–82.
- Cancer.net. (2008). ASCO cancer treatment summaries. Retrieved May 23, 2009, from <http://www.cancer.net/patient/Survivorship/ASCO+Cancer+Treatment+Summaries>
- Centers for Disease Control and Prevention. (2008). Cancer survivorship. Retrieved May 23, 2009, from http://www.cdc.gov/cancer/survivorship/basic_info
- Children's Oncology Group. (2007). Long-term follow-up guidelines for survivors of childhood, adolescent, and young adult cancers. Retrieved August 10, 2008, from <http://www.survivorshipguidelines.org>
- Clayton, M., Mishel, M., & Belyea, M. (2006). Testing a model of symptoms, communication, uncertainty, and well-being in older breast cancer survivors. *Research in Nursing and Health*, 29(1), 18–39.
- Decker, C., Haase, J., & Bell, C. (2007). Uncertainty in adolescents and young adults with cancer. *Oncology Nursing Forum*, 34(3), 681–688.
- Ferrell, B., Dow, H., & Grant, M. (1995). Measurement of the quality of life in cancer survivors. *Quality of Life Research*, 4(6), 523–531.
- Ferrell, B., Virani, R., Smith, S., & Juarez, G. (2003). The role of oncology nursing to ensure quality care for cancer survivors: A report commissioned by the National Cancer Policy Board and Institute of Medicine [Online Exclusive]. *Oncology Nursing Forum*, 30(1), E1–E11. Retrieved May 6, 2009, from <http://ons.metapress.com/content/3k31602727q874h5/?p=bc474fb14dc34565935782355f62c83&pi=0>
- Ferrell, B., & Winn, D. (2006). Medical and nursing education and training opportunities to improve survivorship care. *Journal of Clinical Oncology*, 24(32), 5142–5148.
- Ganz, P. (2005). A teachable moment for oncologists: Cancer survivors, 10 million strong and growing! *Journal of Clinical Oncology*, 23(24), 5458–5460.
- Govtrack.us. (2009). H.R.1927: 111th Congress 2009–2010: Assuring and Improving Cancer Treatment Education and Cancer Symptom Management Act of 2009. Retrieved May 22, 2009, from <http://www.govtrack.us/congress/bill.xpd?bill=h111-1927>
- Haylock, P., & Curtiss, C. (2007). Promoting sustainability through collaboration. Nursing responds: Coming together to improve the care of survivors of adult cancers. *Reflections on Nursing Leadership*, 33, 2.
- Haylock, P.J., Mitchell, S.A., Cox, T., Temple, S.V., & Curtiss, C.P. (2007). The cancer survivors' prescription for living. *American Journal of Nursing*, 107(4), 58–70.
- Hewitt, M., & Ganz, P. (2007). *Implementing cancer survivorship care planning: Workshop summary*. Washington, DC: National Academies Press.
- Hewitt, M., Greenfield, S., & Stovall, S. (2006). *From cancer patient to cancer survivor: Lost in transition*. Washington, DC: National Academies Press.
- Hoffman, B., & Stovall, E. (2006). Survivorship perspectives and advocacy. *Journal of Clinical Oncology*, 24(32), 5154–5159.
- Houldin, A., Curtiss, C., & Haylock, P. (2006). Executive summary: The state of the science on nursing approaches to managing late and long-term sequelae of cancer and cancer treatment. *American Journal of Nursing*, 106(3), 54–59.
- Institute of Medicine. (2005). *From cancer patient to cancer survivor: Lost in transition. Report recommendations*. Retrieved July 20, 2008, from <http://www.iom.edu/Object.File/Master/34/764/recommendations.pdf>
- Itano, J., & Taoko, K. (2005). *Core curriculum for oncology nursing* (4th ed.). St. Louis, MO: Elsevier Sanders.
- Kasper, J., Geiger, F., Freiburger, S., & Schmidt, A. (2008). Decision-related uncertainties perceived by people with cancer—Modelling the subject of shared decision making. *Psycho-Oncology*, 17(1), 42–48.
- Lance Armstrong Foundation. (2008a). Lance's story. Retrieved July 31, 2008, from http://www.livestrong.org/site/c.khLXK1PxHmF/b.2661053/k.9207/Lances_Story.htm
- Lance Armstrong Foundation. (2008b). Livestrong [home page]. Retrieved July 31, 2008, from <http://www.livestrong.org>
- Lance Armstrong Foundation. (2008c). Milestones. Retrieved July 31, 2008, from <http://www.livestrong.org/site/c.khLXK1PxHmF/b.2662471/k.26F8/Milestones.htm>
- Lazarus, R., & Folkman, S. (1984). *Stress, appraisal, and coping*. New York: Springer.
- Lockwood-Rayermann, S. (2006). Survivorship issues in ovarian cancer: A review. *Oncology Nursing Forum*, 33(3), 553–562.
- McKinley, E. (2000). Under toad days: Surviving the uncertainty of cancer recurrence. *Annals of Internal Medicine*, 133(6), 479–480.
- Mellon, S. (2002). Comparisons between cancer survivors and family members on meaning of the illness and family quality of life. *Oncology Nursing Forum*, 29(7), 1117–1125.
- Mishel, M. (1981). The measurement of uncertainty in illness. *Nursing Research*, 30(5), 258–263.
- Mishel, M. (1990). Reconceptualization of the Uncertainty in Illness Theory. *Image: Journal of Nursing Scholarship*, 22(4), 256–262.
- Mullan, F. (1985). Seasons of survival: Reflections of a physician with cancer. *New England Journal of Medicine*, 313(4), 270–273.
- National Cancer Institute. (2008a). About cancer survivorship research: History. Retrieved July 28, 2008, from <http://cancercontrol.cancer.gov/ocs/history.html>
- National Cancer Institute. (2008b). Cancer survivorship research. Retrieved July 28, 2008, from <http://cancercontrol.cancer.gov/ocs/history.html>
- National Cancer Institute. (2008c). Estimated U.S. cancer prevalence. Retrieved July 28, 2008, from <http://cancercontrol.cancer.gov/ocs/prevalence/prevalence.html#survivor>
- National Cancer Institute. (2009). Cancer survivors and their doctors have different expectations about care. Retrieved May 23, 2009, from <http://www.cancer.gov/ncicancerbulletin/040709/page2>
- National Center for Health Statistics. (2009). Classification of diseases and functioning and disability: International classification of diseases, ninth revision, clinical modification (ICD-9-CM). Retrieved May 23, 2009, from <http://www.cdc.gov/nchs/about/otheract/icd9/abtdic9.htm>
- National Coalition for Cancer Survivorship. (2008). History and milestones. Retrieved June 25, 2008, from <http://www.canceradvocacy.org/about/org/history.html>
- Oncology Nursing Society. (2008a). Membership directory: Survivorship, Quality of Life, and Rehabilitation SIG. Retrieved July 31, 2008, from <https://profile.ons.org/Directory.aspx>
- Oncology Nursing Society. (2008b). ONS research agenda and priorities. Retrieved July 20, 2008, from <http://www.ons.org/research/information>
- Organizations collaborate to improve the quality of cancer care. (2006). *Journal of Oncology Practice*, 2(3), 116–119. Retrieved June 25, 2008, from <http://qualityalliance.stateaffiliates-asco.org/jop.pdf>
- Pedro, L. (2001). Quality of life for long-term survivors of cancer: Influencing variables. *Cancer Nursing*, 24(1), 1–11.
- Reuben, S. (2004). *Living beyond cancer: Finding a new balance*. Retrieved July 15, 2008, from <http://deainfo.nci.nih.gov/ADVISORY/pcp/pcp03-04rpt/Survivorship.pdf>
- Rose, C., Stovall, E., Ganz, P., Desch, C., & Hewitt, M. (2008). Cancer quality alliance: Blueprint for a better cancer care system. *CA: A Cancer Journal for Clinicians*, 58(5), 266–292.
- Rowland, J., Aziz, N., Tesaro, G., & Feuer, E. (2001). The changing face of cancer survivorship. *Seminars in Oncology Nursing*, 17(4), 236–240.
- Susan G. Komen for the Cure. (2009). About us. Retrieved May 6, 2009, from <http://www5.komen.org/AboutUs/AboutUs.html>
- Wenzel, L., Donnelly, J., Fowler, J., Habbal, R., Taylor, T., Aziz, N., et al. (2002). Resilience, reflection, and residual stress in ovarian cancer survivorship: A Gynecologic Oncology Group study. *Psycho-Oncology*, 11(2), 142–153.
- Wonghongkul, T., Moore, S., Musil, C., Schneider, S., & Deimling, G. (2000). The influence of uncertainty in illness, stress appraisal, and hope in coping on survivors of breast cancer. *Cancer Nursing*, 23(6), 422–429.