Survivorship Care: Essential Components and Models of Delivery

April 09, 2009 | Oncology Nursing [1], Survivorship [2]
By Wendy Landier, RN, MSN [3]

When caring for patients with a new cancer diagnosis, oncology nurses generally have clear and distinct plans to assist each patient through the phases of diagnosis and treatment. Nurses provide guidance, support, and well-defined patient education regarding the planned treatment, as well as anticipatory guidance regarding management of side effects and emotional responses to diagnosis and treatment.

When caring for patients with a new cancer diagnosis, oncology nurses generally have clear and distinct plans to assist each patient through the phases of diagnosis and treatment. Nurses provide guidance, support, and well-defined patient education regarding the planned treatment, as well as anticipatory guidance regarding management of side effects and emotional responses to diagnosis and treatment. Nurses see each patient through his or her phases of treatment, whether it involves chemotherapy, surgery, radiation, biotherapy, hematopoietic cell transplant, or a combination of modalities, assisting and problem-solving with patients and their families along the way.

Frequent contact with the healthcare system during treatment is the norm, and patients often feel that things are “under control” because they are receiving active treatment directed at their cancer. Once treatment ends, however, patients are often at a loss in coping with the next phase of their life—survivorship—and nurses often lack the resources necessary to guide their patients through this critical phase of cancer care. It is at this juncture that many patients feel “lost in transition” and some describe feeling “abandoned” by the healthcare system.[1] Fortunately, resources are now being developed to assist nurses and other healthcare professionals in providing much-needed follow-up care for cancer survivors.

WHY CANCER SURVIVORSHIP CARE?

Cancer Survivors: Who Are They?
Treatment for cancer has improved tremendously over the past several decades. In the United States today, 66% of adults and 80% of children diagnosed with cancer will survive 5 years,[2] and the current population of cancer survivors now exceeds 11 million.[3] Breast cancer survivors are the most numerous, representing 24% of all cancer survivors, followed by prostate (20%), colorectal (10%), gynecologic (9%), hematologic (8%), urinary tract (7%), melanoma (7%), and thyroid (4%) malignancies (see Figure 1, p. 48). Cancer survivors also represent an aging population; 60% of cancer survivors are over the age of 65 (see Figure 2, p. 49). This ever-expanding population of cancer survivors is a credit to the success of research aimed at improving cancer treatment and supportive care; however, patients are emerging from that treatment with varied and often complex survivorship needs. As Dr. Julia Rowland, Director of the National Cancer Institute's Office of Cancer Survivorship, has pointed out, “Being cancer-free does not mean being free of cancer’s effects.”[4]

Cancer Survivorship: A Distinct Phase of Cancer Care
Although there are several variations defining when the phase of cancer survivorship begins—including the moment of diagnosis, completion of acute therapy, and living 5 years beyond diagnosis[5]—for the purposes of this discussion, we will focus on the definition used by the Institute of Medicine (IOM) in its seminal report released in 2006 entitled “From Cancer Patient to Cancer Survivor: Lost in Transition.”[1] In this report, the IOM defined cancer survivorship as the “phase of care that follows primary treatment.”

It is at the time of therapy completion that patients often experience a loss of the strong “connection” to their care team that sustained them through treatment. No longer returning regularly for treatment appointments, survivors often lack a concrete plan for follow-up and may be at a loss regarding whom to turn to for assistance in managing physical symptoms, emotional distress, and economic issues that often arise during the survivorship phase.

Many cancer survivors explain that reaching the end of therapy is a landmark on which they have set
their sights throughout therapy—with a much-anticipated goal of “getting back to normal.” Yet, when the important end-of-therapy milestone is reached, survivors are often surprised that instead of experiencing celebration and relief, they instead find themselves coping with uncertainty and feelings of abandonment.[6] With active treatment over, anxiety regarding the possibility of cancer recurrence often emerges. Many also discover that what they previously conceived of as “normal” no longer exists. Cancer has forever changed them, and they find that they must adapt to the “new normal” that living with the consequences of cancer and its therapy requires.[7]

The Cancer Control Continuum has been employed by the National Cancer Institute since the 1970s to define the phases of cancer care, including prevention, early detection, diagnosis, treatment, and end-of-life. Survivorship is now recognized as a phase along this continuum, taking its place at the end of primary treatment, and encompassing the domains of psychosocial coping, surveillance, long-term follow-up, management of late effects, and health promotion.[1] The necessity of providing specialized care to meet the unique needs of patients during the survivorship phase of the cancer care continuum is therefore clear.[8] Nurses are in a unique position to take the lead in defining survivorship care—because of nursing’s focus on health promotion and supportive care, and because nurses typically are in the position of assisting patients in managing sequelae such as pain and other symptoms that often occur following treatment.[9,10]

**THE CHALLENGES OF CANCER SURVIVORSHIP**

A diagnosis of cancer forever changes the life of a patient, shakes him or her to the very core. Treatment is often toxic, placing survivors at risk for treatment-related sequelae. Consequences of cancer and its therapy may be psychological, including fatigue, anxiety, depression, sexual problems, and learning to live with the awareness of having faced and survived a life-threatening illness. Psychological challenges faced by survivors after cancer treatment have been reviewed in ONCOLOGY Nurse Edition’s survivorship series by Recklitis, Sanchez-Varela, and Bober.[11] Social challenges (eg, economic hardships, workplace discrimination, problems with interpersonal relationships) are also commonly faced by cancer survivors and have been reviewed by Hara and
Consequences of cancer therapy also generally involve physical changes. These physical changes may be related to the long-term effects of cancer and its treatment (such as disfigurement and difficulties with speech and swallowing resulting from surgery and/or radiation for head and neck cancer) and may require an extensive period of rehabilitation and adaptation on the part of the survivor. Physical changes may also occur in the form of late-onset complications of cancer therapy, such as congestive heart failure occurring as a late consequence of anthracycline chemotherapy for treatment of breast cancer.

While psychosocial challenges faced by survivors often cut across diagnoses and treatment types, physical changes are linked with treatments; therefore, complications are often unique to the specific treatment that each survivor received for his or her particular type of cancer. Ongoing awareness of and surveillance for these potential problems is required in order to identify and treat these physical complications at an early stage, when interventions are most likely to be effective.[13,14] The late physical complications of treatment in adult cancer survivors have been reviewed in this series by Stricker and Jacobs.[15]

In addition, health promotion activities may play a role in preventing some of the late complications of cancer therapy, presenting healthcare providers with a significant opportunity—the so-called “teachable moment”—when survivors are most open to adopting health promotion behaviors, such as smoking cessation, dietary changes, and increased physical activity.[14,16]

**Challenges in Care Delivery**

Delivering care to cancer survivors presents many challenges to healthcare providers and the healthcare delivery system. Foremost among these challenges is the complexity of survivorship care delivery dictated by the diversity of patients, diagnoses, treatments, and potential sequelae,
Survivorship Care: Essential Components and Models of Delivery
Published on Cancer Network (http://www.cancernetwork.com)

Consequences of cancer treatment span the medical, psychosocial, socioeconomic and spiritual domains, and survivors and their healthcare providers often lack awareness of treatment-related risks and the potential interactions of these risks with common comorbidities, such as obesity, diabetes, cardiovascular disease, anxiety, and depression. Although efforts are moving forward to address the absence of evidence-based guidelines to provide overall direction for survivor care,[17] the current lack of standardized guidelines results in a dearth of consensus among providers regarding the specifics of necessary follow-up services.[18]

Lessons from Pediatric Oncology
Childhood cancer survivors represent only 1% of the cancer survivor population in the United States[3] (see Figure 2), yet in many instances pediatric oncology has led the way in advancing cancer treatment and in identifying the importance of monitoring for the long-term consequences of those treatments.[4,19] Much of this success has occurred as a result of the limited numbers of childhood cancer cases, which dictated the need for cooperative group research from the early days of pediatric oncology clinical trials.[20] More recently, the Children’s Oncology Group (COG; the NCI-supported cooperative pediatric oncology clinical trials group) pooled their expertise to develop long-term follow-up guidelines for childhood cancer survivors.[21] The COG’s Long-Term Follow-Up Guidelines represent a hybrid of evidence-based and consensus-based recommendations in which therapeutic exposures are linked to associated late effects via the literature and then coupled with consensus-based recommendations for screening endorsed by an expert panel.[21] These exposure-related guidelines are designed to direct follow-up care for childhood cancer survivors who are 2 or more years following completion of therapy. They are intended to be used in tandem with a cancer treatment summary to identify pertinent late complications for which a survivor is at risk and to develop an individualized plan for ongoing surveillance, health education, and health promotion based on a particular survivor’s specific treatment history.[22,23] These guidelines, along with the standardized treatment summary template and health education materials, are available for downloading from www.survivorshipguidelines.org.

COMPONENTS OF SURVIVORSHIP CARE

Essential elements of cancer survivorship care include: (1) rehabilitation, resulting in optimization of each survivor’s health potential; (2) surveillance for cancer recurrence; (3) detection of and intervention for late consequences of cancer and its treatment; (4) health promotion (eg, nutrition, exercise, smoking cessation), particularly when aimed at reducing the risks related to development of subsequent malignancies and comorbid conditions that may be exacerbated by cancer treatment; (5) psychosocial support (eg, counseling, support groups); and (6) evaluation of and intervention for socioeconomic consequences of cancer and its treatment (eg, job discrimination, school difficulties) (see Table 1, p. 50).[1,5,8]
Two vital components necessary for optimizing cancer survivorship care and ensuring that all essential elements are addressed for each survivor include coordination of care between specialists and primary care providers (PCPs) and the provision of a written follow-up plan.[24,25]

Coordination of Survivorship Care
Coordination of care is an essential element of care for cancer survivors, since often multiple providers are needed in order to optimize care during the survivorship phase. Regular, effective communication between specialists and PCPs is therefore crucial to the provision of seamless care,[26] and delineation of roles and responsibilities between providers is imperative.[27] One healthcare professional should be identified as the coordinator of care, particularly if multiple referrals are needed. This care coordination is a natural role for nursing, although it is sometimes handled by the oncologist or PCP.

Engaging the survivor in the care coordination process, when possible, is another way to ensure that needs are addressed. By providing survivors with targeted education regarding their follow-up needs, and encouraging them to advocate for needed services (eg, reminding providers when upcoming screening tests are due), survivors become an integral part of their healthcare team, working together toward the goal of optimizing health following cancer treatment. Thus, educated patients who are active participants in their own care are essential to the success of survivorship care.

Written Follow-Up Plan
A written follow-up plan (known as a “Survivorship Care Plan” or “Prescription for Living”) is also an integral component of high-quality care for cancer survivors.[10,28] This written plan, initiated by the oncology specialty team, should contain essential facts about the survivor’s diagnosis and treatment, along with follow-up recommendations that address the six essential elements of survivorship care (see Table 1), along with specific recommendations for ongoing adjuvant therapy (eg, hormonal therapy), a schedule for surveillance for cancer recurrence and screening for other cancers, and referrals to specialists for management of identified needs.[29]

Details regarding the Survivorship Care Plan will be discussed in an upcoming issue of ONCOLOGY Nurse Edition.

MODELS OF SURVIVORSHIP CARE DELIVERY

Multiple models have been proposed for delivery of cancer survivorship care. There is no one “correct” model, and a number of factors are involved in determining a model that best fits the needs of a given institution and patient population, including such considerations as local and institutional resources, geographic location, and limitations related to insurance reimbursement.[24] Organized survivorship programs have been present in pediatric oncology practice since the 1980s.[30,31] These early survivorship programs were academically based and often nurse-led, with the goal of following childhood cancer survivors over time in order to monitor for, identify, and treat complications related to cancer treatment. Over the years, a variety of survivorship models have been developed to meet the unique needs of institutions, patient populations, and geographic regions. In 2007, the COG released a Long-Term Follow-Up Program Resource Guide (available for downloading at www.survivorshipguidelines.org), designed to assist institutions in establishing and enhancing services for childhood cancer survivors.[32] This Resource Guide addresses many issues relevant to establishment of adult survivorship programs (eg, challenges and barriers to care delivery, funding and reimbursement, care delivery models, incorporation of survivorship research, patient advocacy, and practical resources such as sample clinic forms and templates).

Many adult survivorship care models are patterned after the models originally established in pediatric oncology. These models include academic/oncology-based models (which may include programs that are disease-based, treatment-based, or comprehensive), community-based models (primary care-based), and “shared care”—combining elements of both models.[33] Within each of the models, diverse care delivery systems have been established by various institutions, including a consultative model, a prospective ongoing care model, and an integrated care model.[34] An overview of survivorship care models is provided in Table 2, and a review of care delivery systems is provided in Table 3 (p. 52).
Survivorship Care: Essential Components and Models of Delivery

Published on Cancer Network (http://www.cancernetwork.com)

Academic/Oncology-Based Models
Academic/oncology-based models are typically based in a cancer center, but may also be based at a community oncology practice. Within this model, survivorship programs may be organized by diagnosis (eg, breast cancer, prostate cancer, adult survivors of childhood cancer) or by treatment type (eg, radiation, hematopoietic cell transplant), or the program may provide comprehensive care for all cancer survivors without restriction as to diagnosis or treatment. The academic/oncology-based survivorship models were first employed in pediatric oncology over 2 decades ago, and many cancer centers continue to find this model suitable for provision of survivorship care, particularly in populations with complex survivorship needs or in centers with large numbers of survivors.

Community-Based Models
In community-based models, cancer survivorship care is provided in the survivor’s home community by the PCP (specializing in internal medicine, family practice, or pediatrics). Referral for specialist care is provided by the PCP when needed, and primary care may be augmented through use of community resources (eg, support groups, pastoral care, physical and occupational therapy services). Community-based survivorship care was evaluated by Grunfeld et al. in a study of early-stage breast cancer survivors randomized to follow-up care provided at a cancer center or by their family practitioner; there were no differences in outcome in regard to recurrence-related serious clinical events or quality of life outcomes between the groups.[35] Yet Mao et al. noted areas of difference in their cross-sectional survey of breast cancer survivors seen in an outpatient clinic of a large university hospital. They found that while survivors highly endorsed PCP care in areas related to psychological well-being, health promotion, and holistic care, ratings of PCP care related to specific cancer survivorship issues (ie, symptom diagnosis and management, surveillance for late effects) was lower, and significant concern was expressed regarding inter-specialty communication, with only 28% of survivors perceiving that their PCP and oncologist communicated well.[27]
### Table 2: Models of Survivorship Care

<table>
<thead>
<tr>
<th>MODEL/SUBTYPE</th>
<th>EXAMPLES</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Academic/Oncology-Based Care</strong></td>
<td>Cancer centers, community oncology practices</td>
</tr>
<tr>
<td>• Disease-Based Programs</td>
<td>Breast cancer, prostate cancer, adult survivors of childhood cancer</td>
</tr>
<tr>
<td>• Treatment-Based Programs</td>
<td>Radiation therapy, hematopoietic cell transplant</td>
</tr>
<tr>
<td>• Comprehensive Programs</td>
<td>All cancer survivors regardless of diagnosis, age, or treatment</td>
</tr>
<tr>
<td><strong>Community-Based Care</strong></td>
<td>Primary care practices</td>
</tr>
<tr>
<td>• Family Practice/Internal Medicine-Based</td>
<td>Survivors of adult and childhood cancers</td>
</tr>
<tr>
<td>• Pediatric-Based</td>
<td>Young childhood cancer survivors</td>
</tr>
<tr>
<td><strong>Shared Care</strong></td>
<td>Shared primary and oncology care</td>
</tr>
<tr>
<td>• Without transition</td>
<td>Survivor is seen periodically at the cancer center and co-followed by the PCP for primary care needs (eg, intercurrent illness, health promotion, management of comorbidities)</td>
</tr>
<tr>
<td>• With transition</td>
<td>Survivor is followed by cancer center for a set time period and then care in its entirety is transferred to the PCP, who maintains periodic contact with the cancer center</td>
</tr>
</tbody>
</table>
Shared Care
In the “Shared Care” model, patients receive survivorship care through the combined services of both the cancer center and PCP.[33,36] In this model, the cancer center may continue to follow the patient on a periodic basis (eg, yearly), with care for intercurrent illness and health maintenance provided by the PCP. Alternatively, the cancer center may transition the patient’s care back to the PCP in its entirety at a set point following treatment (often 1 to 2 years following completion of therapy). The PCP then re-consults the cancer center if problems arise.

The role of the PCP in this model is to assess and manage the “totality” of the survivor’s health care needs—both physical and emotional. Such needs may include management of comorbid conditions, preventive care, health promotion, and coordination of specialist referrals.[24] The role of the specialist in the shared care model is to provide focused expertise, guidance, and treatment according to his or her specialty, and to clearly communicate the plan for survivorship care to the PCP. Implicit to the success of this model is continued two-way communication between the cancer center and PCP regarding the patient’s condition and any new developments in the oncology field that may be relevant to the patient’s care and follow-up. The “Shared Care” model is particularly suitable for patients who received less intensive therapy and so are at lower risk for long-term complications. With some refinements, this model also may be appropriate for moderate-risk patients. However, follow-up care for patients who received intensive therapy (eg, hematopoietic cell transplant) is generally overseen by the cancer center on an ongoing basis.

SURVIVORSHIP CARE DELIVERY SYSTEMS
Consultative
The consultative system of survivorship care delivery may involve a one-time comprehensive consultation with a cancer center–based survivorship program, during which the survivor’s therapy is thoroughly reviewed and a detailed plan for follow-up is developed and conveyed to the survivor and his PCP, or it may involve additional consultations, sometimes provided on a yearly basis, during which the cancer center provides additional evaluation and updating of the survivor’s follow-up plan. Consultative systems rely on the PCP to provide ongoing care and management of the survivor’s everyday healthcare needs.

Ongoing Care
Ongoing care is a specialized care delivery system in which the cancer survivor is followed in a survivorship care program within a cancer center or oncology practice. These ongoing survivorship programs are generally academically based and may be organized by disease or treatment modality, as described. Care in these specialized survivorship programs is often nurse-led (eg, care is coordinated by a nurse or provided directly by a nurse practitioner). In some programs, particularly those serving childhood cancer survivors and those at high risk of long-term complications (eg, brain tumor survivors), care may be provided by a multidisciplinary team. Team members are specific to each survivor’s needs and may include an oncologist, surgeon, radiation oncologist, advanced practice nurse, PCP, psychologist, social worker, dietitian, rehabilitation specialist, and medical subspecialists (eg, endocrinologist, cardiologist) if needed.
Survivorship Care: Essential Components and Models of Delivery

Integrated Care

Integrated care is a system in which survivorship care is embedded directly within the primary oncology team. In this system, survivors remain under the care of their original oncology treatment team, and receive their survivorship care from a member of their treatment team, generally a mid-level provider. Survivorship care may then be transitioned to a primary care provider when deemed appropriate by the treatment team.

CONCLUSIONS

Survivorship care has been identified as an integral and important phase of the cancer care
continuum. It is during the survivorship phase that healing from cancer and its treatment can truly be accomplished. Although there is currently no consensus regarding the best strategy for providing survivorship care to the rapidly burgeoning survivorship population, many models have been developed to meet the needs of a variety of institutions and patient populations. Regardless of the model or system of survivorship care delivery, well-coordinated, effective, and comprehensive survivorship services are required in order for cancer survivors to have the best chance for achieving their optimal level of health following cancer treatment.


**Source URL:**
http://www.cancernetwork.com/oncology-nursing/survivorship-care-essential-components-and-models-delivery

**Links:**
[1] http://www.cancernetwork.com/oncology-nursing
[3] http://www.cancernetwork.com/authors/wendy-landier-rn-msn