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CANCER SURVIVOR DEFINITION

The Institute of Medicine's (IOM; now the National Academy of Medicine) landmark report, *From Cancer Patient to Cancer Survivor: Lost in Translation*, raised awareness of the need to address the specific issues that cancer survivors encounter after completing their cancer treatment (1). In 1986, the National Coalition for Cancer Survivorship introduced one of the first definitions of *cancer survivor* by stating that a patient who has had cancer is a cancer survivor from the time of diagnosis through the remainder of his or her life (2). This broad definition takes into account the entire spectrum of the cancer journey—diagnosis, treatment, remission, surveillance, after-cancer care, and end of life. The cancer journey affects caregivers, family members, and friends; therefore, all of these people also are recognized as survivors. The National Cancer Institute (NCI) customized the definition of survivorship, stating that it is the “health and life of a person with cancer post treatment until the end of life” (3). Survivorship encompasses the physical, psychosocial, and economic issues of cancer beyond the diagnosis and treatment phases. Survivorship involves issues related to the ability to obtain healthcare and follow-up treatment, late effects of treatment, second cancers, and quality of life (3). The focus of this chapter is the care of adult survivors who have completed their curative treatment. This handbook's authors acknowledge NCI's definition and recognize survivorship as a distinct period that commences after treatment is complete and the time during which recurrence most likely has passed. Healthcare providers in all types of clinical settings and practices need to prepare to care for growing numbers of cancer survivors.

This chapter introduces basic concepts used in the specialty of cancer survivorship such as risk stratification and survivorship care models that transition survivors from treating oncologists to providers who specialize in survivorship care. A clinical vignette demonstrates how survivorship concepts, models, and risk stratification can be integrated into routine clinical practice.

SURVIVORSHIP STATISTICS

According to statistics from the Surveillance, Epidemiology, and End Results (SEER) database, approximately 15.5 million cancer survivors resided in the United States in 2016 (4,5). SEER data estimate this number will increase to 20.3 million by 2026.

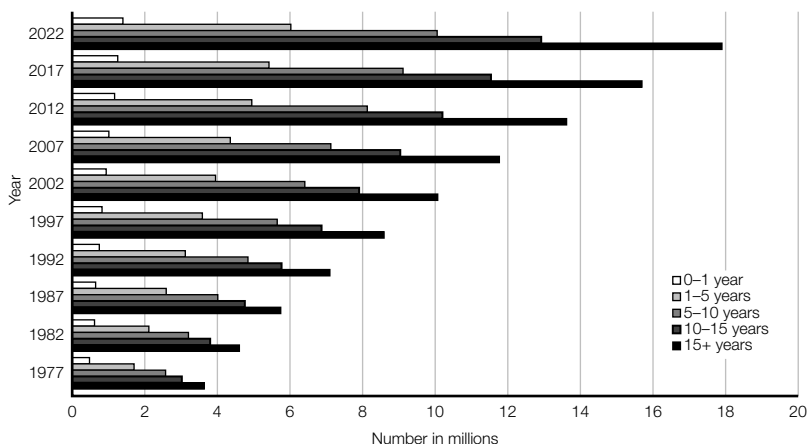


FIGURE 1.1 Cancer survivor statistics by age group.

Source: Adapted from de Moor JS, Mariotto AB, Parry C, et al. Cancer survivors in the United States: prevalence across the survivorship trajectory and implications for care. *Cancer Epidemiol Biomarkers Prev.* 2013;22(4):561–570. doi:10.1158/1055-9965.EPI-12-1356

By age distribution, 74% are 60 years of age and older, 21% are 40 to 59 years old, 4% are 20 to 39 years old, and fewer than 1% are younger than 20 years old (4,5). Approximately two-thirds of patients with cancer live at least 5 years after receiving their diagnosis, with many survivors living 15 years or longer after diagnosis (Figure 1.1). The most common cancers for men are prostate, colon, rectum, and melanoma, whereas breast, uterine corpus, and colorectal cancers are the most common cancers for women (6).

FORCES DRIVING SURVIVORSHIP CARE

In 1985, Fitzhugh Mullan, a physician and cancer survivor, published “Seasons of Survival: Reflections of a Physician with Cancer” (7). This article chronicled his personal cancer story and launched a movement in which patients with cancer shared their concerns related to life after cancer treatment (7). Dr. Mullan’s work and the IOM report gave cancer patients a forum in which to voice their concerns regarding the impact of symptom management (physical and psychosocial) after treatment, the onset of late effects, and poor coordination of medical care attributed to a lack of communication among providers (1,7). Other factors contributing to the increase in cancer survivors include an aging population, early detection, and improved treatment modalities (8).

In 2013, the IOM published a second report, *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*, which called for a dramatic shift in the broken, cost-prohibitive cancer-care delivery system. This care model defined

survivorship as a distinct cancer care phase (9) and described a patient-centered, evidence-based approach to care; a system for sharing of critical patient information; and ways to cultivate collaborative practice among all caregivers. Organizations such as the Centers for Disease Control and Prevention, NCI, and the American Cancer Society continue to highlight the need to recognize and address cancer survivors' long-term needs. The Commission on Cancer, an accrediting body, has published quality measures focused on improving cancer care (10). The measures mandate that an all-inclusive treatment summary and follow-up plan be provided to patients who complete curative cancer treatment. Chapter 2 provides a detailed description of these critical documents and their role in survivorship care.

DOMAINS OF SURVIVORSHIP CARE

The premise of survivorship care is to shift patient care from a model of illness to one of wellness. Typically, patients are transitioned to a survivorship clinic after surviving beyond the interval during which risk is highest for recurrence of their primary malignancy. The IOM outlined four domains for the delivery of survivorship care: surveillance, monitoring for late effects, preventive services, and psychosocial health (1). These domains are listed in Figure 1.2.

Cancer surveillance and screening
<ul style="list-style-type: none"> • Detection and treatment of late malignancy recurrence or new second malignancies
Late effects/side effects management
<ul style="list-style-type: none"> • Health maintenance and observation of vital organ function
Risk reduction and cancer prevention
<ul style="list-style-type: none"> • Lifestyle changes to prevent cancer and risk assessment
Psychosocial functioning
<ul style="list-style-type: none"> • Psychosocial support services to maintain healthy relationships and restored life

FIGURE 1.2 Core domains of survivorship care as recommended by the Institute of Medicine.

Source: Institute of Medicine. *From Cancer Patient to Cancer Survivor—Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine symposium*. Washington, DC: The National Academies Press; 2006.

Surveillance is conducted to detect recurrence of the primary malignancy and assess for the likelihood of any second cancer. Prevention counseling is provided to encourage lifestyle changes including but not limited to smoking cessation, healthy living, energy balance, and dietary changes. The body of knowledge regarding the late effects of cancer treatments comes predominantly from studies of childhood cancer survivors. Children who received anthracycline during treatment and are now in their 40s and 50s are experiencing accelerated coronary artery disease (11–13). The body of knowledge regarding late treatment effects for adults with cancer continues to grow.

Other cancer-treatment modalities such as radiation may increase risk for other symptoms and conditions (11). Therefore, screening for late effects based on the specific treatment received is essential. The psychosocial and economic consequences of surviving cancer treatments are as important as the physical late effects. Patients and their families often face many challenges, including economic stress, loss or disruptions of relationships, and emotional distress that may last or manifest long after therapy is completed.

SURVIVORSHIP CLINIC MODELS

The University of Texas MD Anderson Cancer Center has three types of survivorship clinics that can serve as models of care for cancer survivors:

1. In the first model of care, survivorship patients transition from their primary disease treatment site to a cancer prevention center with multidisciplinary healthcare providers. Clinical leaders in cancer prevention provide operational oversight of these clinics. Included in this model are patients with breast, thyroid, and colon cancers.
2. A second model is one in which disease-specific clinics, such as genitourinary, melanoma, and sarcoma clinics, provide survivorship care within each of their each disease-specific centers. A steering committee with representation from each primary oncology discipline (radiation, surgical, and medical) within the center governs the operation of each clinic. The primary oncology discipline refers patients to clinics in which care is delivered based on the four domains of survivorship care.
3. A third model is referred to as a comanagement model and is used in MD Anderson's hematology malignancy clinics. Patients who have received a stem-cell transplant schedule visits with a survivorship provider when they see their stem-cell transplant physician. Clinical operations are governed through an internal operations leadership team.

THE INTERDISCIPLINARY SURVIVORSHIP TEAM

The emergence of survivorship as a distinct phase of cancer care carries with it established and new knowledge regarding care delivery, practice, and technology. To address these issues, MD Anderson has developed survivorship practice algorithms. Each disease-specific algorithm defines patient eligibility, surveillance, late effects, risk reduction and prevention, and psychosocial function. A discussion regarding algorithms as clinical tools appears in Chapter 2 of this handbook.

Individuals' responses to treatment and the threat of recurrence are contingent on the type and stage of a primary malignancy. A risk stratification approach can help to address each survivor's unique, complex needs. McCabe and colleagues described risk-based care as "a personalized systematic plan of periodic screening, surveillance, and prevention relevant to the cancer experience" (14).

MD Anderson has developed an interdisciplinary team approach that is the foundation of algorithms for cancer survivors. This model of care addresses each patient's treatment response and recurrence threats that are contingent upon the type and stage of the primary malignancy. Age, sex, and overall health status primarily influence treatment type and may affect responses to treatment received.

Care for cancer survivors should be tiered based upon risk factors and degree of care required. Figure 1.3 provides an example of each tier.

- Tier 1: Patients in this group are at low risk for complications or recurrence. The aims of care are symptom management, smoking-cessation counseling, energy balance, and healthy living
- Tier 2: These patients are at risk for late effects of treatment; they have received combined-modality therapies including chemotherapy, radiation, and surgery. This subgroup is at higher risk for secondary cancers, and primary care providers and oncologists should comanage follow-up care
- Tier 3: Patients in this category are at high risk if they experience a cancer recurrence or late effects from their treatment. Patients who undergo stem-cell transplantation, for example, fall into this tier. These patients should be followed closely by an oncologist and primary care provider to manage comorbid conditions and health issues

As providers in a major comprehensive cancer center with 12 disease-specific clinics, clinicians at MD Anderson have established survivorship care from a unique

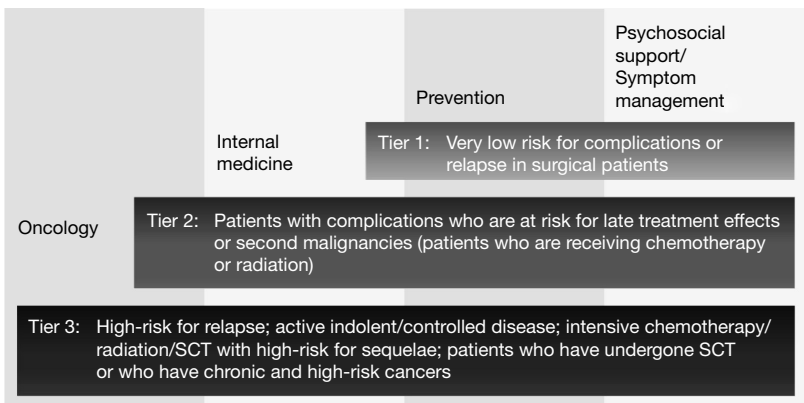


FIGURE 1.3 Stratified tiers of medical risk. SCT, stem cell transplantation.

perspective. Clinical, educational, and research aspects are combined to provide high-quality survivorship care. Care for long-term survivors must be tailored to each patient. Models of care delivery can vary in their operational structure but must be clinically designed to optimally address complication risks and include the key IOM domains for the delivery of survivorship care: surveillance, prevention, monitoring for late effects, and psychosocial health. Healthcare providers must deliver care based on individual survivor needs.

The number of cancer survivors continue to increase. The aim of survivorship care is to address the impact of cancer care and its therapies in an effort to improve survivors' health and quality of life. Therefore, care for long-term survivors must be tailored to each patient. Models of care delivery are most optimal when they address complication risk while including the key domains of surveillance, prevention, monitoring of late effects, and psychosocial health.

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