

# Chapter 8

## Survivorship



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### Abbreviations

AHRQ	Agency for Health Care Research and Quality
ASCO	American Society of Clinical Oncology
CoC	Commission on Cancer
FP	Family physician
IOM	Institute of Medicine
NCCN	National Comprehensive Cancer Network
NCI	National Cancer Institute
PCP	Primary care provider
SCP	Survivorship care plan

### Introduction

One of the great successes of cancer care in the twenty-first century is that it has created a large cohort of cancer survivors who have unique needs as a result of the experience of cancer. In 2017, it is estimated that there will be 1,688,780 new cancer cases and the overwhelming majority will survive to add to the ever-growing cohort of cancer survivors [1]. Over the past 30 years, the 5-year relative survival rate for all cancers combined has increased for both sexes and among whites and blacks [1]. This success has translated into more than 15.5 million Americans alive with a history of cancer on January 1, 2016, and a projected 20 million-plus by January 1, 2026 [2]. This rising number of individuals who have had the personal experience of a cancer diagnosis and treatment have taught us that being a cancer patient is life

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changing and the effects of the experience last long beyond the active treatment phase.

As early as 1985, the renowned physician and cancer survivor, Fitzhugh Mullan, MD, described the experience of cancer as a series of seasons. He is credited with coining the term “cancer survivor” to describe his experience. In his essay published in the *New England Journal of Medicine* entitled “Seasons of Survival: Reflections of a Physician with Cancer,” Dr. Mullan put out a call to action to “not only find therapies that will prevent or arrest the disease quickly but also to map the middle ground of survivorship and minimize its medical and social hazards” [3]. Furthermore he spoke to the need for studying survivorship as a “phenomenon in itself” that had unique characteristics separate from the traditional studies of tumor biology and treatment. In this book, we use the definition of cancer survivor as listed in the National Cancer Institute (NCI) Dictionary of Cancer Terms that considers a person to be a cancer survivor from the time of diagnosis until the end of life [4].

While this call to action simmered for many years, it exploded into life when National Academies of Science Institute of Medicine (IOM) convened the Committee on Cancer Survivorship: improving care and quality of life. The report that followed was part of a series of examinations by the IOM on the experience of cancer in the United States. This particular committee was charged with reporting on the survivors of adult cancer after primary treatment. The report published in 2005, *From Cancer Patient to Cancer Survivor: Lost in Transition*, had three aims based on an acknowledgement by the committee that the effects of cancer treatment and the experience of cancer had substantial impact on the physical and psychosocial health of survivors [5].

### ***Aims of the IOM Report “From Cancer Patient to Cancer Survivor”***

- Raise awareness of the medical, functional, and psychosocial consequences of cancer and its treatment.
- Define quality health care for cancer survivors and identify strategies to achieve it.
- Improve the quality of life of cancer survivors through policies to ensure their access to psychosocial services, fair employment practices, and health insurance [5].
- In raising awareness of cancer survivorship, the committee identified four essential components: prevention, surveillance, intervention, and coordination [5]. From a medical perspective, the prevention and identification of recurrent or new cancers are essential for physical and mental health and well-being. Recognition of the late effects of cancer treatments is also necessary to promote wellness. As a partner to prevention, there is a need for the development of strategies for surveillance of cancer recurrence and new primaries and assessing the late effects of treatment on the physical and psychosocial health across the spectrum.

Interventions that holistically address the effects of cancer and its treatments on the person, their caregivers, and society are essential to supporting a cancer patient's return to wellness. Lastly, coordination and communication among patients, cancer care providers, and primary care providers are necessary to ensure that the transition from treatment to living again is overseen in a seamless fashion.

To address the aims of the Committee, ten recommendations in ten domains were offered to the stakeholders of the cancer experience, ranging from cancer patients and advocates to public and elected officials [5].

### ***Areas for Recommendation in IOM Report from Cancer Patient to Cancer Survivor***

1. Raising awareness of cancer survivorship
2. Providing a care plan for survivorship
3. Developing clinical practice guidelines for survivorship care
4. Defining quality health care for cancer survivors
5. Overcoming system delivery challenges
6. Survivorship as a public health concern
7. Improving healthcare professional capacity
8. Addressing employment-related concerns
9. Improving access to adequate and affordable health insurance
10. Making investments in research

Underlying all of the recommendations was the recognition of cancer survivorship as a distinct phase of cancer care that needs to be recognized by the medical community and state and federal organizations that provide care and resources for health. There was a clear message that research into effective assessments, treatment, and support services for cancer survivorship is necessary and as important as research into the diagnosis and treatment of active cancer. Additionally, there has been an explicit call to insurers and payers of health care to ensure that evidence-based services rendered to the cancer survivor along the continuum of care are fully reimbursed to providers. The recommendations have provided a detailed list of actions to be taken on behalf of the cancer survivor. While full implementation has not been completed, much has been accomplished in the intervening years.

Following the 2005 IOM report, a number of national organizations began to implement the recommendations to improve and support cancer survivorship. Two areas of intense activity included the development of tools for use by providers of care to cancer survivors and integration of cancer survivorship into cancer program accreditation standards. Organizations such as American Society of Clinical Oncology, Journey Forward, LiveStrong, Penn Medicine OncoLink, the American Cancer Society, electronic health record providers, and others have worked to

provide tools to make the delivery of survivorship care plans and treatment summaries easier for oncology teams. With the American College of Surgeons Commission on Cancer (CoC), *Cancer Program Standards 2012: Ensuring Patient-Centered Care*, accredited hospital cancer programs were required to develop an implementation plan for psychosocial distress screening and survivorship care plans [6, 7]. Recognizing the challenges associated with meeting these new patient care standards, programs were asked to have significant implementation by 2015. Even this proved daunting and based on feedback from accredited programs, additional modifications to include a broader group of health professionals who could provide patients with a survivorship care plan were integrated into the updated Standard 3.3 Survivorship Care Plan in CoC *Cancer Program Standards 2016: Ensuring Patient-Centered Care* [8].

The timing of this attention to cancer survivors also coincided with a national movement toward inter-professional and multidisciplinary health care. Thus, health providers of all types were empowered to engage in supporting cancer survivors at a heightened level. Given the key role of nurses in cancer care, the nursing profession embraced the opportunity to provide leadership and research in cancer survivorship and particularly in the areas of distress assessment and management and development of survivor-focused comprehensive programs. All cancer-related disciplines have been inspired to participate in new avenues of research into the development of effective cancer survivor programs and communication tools. In addition, how to reengage with primary care providers and navigate the transition of patients from treatment to living again have been studied to develop evidence-based approaches to providing support for the patient with cancer.

## **Transition from Treatment to Living Again**

While recognizing that cancer survivorship begins at diagnosis, the transition from active treatment to living again has been an area of intense exploration over the past few years. The growth of clinical practice guidelines regarding the key areas of focus for cancer survivors after active treatment has helped healthcare providers screen for issues and provide evidence-based interventions. Many clinical practice guidelines have been developed to reflect the key areas impacting quality of life for cancer survivors.

Ferrell and colleagues at the City of Hope National Medical Center are credited with adapting quality-of-life measures to a conceptual framework applied to cancer survivors [9]. The model takes into account four domains: physical well-being and symptoms, psychological well-being, social well-being, and spiritual well-being. Using a patient-centered approach, the quality-of-life model validated the key health effects of cancer and its treatment over time and provided a framework from which assessments and programs could be developed. For the cancer survivor, the physical well-being of cancer survivorship can be captured by understanding the patient's functional activities, strength and levels of fatigue, quality

of sleep and rest, overall physical health, fertility, and pain. Of particular concern to patients is psychological well-being. Beyond the distress of diagnosis and being in control of treatment, overall control of one's life, anxiety, depression, and enjoyment of life are specific elements relevant to the cancer survivor. The patient moving onto life after treatment must also manage the fear of recurrence. Patients who have undergone systemic chemotherapy may have challenges with cognition and attention. The effects of chemotherapy on the brain of cancer survivors is an area of rich exploration at present. Ferrell and colleagues were also able to capture social and spiritual well-being domains of importance for cancer survivors. The impact of cancer transcends the individual and impacts family, relationships, roles, finances, and work. Appearance and sexual function may be impacted by physical changes after treatment and interplay of a diagnosis of cancer in a relationship. Spiritually, cancer survivors note reflection on the meaning of illness, dealing with uncertainty and finding inner strength and hope and engagement in religion. This understanding of the experience of life after cancer has provided a framework for the development of tools and programs to support survivors.

The National Comprehensive Cancer Network (NCCN) has taken a leadership role in producing a comprehensive evidence-based resource of clinical practice guidelines available to cancer survivor care providers at its website, [www.nccn.org](http://www.nccn.org). Two guidelines of interest are the Survivorship and Distress Management guidelines [10, 11]. The guideline developed for survivorship provides an evidence-based approach to cancer survivor assessment and intervention. It is created and updated by a NCCN Survivorship panel which reviews key literature and provides regular updates to the guidelines. The panel is a multidisciplinary and inter-professional group of experts representing the broad range of individuals who are integral to the care of cancer patients. This group includes an oncologist, bone marrow transplant expert, urologist, gynecologist, nutritionist, cardiac specialist, infectious disease specialist, primary care provider, exercise physiologist, nurse, epidemiologist, and patient advocate. Within the Survivorship guideline, algorithms cover ten domains: cardiac toxicity; anxiety, depression, and distress; cognitive function; fatigue; menopause; pain; sexual function; sleep disorder; healthy lifestyle; and immunizations and infection. Also included is a comprehensive list of online support tools with topics ranging from physical and mental health to legal and employment issues and integrative therapies. It is important to note that inclusion of survivorship guidelines and distress management guidelines in this publically available resource adds impact to the concept that cancer survivorship is a separate but important dimension in the life of cancer patients.

Another organization which has championed the cause of cancer survivorship is the American Society of Clinical Oncology (ASCO). Similar to the NCCN, ASCO has a multidisciplinary and inter-professional Survivorship Committee. As an organization, ASCO has worked to help provide resources and define the answer to the question "Who is responsible for survivorship care?" The Survivorship Compendium available on the ASCO website at [www.asco.org](http://www.asco.org) has multiple tools, templates, and educational products to support the provider of cancer survivorship care, including

a professional education curriculum [12]. The ASCO Core Curriculum for Cancer Survivorship Education was developed after the ASCO Survivorship Committee in collaboration with the ASCO Professional Development Committee performed an environmental scan and recognized that while many resources exist, there is no single resource that prepares providers comprehensively for work with cancer survivors. Of particular emphasis is the importance of communication in care coordination for cancer survivors [13].

Many models of care exist to support the cancer survivor. However, the effectiveness of these models remains uncertain and have many challenges. Based on a technical brief prepared for the Agency for Healthcare Research and Quality (AHRQ), Halpern and colleagues analyzed the current evidence for cancer survivor health outcomes and provided a broad overview of the models of cancer survivorship care [14]. Four categories of programs were reviewed: physician-led, nurse-led, Survivorship Care Plan (SCP) development as a key component, and comparison of group versus individual counseling. The main conclusions were that additional studies were needed since limited information was available to date. Research should be based on the experiences of cancer survivors and a taxonomy should be developed to help create a common language allowing for the development of outcome metrics that are generalizable and for comparing outcomes across studies. Care coordination remains a challenge and integration across disciplines is difficult at best.

ASCO has also provided a way of considering long-term follow-up care for cancer survivors [15]. Eight different models of care with a summary of advantages and disadvantages are provided. The models are described based on the discipline taking the lead on care as well as whether a specialized setting has been created for care delivery. An emphasis on wellness versus disease management is a feature of many models. Shared models of care between oncology providers and primary care providers include a discussion of whether or not the patient transitions completely out of oncology provider care at some point (Table 8.1).

Other national cancer advocacy and education organizations have contributed to supporting the growing cancer survivor community and their care providers. This includes the LIVESTRONG organization which worked for a decade (2005–2015) in creating the Survivorship Centers of Excellence Network to advance survivorship care and improve the quality of life of cancer survivors after treatment [16]. Using the established NCI-designated comprehensive cancer centers, LIVESTRONG supported programs of a variety of types offering information, care, and services to cancer survivors, their families, and healthcare providers. Eight goals were established for the program centering on raising awareness of cancer survivorship, creating a body of evidence for survivorship care, increasing accessibility for underserved populations, and ensuring that survivor care was covered by insurance. The program successfully identified the benefits and challenges of providing survivorship care. The lessons learned have been used to create a new patient-centered effort to acknowledge and involve all cancer survivors from the beginning of their journey into more global LIVESTRONG Cancer Institutes that integrate principles of survivorship along the continuum of care.

**Table 8.1** Advantages and disadvantages of models of survivorship care

Model	Characteristics	Advantages	Disadvantages
Oncology specialist	Follow-up with oncology team	Continuity of oncology care	Focus on illness and relapse
Multidisciplinary survivorship clinic	Specialized team of experts, especially good for pediatrics	Complex patients benefit most, easy to use; experts in long-term care	Not needed by all; resource intensive
Community generalist care	Survivor care delivered by primary care provider	Focus on wellness	Difficult to stay current on changes in cancer care
Shared care of survivor	Care coordinated between primary care and oncology specialist	Flexible for all patients regardless of complexity; patient may or may not transition completely out of oncology care	Requires a high level of communication; time intensive
Disease- or treatment-specific clinic	Homogenous patient population	Easy for guideline compliance	Only available for cancers with high incidence
General survivorship clinic	Provides care for all cancers	Single provider with psychosocial expert support	Difficult to develop expertise in all cancers
Consultative survivorship clinic	One-time visit focused on delivery of survivorship care plan and treatment summary	Empowers patients and uses fewer resources	Limits long-term evaluation of side effects
Integrated survivorship clinic	Survivor care delivered as part of treatment setting	Survivorship expert delivers care within oncology setting	Patient may expect primary care to be delivered in the same setting and marginalizes primary care providers

## Distress Assessment and Management

A core component of providing care for cancer survivors is accurately assessing their needs—physical, psychosocial, and spiritual. Most care providers are comfortable with discussions of physical needs and changes after a cancer diagnosis. However, the other areas remain challenging. Patients are often reluctant to mention in a clinical care setting the concerns or issues they may have that fall outside of physical health and well-being. Thus, heightened awareness of holistic approaches to well-being while surviving cancer is needed to stimulate the development of assessment tools and intervention guidelines.

One of the ways to heighten awareness is to mandate it in accreditation settings. The American College of Surgeons CoC in its *Cancer Program Standards 2012: Ensuring Patient-Centered Care* created accreditation Standard 3.2 mandating programs to develop and implement a process to integrate and monitor on-site

psychosocial distress screening and referral for care [6]. The importance of screening for distress and psychosocial health needs as part of a high-quality cancer program was emphasized in the 2007 IOM report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, which served as the impetus for expanding access to services and developing tools for assessment [17].

The 2007 IOM report was based on the work of the NCCN that quickly developed the clinical care guideline Distress Management [11]. A multidisciplinary and inter-professional panel of experts in oncology, nursing, social work and counseling, psychology, psychiatry, and clergy was convened to review psychosocial care and to make recommendations regarding integration into cancer programs. Four steps are outlined as part of the process:

1. Screening for distress and psychosocial needs, including measuring the level of distress and screening at regular intervals and at times of vulnerability
2. Making and implementing a treatment plan to address the needs
3. Referring to appropriate services for care
4. Reevaluating and adjusting the plan as needed

In support of cancer care for the whole patient, the 2012 CoC Standard 3.2 was endorsed by the American Psychosocial Oncology Society, Association of Oncology Social Work, and Oncology Nursing Society with a joint position statement [18]. In it, a call for a universal definition of distress and the use of validated instruments for assessment was added to the recommendations of the NCCN as noted above. Furthermore, a task force was created to provide assistance and recommendations for meeting the standard [19]. Inclusion of a psychosocial representative on the hospital cancer committee with documentation of distress screening discussions is necessary to ensure that the standard is fully met. Timing for screening should occur not just at the initial visit but also at clinical visits when patients are at highest risk of distress such as during transitions of care. Both clinician-administered and patient-administered assessments of distress are valid and both have their place. Because oncology providers may fail to recognize patient distress, standardized screening is necessary. Prior to implementing screening, cancer programs need to develop pathways of full evaluation and referral so that if a screened patient is identified as distressed, intervention can be offered and begun as soon as possible. Documentation of the screening tool and results is imperative for communicating with other providers and to provide information to measure outcomes.

Many types of healthcare providers are able to administer the distress scales and provide support. In particular, distress assessment and management leadership has been embraced by oncology nursing professionals.

Distress as defined by the NCCN and adopted for use by others is defined as a multifactorial, unpleasant, emotional experience of a psychological, social, and/or spiritual nature that may interfere with the ability to cope effectively with cancer, its physical symptoms, and its treatment. [11] Distress exists along a continuum. Some patients due to other physical and mental health concerns may be at higher risk for moderate-to-severe distress. High levels of distress can make decision-making difficult and at its worst can promote nonadherence to treatment [20].



Given how the CoC Cancer Program Standard has only recently been fully implemented, data is sparse about the effectiveness of distress management in cancer survivors. However, there is at least one randomized controlled clinical trial that shows some evidence of diminished distress at future screenings in lung and breast cancer patients who underwent distress management as part of a comprehensive cancer program [21]. However, barriers remain to implementation such as buy-in among cancer professionals, lack of information on how to implement the screening, and ensuring that appropriate referrals are made when elevated stress is found [22].

## Survivorship Care Plans

The road map to cancer survivorship for the patient and care providers is the survivorship care plan (SCP). It is the key document that represents communication and care coordination during the posttreatment phase. It was explicitly called for in the IOM 2005 report as Recommendation 2 and it is to have two components: a comprehensive care summary and a follow-up plan that is clearly explained [5]. Additionally, it is to be written by the principal provider of oncology treatment and should be reimbursed by third-party payers. Information needed for long-term care includes cancer type, treatments, and possible side effects; a schedule for recommended follow-up; recommendations about preventive practices and how to maintain health; and availability of psychosocial services and information about legal protections for employment and health insurance.

The CoC implemented the Survivorship Care Plan Standard 3.3 beginning with the 2012 Standards and expected full implementation by 2015. As noted earlier, additional modifications with the 2016 Standards allowed a wider variety of individuals to provide the SCP than was originally described. This modification acknowledged both the broad range of cancer professionals who work intimately with cancer patients and the challenges of creating a tool that meets the needs of most patients and providers. In accordance with the IOM 2005 report, the treating oncology provider was initially the sole person who could provide the SCP to the patient. This was modified in the CoC 2016 Standards to include a wider array of oncology health professionals who often provide support and ongoing education for patients. The current list includes physicians, registered nurses, advanced-practice nurses, nurse practitioners, physician assistants, and credentialed clinical navigators. In a partnership with the ASCO, the CoC references the data elements described by ASCO to be included in the treatment summary and SCP [23]. The key components of the SCP include the treatment summary and the follow-up care plan. The treatment summary should include contact information, diagnosis, stage, treatments received, ongoing toxicity or side effects, genetic testing results, or recommendations. The follow-up care plan should include contact information, ongoing therapy, schedule for visits, a list of future tests, symptoms of possible recurrent cancer, late or long-term treatment effects, and psychosocial concerns. Ideally the SCP is pro-

vided to the patient at the end of the active treatment but at minimum to meet CoC Standard 3.3 delivery must occur within 6 months after completion of adjuvant therapy other than long-term hormonal therapy and up to 18 months after diagnosis for patients on long-term hormonal therapy.

A wide variety of organizations have worked to create both patient-generated and oncology provider-generated SCP templates. One of the most commonly used templates is the ASCO Treatment Summary and Survivorship Care Plan template [24]. It is suitable for most cancer types. Modified disease-specific templates for the most common types of cancers are also available. It is a provider-generated document that can be used to share both with the patient and primary care providers. The OncoLife Survivorship Care Plan by Penn Medicine is an online tool that allows patients to start the process and work with their providers to complete a full treatment summary and follow-up plan [25]. The Journey Forward organization has developed a mobile app for patients to start their SCP and complete it with their oncology team. It also includes a guided assessment to help patients identify specific concerns to be brought to their cancer team [26]. The American Cancer Society has developed a mobile app related to survivorship care. This app is for oncology providers to have easy access to evidence-based follow-up, side effect/long-term effects, and recommended testing for a variety of cancers which can then be used to develop SCP for patients or used by primary care providers for ongoing care [27].

One of the goals of SCPs and survivorship care has been to improve health and quality-of-life outcomes for cancer survivors. However, to date it has been difficult to show improved outcomes. A systematic review in 2014 of ten prospective studies of 2286 cancer survivors of a variety of common malignancies failed to show a significant effect of SCPs on cancer survivor distress, satisfaction with care, cancer care coordination, or oncologic outcomes in randomized controlled trials [28]. It has been suggested that many factors may be at play making it difficult to show benefit of using a tool such as the SCP [29]. The lack of standardization of SCPs makes it difficult to assess outcomes. Current SCPs do not contain the full complement of recommendations from the 2005 IOM Report. It has been postulated that the lack of comprehensive inclusion of the 2005 IOM recommendations may contribute why it has been difficult to demonstrate improved outcomes. Lastly, there are continued challenges in the transition from the oncology team to reengagement with the primary care team and effective communication among providers.

## **Implementation of the Survivorship Care Plan-A View from a Family Physician**

Family physicians (FPs) and other primary care providers (PCPs) are often the initial point of contact for patients presenting with cancer and follow-up care. Thus, the primary care team is well positioned to support the cancer survivor from the time of diagnosis and across the continuum of cancer survivorship. Initial symptoms of concern may be expressed and the FP or PCP will complete a physical

examination, create a differential diagnosis, and initiate a workup to determine the presence and/or absence of cancer. Educated patients through public health strategies are more prepared to look for symptoms of concern and these are commonly the presenting complaint at an office visit. Family history and patterns of heredity assist in prioritizing potential cancers of major concern for each patient. However, PCPs still need to be cognizant of the cancer potential in a differential diagnosis. Cancer treatments including surgery, chemotherapy, and radiation therapy have improved and patients with cancer may survive longer and have decreased morbidity. However, the complexity of the treatments has also increased and the rapid pace of changing treatment protocols adds to the difficulty of staying knowledgeable about the various impacts of the treatment on each patient. Thus, it is important to develop a SCP for patients that can be communicated in language that is understandable to the patient and the family who may then bring the document to their FP or PCP for further discussion.

The initial diagnosis may be made by the FP or PCP and will often require a referral to surgery and/or medical oncology for development of a treatment plan. Often patients will return to the FP or PCP and request further clarification of their treatment options. The FP (PCP) may be a trusted care giver for several years and the patients desire their opinion. To this end, it is often difficult for the FP or PCP to assist in the decision-making process as they may or may not have received the consultation information from the surgeon or the oncologist. Because of this, it is essential to make sure that all members of the potential treatment team are included regularly in communications to facilitate supportive discussions with patients and to ensure that coordination of care occurs. The care given by the FP or PCP and the supportive assistance to the patient will be much improved with a robust SCP provided to the patient as early as possible.

A comprehensive SCP is especially important in rural communities. The FP or PCP will most likely need to refer to a larger tertiary center for specialized surgical and oncology consultations. Trying to guide a family through a difficult medical diagnosis is more difficult when the medical documentation does not reach the primary care team in time. The importance of a SCP, broadly shared, fully completed, and provided early in the cancer survivorship continuum, cannot be overemphasized. A list of helpful items to provide to the primary care team in a timely fashion is noted here:

### ***What Does a FP or PCP Need to Know About a Patient's Cancer Care?***

#### **Chemotherapy Information**

1. Type of chemotherapy and the mode of delivery
2. Timing of the chemotherapy and the location of the administration
3. Important laboratory tests and reasons why the chemotherapy may be held

4. Will the surgeon/oncologist follow the patient throughout the duration of treatment?
5. Potential side effects
6. Information regarding the prognosis if appropriate and the benefit/risks of the chemotherapy strategy

### **Radiation Information**

1. Radiation treatment protocol, including frequency and length of treatments
2. Potential side effects of the radiation
3. Benefit/risk of the radiation therapy

### **Surgery Information**

1. Procedure name and whether organs or partial organs were removed
2. Possible complications—early and late
3. Potential impact on nutrition or mobility

### **Follow-Up Strategies**

1. Frequency of patient visits to the surgeon/oncologist
2. Recommended testing and frequency of testing to identify cancer recurrence
3. Recommended testing for potential side effects
4. Ongoing therapy such as hormonal therapy—duration and type
5. Coordination of visits to both the FP or PCP and the oncology team
6. Management strategy of chronic conditions and ongoing care plan

As the patient receives treatment for their cancer diagnosis and enters the post-treatment survivorship phase, strategies to maintain or improve overall health are important. FPs and PCPs are well skilled in establishing preventive protocols for additional diseases [30]. However, the team needs an accurate understanding of the potential disease manifestations that may occur related to the initial cancer diagnosis and treatments. The development of the SCP, and in particular the treatment summary, clarifies these elements of need for the patient and the FP or PCP as outlined earlier in this chapter. Transitioning from cancer treatment to the posttreatment survivorship phase requires thoughtful communication between the oncology team and the FP or PCP with the inclusion of the patient and their family in order for the most effective care to be provided. By including the FP or PCP, patients may receive more preventive care, targeted for their particular risks [31]. Because of the complexity of cancer diagnosis, the potential for recurrence and in some instances ongoing therapy, patients may desire to continue follow-up with the oncology team which reflects a shared model of care for the survivor.

As the patient continues to survive and thrive, there is usually less contact with the oncology specialist and the patient may return more frequently to the FP or PCP for additional concerns. If the SCP has not been shared with the primary care team, the patient may present for a new concern or symptom and the physician may not have any information. Most FPs or PCPs will ask if there have been any changes since the last appointment. However, it is difficult to allow enough time for a visit, if the past history of a cancer is unknown until the time of the visit. A lack of information from the oncology care team usually leads to record requests and a delay in further care for the patient especially if the oncology care was not in the same health system.

The transition from original diagnosis of cancer to surviving cancer is a difficult journey. The SCP can ease some of the complexities of care by creating a road map for the patient and the primary care team to work toward wellness in this new phase of cancer survivorship. However, more than likely patients will have multiple comorbidities not accounted for in the SCP [31]. Treating the cancer and looking for recurrences are essential but if chronic conditions are not continuously addressed such as hypertension or asthma, the patient may be at higher risk for other problems. Plans need to be in place for the follow-up care of preexisting conditions. The patient may suffer from inadequate management of chronic conditions if the oncology team assumes that the FP or PCP is following the condition and the FP or PCP assumes that the oncologist is following the condition. In effect, no one is following the chronic conditions. Maintaining and establishing this care with the assistance of the FP or PCP on the patient care team will enable quality of care. The hand-off from the specialist is especially critical for the follow-up of chronic conditions. It is appropriate to look for any medication changes that may have resulted during cancer treatment and to make sure that patients have regular medication refills. Chronic conditions such as diabetes, hypertension, arthritis, COPD, and hypothyroidism need to be followed and an appropriate strategy for regular appointments maintained. This can be exhausting for the patient especially under stress from the cancer diagnosis. Ultimately, the patient must be empowered to guide their SCP with the mutual and coordinated support of both the primary care team and the oncology team.

## Summary

There are over 15 million people in the United States who are alive today after completing treatment for cancer. It has been recognized that there is a continuum of experience after a diagnosis of cancer known as cancer survivorship with an impact on quality of life. The period of time after completion of active treatment has been recognized as a unique phase in cancer survivorship as patients transition from a focus on cancer to overall health and well-being. All patients with cancer have varying levels of distress which can be managed if properly assessed. Tools have been created to help patients and healthcare providers have a treatment summary and

follow-up plan known as a survivorship care plan (SCP). Coordination of care between the patient, oncology team, and primary care team remains a challenging but intensely desired goal. Cancer program accreditation standards have been created to help improve outcomes of care for this ever-growing group of people. Many national organizations have become stakeholders in the health and well-being of cancer patients in the posttreatment phase of cancer survivorship. Evidence-based clinical guidelines have been developed and outcomes are being measured to demonstrate effectiveness of cancer survivorship programs.

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