A Work in Progress: Developing the New NCCN Guidelines for Survivorship

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The National Coalition for Cancer Survivorship and the NCI consider a person to be a cancer survivor from diagnosis throughout the balance of his or her life, and include family, friends, and caregivers impacted by the diagnosis in the definition.\(^1\) In this context, the number of cancer survivors living in the United States is increasing. Currently estimated to be approximately 13.7 million, it is anticipated to increase to almost 18 million within the next decade. Many of these survivors will be older than 65 years, diagnosed more than 5 years ago, and survivors of melanoma, breast cancer, prostate cancer, or colorectal cancer.\(^2,3\) Although this population is heterogeneous, most survivors face common challenges of long-term morbidity and potential premature mortality related to the cancer, preexisting comorbidities, or the treatment itself.\(^4-6\)

In light of this, the Institute of Medicine (IOM) brought the issues of cancer survivorship to the forefront in 2006 and defined 4 essential aspects of survivorship care: 1) surveillance for recurrence, second cancers, and medical or psychosocial late effects; 2) prevention of recurrence or new cancers or other late effects of cancer and its treatment; 3) intervention for the long-term and late effects of cancer and its treatment, including medical problems, psychosocial concerns, and practical issues related to employment and finances; and 4) coordination of care among health care providers to ensure all needs are met.\(^7\)

Cancer survivors face a myriad of potential concerns and issues. These include the possible physical effects of cancer and its treatment and the potential emotional fallout of being diagnosed with a life-threatening illness. Survivors also must adhere to or adopt healthy lifestyle behaviors, such as tobacco cessation, maintaining a healthy weight, engaging in regular physical activity, and consuming a healthy diet.\(^8\) Finally, survivors face practical issues related to employment, disability, and insurance.\(^7\)

With the increasing number of cancer survivors, the oncology community's focus on cancer survivorship turns much needed attention to these many issues.\(^2,9\) Unfortunately, many of these are addressed piecemeal by various health care providers who may not be well equipped to handle the aftermath of cancer and its treatment.\(^10\) Survivors may have a primary care provider, multiple oncology providers of various disciplines, and other subspecialists. Additionally, advanced practice clinicians and allied health professionals such as physical therapists and mental health professionals may be involved in their care.\(^11,12\) Because of this complexity, ASCO recently cited a need for standardized, evidence-based practice guidelines for the management of effects after treatment and for health promotion of survivors.\(^13\)

Currently, very little evidence or standards of practice exist to guide care during this important period in the survivor's life. Guidelines on physical activity and nutrition have been published by the American College of Sports Medicine and American Cancer Society.\(^8,14\) However, current guidelines lack practical implementation recommendations for providers. In addition, very few guidelines or standards of practice exist for the management of late or long-term effects of cancer and its treatment. Given the wide range of potential health care providers for a given cancer survivor, the growing use of advanced practice clinicians as providers of survivorship care, the potential for transitioning survivors back to primary care for most of their health care, and the projected shortage of oncologists in the not-so-distant future,\(^9,12,15\) many believed it was the right time to develop a guideline to

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address some of the common issues facing cancer survivors. This guideline could serve to frame the context of survivorship care to ensure more comprehensive coverage of the issues a cancer survivor might face.

To develop guidelines for survivorship, NCCN assembled a multidisciplinary panel of experts from member institutions. Unlike panels in which most members are oncology-trained providers, this panel included a wide mix of oncologists, bone marrow transplant clinicians, gynecologists, urologists, infectious disease specialists, psychologists, exercise physiologists, nurses, epidemiologists, and patient advocates. General principles of cancer survivorship were defined and used to help guide algorithm development.

Eight common issues affecting a large proportion of cancer survivors were chosen as the topics for the inaugural version. The panel was divided into subcommittees based on expertise, and each subcommittee was tasked with a literature review and development of an algorithm detailing screening, diagnostic workup with differential diagnoses, and potential intervention recommendations for their particular topic. The subcommittees then presented their algorithms to the entire panel for review and revision. After the algorithms were approved by the panel, institutional comments were invited from each NCCN Member Institution and incorporated into the final version. For many of the topics addressed in this inaugural version of the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship, the finalized algorithm was a combination of literature review and panel consensus based on current clinical practice, because strong evidence to guide management is not readily available for many of these topics.

For the purposes of the guideline, NCCN endorsed the National Coalition for Cancer Survivorship’s definition of a cancer survivor and recognized the impact that cancer can have on family, friends, and caregivers.1 In focusing on the adult cancer survivor, the panel attempted to incorporate the essential elements of survivorship care into guideline development. Basic principles include regular assessment of cancer survivorship, the panel attempted to incorporate the essential elements of survivorship care into guideline development. Basic principles include regular assessment of toxicities, and adherence to healthy lifestyle recommendations.

The panel recognizes that an in-depth assessment of all topics is not feasible during a typical 15- to 20-minute clinic visit. To assist clinicians in concentrating their efforts on only the necessary assessments for a particular survivor, the panel developed a sample assessment tool to guide the course of the assessment. Although this tool has yet to be validated, it is tailored to the topics in the NCCN Guidelines for Survivorship and can be used to guide clinicians toward specific algorithms and in-depth assessments for a particular issue. The panel envisions the tool being adapted to various practice models, and potentially incorporated into electronic medical records or provided as a hardcopy document to be completed by survivors presenting for their survivorship visit.

These NCCN Guidelines were not meant to be comprehensive in their inaugural version; instead, they were designed as a library of clinical algorithms that could be expanded or revised based on growing evidence. Thus, new topics important to cancer survivors can be included in later versions. The guidelines are geared toward all types of health care providers who care for adult cancer survivors, from oncologists in the community and referral centers, to advanced practice clinicians, to primary care physicians who provide care to survivors for all types of medical issues. The panel hopes that providers can turn to the NCCN Guidelines for information on addressing late and long-term effects such as anxiety or depression, cognitive dysfunction, fatigue, pain, sexual dysfunction, and sleep disorders. We hope that the guidelines shed light on the immunizations that survivors should receive, and help providers encourage their patients to implement healthy lifestyle behaviors.
The guidelines do not address disease-specific surveillance or preventive screening. Rather, they were designed to complement the disease-specific and cancer screening guidelines already published by NCCN. Thus, it is our hope that providers can use these guidelines in conjunction with the appropriate disease-specific guideline to develop a framework of care that is appropriate for an individual survivor and coordinated with other health care providers within an individual survivor’s medical profile. These guidelines are geared toward survivors who have completed treatment and are currently considered to be disease-free, but the panel recognizes that many of the topics incorporated in these guidelines may be applicable to survivors living with metastatic disease, and encourages providers to consider using these guidelines with appropriate adaptation in their care.

The NCCN Survivorship Panel recognizes that much work remains. Since the guidelines were presented at the NCCN Annual Conference in March 2013, we have received feedback from NCCN Member Institutions and community physicians regarding the content and ease of use. The panel met for our first in-person meeting, during which we worked to incorporate changes to make future versions of the guidelines better. We have decided to add new algorithms and expand some of the existing ones, striving to maintain our focus on general principles of survivorship, healthy behavior and preventive health recommendations, and management of the effects of cancer and its treatment.

We hope that over time the NCCN Guidelines for Survivorship will be a comprehensive library of management algorithms spanning a wide variety of issues that ultimately improve survivorship care in both the disease-free and metastatic settings. The panel looks forward to the input of the oncology community in further developing these important guidelines.

References


