

NCCN

Survivorship: Introduction and Definition

Clinical Practice Guidelines in Oncology

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Overview

A report issued by the US Centers for Disease Control and Prevention and the NCI and data from the American Cancer Society estimate that the number of cancer survivors in the United States increased from approximately 3 million in 1971 to 13.7 million in 2012.^{1,2} These numbers are predicted to reach almost 18 million by 2022. This striking increase is generally attributed to rising cancer incidence rates

Abstract

Many cancer survivors experience physical and/or psychosocial side effects, which can be severe, debilitating, and sometimes permanent. These NCCN Guidelines for Survivorship provide screening, evaluation, and treatment recommendations for common consequences of cancer and cancer treatment for health care professionals who work with survivors of adult-onset cancer in the posttreatment period. These introductory sections of the guidelines include the panel's definition of cancer survivors, a discussion of the effects of cancer and its treatment, general principles and standards for survivorship care, and guidance regarding screening for problems that require further assessment. (*J Natl Compr Canc Netw* 2014;1:34–45)

NCCN Categories of Evidence and Consensus

Category 1: Based upon high-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2A: Based upon lower-level evidence, there is uniform NCCN consensus that the intervention is appropriate.

Category 2B: Based upon lower-level evidence, there is NCCN consensus that the intervention is appropriate.

Category 3: Based upon any level of evidence, there is major NCCN disagreement that the intervention is appropriate.

All recommendations are category 2A unless otherwise noted.

Clinical trials: NCCN believes that the best management for any cancer patient is in a clinical trial. Participation in clinical trials is especially encouraged.

Please Note

The NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines®) are a statement of consensus of the authors regarding their views of currently accepted approaches to treatment. Any clinician seeking to apply or consult the NCCN Guidelines® is expected to use independent medical judgment in the context of individual clinical circumstances to determine any patient's care or treatment. The National Comprehensive Cancer Network® (NCCN®) makes no representation or warranties of any kind regarding their content, use, or application and disclaims any responsibility for their applications or use in any way. **The full NCCN Guidelines for Survivorship are not printed in this issue of JNCCN but can be accessed online at NCCN.org.**

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Disclosures for the NCCN Survivorship Panel

At the beginning of each NCCN Guidelines panel meeting, panel members review all potential conflicts of interest. NCCN, in keeping with its commitment to public transparency, publishes these disclosures for panel members, staff, and NCCN itself.

Individual disclosures for the NCCN Survivorship Panel members can be found on page 45. (The most recent version of these guidelines and accompanying disclosures are available on the NCCN Web site at NCCN.org.)

These guidelines are also available on the Internet. For the latest update, visit NCCN.org.

Journal of the National Comprehensive Cancer Network

(mainly resulting from an aging population), earlier detection, and better treatment.

An analysis of the SEER database showed that 45% of survivors were 70 years of age or older in 2012.² In fact, an estimated 1 of every 5 persons older than 65 years is a cancer survivor. Only 5% are younger than 40 years, and survivors of childhood cancer constitute between 0.5% and 3.0% of the survivor population.^{2,3} The most common cancer sites in the survivor population are breast, prostate, colon/rectum cancers, and melanoma, together accounting for approximately 60% of survivors.² Approximately 64% of survivors were diagnosed 5 or more years ago, whereas 15% of survivors were diagnosed 20 or more years ago, and approximately 5% have survived 30 years or longer.²

Unfortunately, many of these cancer survivors experience physical and/or psychosocial late and/or long-term effects of the illness, which can be severe, debilitating, and sometimes permanent. Survivors may be discharged from the care of their oncologist and feel isolated and scared. Furthermore, their primary care physicians (PCPs), who may now be responsible for their care, often do not know how best to care for the specific concerns and needs of cancer survivors.⁴ ASCO's recent statement, "Achieving High-Quality Cancer Survivorship Care," cites a need for standardized, evidence-based practice guidelines for the management of complications and health promotion of survivors.⁵ ASCO, NCCN, and other groups working in parallel hope to provide this guidance.

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^gSexual Function; ^hSleep Disorders

Specialties: ξBone Marrow Transplantation; εEpidemiology;
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‡Hematology/Hematology Oncology; ΦInfectious Diseases;
ΠInternal Medicine; †Medical Oncology; ΨNeurology/Neuro-
Oncology; #Nursing; ¥Patient Advocacy; €Pediatric Oncology;
θPsychiatry, Psychology, Including Health Behavior; £Supportive
Care Including Palliative, Pain Management, Pastoral Care, and
Oncology Social Work; ¶Surgery/Surgical Oncology; ωUrology

GENERAL PRINCIPLES OF THE SURVIVORSHIP GUIDELINES

- These guidelines are designed to provide a framework for the general survivorship care and management of potential long-term and/or late effects of cancer and its treatment that survivors may experience.
- These guidelines are not intended to provide specific guidance on the surveillance and follow-up requirements for a survivor's primary cancer.
- The panel does not assume that all survivorship issues will be addressed at every visit. The panel recommends periodic screening assessments and appropriate follow-up care as clinically indicated.
- These guidelines provide screening, evaluation, and treatment recommendations for common consequences of cancer and cancer treatment, and are intended for health care professionals who work with survivors of adult-onset cancer in the post-treatment period, including those in both the oncology and primary care practices.
- These guidelines, with the appropriate disease-specific guideline, provide a framework for the coordination of care between the survivor's healthcare providers to insure that needs are appropriately addressed.
- These guidelines are focused on survivors after the completion of cancer treatment and in clinical remission.
- The topics, assessments, and interventions may also be applicable to those survivors living with metastatic disease, as clinically appropriate. (Also see the NCCN Guidelines for Palliative Care; to view the most recent version of these guidelines, visit NCCN.org)

SURV-1

Survivorship, Version 2.2014

DEFINITION OF SURVIVORSHIP

- An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted.^a
- These guidelines focus on the vast and persistent impact both the diagnosis and treatment of cancer have on the adult survivor. This includes the potential impact on health, physical and mental states, health behaviors, professional and personal identity, sexuality, and financial standing.

ASSESSMENT BY HEALTH CARE PROVIDER AT REGULAR INTERVALS

- A periodic assessment is recommended for all survivors to determine any needs and necessary interventions.
- Care providers are also encouraged to assess the following at regular intervals to determine whether reversible or contributing causes for symptoms exist:
 1. Current disease status
 2. Functional/performance status
 3. Medication
 4. Comorbidities
 5. Prior cancer treatment history and modalities used

^aAdapted with permission from the National Coalition for Cancer Survivorship as shown in the National Cancer Institute's About Cancer Survivorship Research: Survivorship Definitions web page available at <http://dccps.cancer.gov/ocs/definitions.html>.

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SURV-1 and SURV-2

Cont. from page 35.

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These guidelines provide screening, evaluation, and treatment recommendations for common consequences of cancer and cancer treatment for health care professionals who work with survivors of adult-onset cancer in the posttreatment period, including those in specialty cancer survivor clinics and primary care practices. The recommendations in these guidelines therefore pertain to patients who may be in remission, those for whom cancer has become a chronic disease, and those who are cured. These guidelines are designed to provide a framework for the management of long-term and/or late effects of cancer and its treatment. These guidelines focus on the vast and persistent impact both the diagnosis and treatment of cancer have on the adult survivor's health, physical and mental states, health behaviors, professional and personal identity, sexuality, and financial standing. These guidelines, with the appropriate disease-specific guideline, provide a framework for the coordination of care between the survivor's health care providers to ensure that needs are appropriately addressed. Although these guidelines are focused on survivors who are in clinical remission after the completion of cancer treatment, the topics, assessments, and interventions may also be applicable to survivors living with metastatic disease, as clinically appropriate (also see the NCCN Clinical Practice Guidelines in Oncology [NCCN Guidelines] for Palliative Care, available online at [NCCN.org](http://www.nccn.org)). These guidelines are not intended to provide guidance on the surveillance and follow-up requirements of a survivor's primary cancer (see NCCN disease-specific guidelines, available at [NCCN.org](http://www.nccn.org)), nor are they intended to provide guidance for the care of survivors of childhood cancer (detailed guidelines for the care of childhood cancer survivors are available from the Children's Oncology Group at <http://www-survivorshipguidelines.org/>).

For this inaugural version of the NCCN Guidelines for Survivorship, the panel focused on 8 common issues of survivors: 1) anxiety and depression, 2) cognitive decline, 3) pain, 4) female and male sexual dysfunction, 5) immunizations and prevention of infections, 6) fatigue, 7) sleep disorders, and 8) exercise. Additional topics will be addressed in subsequent years.

Cancer Survivors

The NCCN Survivorship Panel supports the NCI's definition of a cancer survivor: "An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted and included in this definition and are therefore included in this definition."⁶ Throughout these guidelines, however, 'survivor' refers to an individual with a history of cancer; family, friends, and caregivers are not addressed in this inaugural version.

Health Behaviors of Cancer Survivors

Analysis of data from the Behavioral Risk Factor Surveillance System indicates that a large proportion of cancer survivors have significant comorbidities, smoke, are obese, and/or do not engage in physical activity.⁷ Analysis of data from the National Health Interview Survey showed similar results,⁸ as have other studies.⁹ In addition, many survivors forego recommended cancer screenings (ie, colorectal and cervical screening).¹⁰

The Effects of Cancer and Its Treatment

For some survivors, the consequences of cancer are minimal; these patients can return to a normal life after the completion of treatment. In fact, most cancer survivors report being in good general health and experience good to excellent quality of life.^{11,12} Also, a recent survey of 659 survivors of breast, colorectal, and prostate cancers found that most do not suffer from psychological morbidity or have a large number of unmet supportive care needs.¹³ Other surveys have similarly found that most survivors enjoy a high quality of life without a large number of cancer-related symptoms.¹⁴

However, many survivors do experience physical and/or psychosocial effects of cancer and its treatment.¹⁵ Some sequelae become evident during anti-cancer treatment (long-term effects), whereas others may not manifest for months or years after active therapy (late effects). The problems can range from mild to severe, debilitating, or even life-threatening. Some problems are temporary or improve with time, whereas others problems are progressive or permanent. This topic has been well reviewed.^{12,16}

A recent review suggests that at least 50% of survivors experience some late effects of cancer treatment.¹⁶ The most common problems in cancer survivors are depression, pain, and fatigue.¹⁷ The

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exact prevalence of various effects of cancer and its treatment are hard to quantify, because few studies have addressed these issues in a longitudinal fashion, comparing patients with and without a history of cancer to differentiate between the effects of cancer and the effects of aging.¹² In general, the prevalence of late effects in cancer survivors is believed to have increased over time, likely because anticancer interventions have become more complex and intense with combinations of surgery, radiation, chemotherapy, hormone therapy, and targeted biologics.¹⁸

Physical Effects

Physical problems in cancer survivors include pain, musculoskeletal issues, fatigue, lack of stamina, urinary/bowel problems, lymphedema, premature menopause, cognitive deficits, and sexual dysfunction.^{12,19–21} The effects of cancer treatment on the heart and bone are also well-known.^{22–25}

Second Cancers

Importantly, subsequent malignant neoplasms commonly occur in survivors because of genetic susceptibilities (eg, cancer syndromes), shared causative exposures (eg, smoking, environmental exposures), and mutagenic effects of cancer treatment.^{26,27} Treatment-related subsequent primary cancers vary with the type and intensity of anticancer treatment and are associated in particular with radiation and specific chemotherapeutic agents. These are especially well studied in long-term survivors of childhood cancers.^{28–31} Studies by individual cancer type show that the incidence of subsequent unrelated cancers ranges from 2% in survivors of malignant lymphoma to 30% in survivors of small cell lung cancer.¹⁶

Psychosocial Effects

Cancer has positive effects on a significant portion of individuals, including strengthened relationships, a sense of gratitude or empowerment, and an increased appreciation for life.^{32–37} Many survivors, however, experience psychologic distress after active treatment, and some experience a combination of positive and negative psychologic effects. Distress can result from the fear of recurrence or death, or secondary to physical, social, or practical problems.^{32,35,38} In fact, as many as 19% of survivors meet the criteria for posttraumatic stress disorder.^{32,35,39–41}

Practical and social problems of survivors include issues surrounding employment, finances, and health and life insurance.^{32,42–45}

Standards for Survivorship Care

In 2005, the Institute of Medicine (IOM) and the National Research Council compiled a report entitled, “From Cancer Patient to Cancer Survivor: Lost in Transition.”¹⁸ According to this report, the essential components of survivorship care are

- Prevention of new and recurrent cancers and other late effects
- Surveillance for cancer spread, recurrence, or second cancers
- Assessment of late psychosocial and medical effects
- Intervention for consequences of cancer and treatment (eg, medical problems, symptoms, psychologic distress, financial and social concerns)
- Coordination of care between primary care providers and specialists to ensure that all of the survivor’s health needs are met.

In addition, the IOM report discusses the importance of policies that ensure access to and health insurance coverage for all aspects of survivorship care, including psychosocial services. Cancer survivors with untreated distress have poorer compliance with surveillance screenings and are less likely to exercise and quit smoking.⁴⁶ A 2008 IOM report, “Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs,”⁴⁷ concluded that psychosocial screening and care should be a part of the new standard for quality cancer care and should be integrated into routine care across the trajectory of cancer, which includes the period after active treatment. See the NCCN Guidelines for Distress Management and the section on “Anxiety and Depression” in the full version of these guidelines (both available online at NCCN.org for recommendations on screening for and treating distress.

In September 2011, the LIVESTRONG Foundation convened a meeting of experts and stakeholders in the survivorship field to define essential elements of survivorship care. After 2 days of consensus building, the group agreed on the following elements that all medical settings must provide for cancer survivors, either directly or through referral (<http://livestrong.org/pdfs/3-0/EssentialElementsBrief>):

- Survivorship care plan, psychosocial care plan, and treatment summary
- Screening for new cancers and surveillance for recurrence

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- Care coordination strategy that addresses care coordination with PCPs and primary oncologists
- Health promotion education
- Symptom management and palliative care

In 2012, the Commission on Cancer (CoC) of the American College of Surgeons updated their accreditation standards for hospital cancer programs (<http://www.facs.org/cancer/coc/programstandards2012.html>). Their patient-centered focus now includes the development of a survivorship care plan for all patients. This requirement is to be phased in by 2015.

Implementation of these standards for survivorship care has been challenging, and reasons for the difficulties have been described.⁴⁸ To move toward the goal of all cancer survivors receiving all essential components of care, advances must be made in 1) survivorship research; 2) education of health care providers; 3) education and empowerment of survivors; and 4) policies that address reimbursement and resource allocation issues.

The Role of Primary Care Offices in Survivorship Care

With the population of cancer survivors growing at a rapid pace, the demand for follow-up care is expected to increase. An increasing proportion of this care will likely be performed by primary care teams. Because studies have shown that primary care providers often do not know how best to care for the specific concerns and needs of cancer survivors,⁴ education for primary health care providers regarding appropriate survivorship care will be increasingly important.

A study in the Netherlands found that patients with cancer 2 to 5 years after diagnosis increased their number of consultations with primary care compared with age- and sex-matched controls without cancer by 15% for colorectal cancer ($P < .05$), 24% for breast cancer ($P < .001$), and 33% for prostate cancer ($P < .001$).⁴⁹ These survivors also had more chronic conditions than controls. Although an American study using the SEER-Medicare database showed a smaller increase in primary care use by breast cancer survivors (10% increase in year 4 after diagnosis; $P < .05$),⁵⁰ these results show that PCPs are providing a substantial amount of survivorship care. In fact, according to IOM analyses of the 2001 and 2002 National Ambulatory Medical Care Survey and the National Hospital Ambulatory Medical

Care Survey, approximately one-third of the more than 36 million cancer-related visits to physicians' offices were made to primary care.¹⁸

However, in a recent survey of survivors regarding their preferences for follow-up care, most participants said that the PCP should only provide care if the responsibility was shared with the oncologist.⁵¹ One of the reasons commonly cited for this preference was that survivors believe their PCPs lack the needed expertise to deal with their specific issues. In addition, survivors cited a desire for continuity of care. A survey of 218 survivors of breast cancer found a similar preference for oncologists over PCPs for provision of follow-up care,⁵² and a survey in the United Kingdom found similar attitudes.⁵³ Importantly, however, 2 randomized trials comparing survivorship care administered by PCPs (provided guidelines outlining appropriate follow-up care) versus oncologists found no difference in disease-related outcomes, including survival.^{54,55}

Survivorship Care Plans

Because primary care offices are in fact already caring for cancer survivors, it is critical for information to be shared between oncology and primary care teams. Good communication at the oncology/primary care interface may allow survivors to feel the continuity of care they desire. The CoC accreditation standards include the provision of a survivorship care plan at the completion of treatment, as recommended in the IOM report.¹⁸ According to the report, the plan should include

- A personalized treatment summary
- Information on possible late and long-term effects
- Information on signs of recurrence
- Guidelines for follow-up care
- Identification of providers
- Recommendations for healthy living
- Identification of supportive care resources

However, a randomized controlled trial of 408 survivors of breast cancer that assessed the effects of survivorship care plans found no differences in patient-reported outcomes, including cancer-specific distress, between patients who received a discharge visit and a care plan and those who received only a discharge visit.⁵⁶ Although criticisms of this trial have been published, including the relevance of its outcome measures,⁵⁷⁻⁵⁹ definitive data supporting

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the benefits of survivorship care plans are clearly lacking. Furthermore, providing a survivorship care plan is time-consuming and resource-intensive and could have unforeseen harms.⁵⁹ For these reasons, the NCCN Survivorship Panel does not currently require the use of survivorship care plans for compliance with these guidelines, although the provision of a survivorship care plan to all survivors at the completion of treatment is recommended if appropriate resources are available. Data from ongoing trials will help inform future recommendations.

Surveillance for Cancer Recurrence

Screening for cancer recurrence is an important aspect of survivorship care. In general, this surveillance is performed by the oncology team. When surveillance is overseen by the primary care team, the oncologist should provide evidence-based recommendations based on currently available guidelines. Specific recommendations vary between cancer site and stage and are not addressed in these guidelines. Please see individual NCCN Guidelines for Treatment of Cancer by Site (available online at NCCN.org).

Screening for Effects of Cancer and Its Treatment

All survivors should be periodically screened for symptoms related to cancer and prior cancer treatment, with appropriate follow-up care as clinically indicated. The panel does not assume that all survivorship issues will be addressed at every visit. Some tools that screen for long-term and late physical and psychosocial effects of cancer and its treatment in survivors have been validated.^{60–64} In addition, the NCCN Survivorship Panel created a sample screening instrument that can be self-administered or administered by an interviewer. Although this instrument has not yet been piloted or validated, the answers can be used to guide providers to topics within the guidelines that require more in-depth assessment.

In addition, care providers should assess the following to determine whether reversible or contributing causes for symptoms exist:

- Current disease status
- Functional/performance status
- Current medications
- Comorbidities
- Prior cancer treatment history and modalities used

This information can also inform about the patient's risk for specific late or long-term effects. For example, patients who received pelvic irradiation or surgery are at risk for sexual dysfunction; patients with a history of brain involvement have an elevated risk for cognitive dysfunction. In general, those who underwent more intensive therapy are at higher risk for physical symptoms.

According to the NCCN Guidelines for Distress Management (to view the most recent version of these guidelines, visit NCCN.org), risk factors for psychosocial distress include cognitive impairment, severe comorbid illnesses, uncontrolled symptoms, communication barriers, or a history of psychiatric disorder, depression, or substance abuse. Social issues, such as living alone, having young children, being of younger age or female, and prior physical or sexual abuse, are also risk factors for psychosocial distress.

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Individual Disclosures for the NCCN Survivorship Panel					
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