



The Oncology Nurse-APN/PA®

The Official Publication for the Hem/Onc Nurse & Advanced Practitioner

Survivorship Care: Planning for Action

*Proceedings from the 2015 AONN+
West Coast Regional Meeting*



The Oncology Nurse-APN/PA®

The Official Publication for the Hem/Onc Nurse & Advanced Practitioner

PUBLISHING STAFF
 Senior Vice President, Group Publisher
 Nicholas Englezos
 nenglezos@the-lynx-group.com
 Vice President/Group Publisher
 Russell Hennessy
 rhennessy@the-lynx-group.com
 Vice President/Director of Sales & Marketing
 Joe Chanley
 jchanley@the-lynx-group.com
 Director, Client Services
 Dave Dempsey
 ddempsey@the-lynx-group.com
 Editorial Director
 Kristin Siyahian
 ksiyahian@the-lynx-group.com
 Managing Editor
 Kristen Olafson
 kolafson@the-lynx-group.com
 Copyeditors
 Mollie Friedman
 Peggy Roeske
 Production Manager
 Melissa Lawlor

THE LYNX GROUP
 President/CEO
 Brian Tyburski
 Chief Operating Officer
 Pam Rattananont Ferris
 Vice President of Finance
 Andrea Kelly
 Human Resources
 Jennine Leale
 Director, Strategy & Program Development
 John Welz
 Director, Quality Control
 Barbara Marino
 Quality Control Assistant
 Theresa Salerno
 Director, Production & Manufacturing
 Alaina Pede
 Director, Creative & Design
 Robyn Jacobs
 Creative & Design Assistants
 Lora LaRocca
 Wayne Williams
 Content Marketing Director
 Samantha Weissman
 Digital Content Managers
 Allison Musante
 Anthony Trevean
 Digital Programmer
 Michael Amundsen
 Jr Digital Media Specialist
 Charles Easton IV
 Meeting & Events Planner
 Linda Mezzacappa
 Senior Project Manager
 George Fuller
 Project Managers
 Deanna Martinez
 Jeremy Shannon
 Project Coordinator
 Rachael Baranoski
 IT Manager
 Kashif Javaid
 Administrative Assistants
 Sara Mohamed
 Colette Puhalski
 Office Coordinator
 Robert Sorensen

Green Hill Healthcare Communications, LLC
 1249 South River Road - Ste 202A
 Cranbury, NJ 08512
 phone: 732-656-7935 • fax: 732-656-7938

TABLE OF CONTENTS

4	The History of Cancer Survivorship
5	The 4 Stages of Cancer Survivorship
6	Survivorship Care
8	Survivorship Care Plans
8	Survivorship Care Models
9	Patient–Clinician Communication Essentials
10	Addressing Quality-of-Life Issues
12	Financial Implications of Cancer Treatment
14	Conclusion

The Oncology Nurse-APN/PA®, ISSN 1944-9798 (print); ISSN 1944-9801 (online) is published 6 times a year by Green Hill Healthcare Communications, LLC, 1249 South River Road, Suite 202A, Cranbury, NJ 08512. Telephone: 732.656.7935. Fax: 732.656.7938. Copyright © 2015 by Green Hill Healthcare Communications, LLC. All rights reserved. *The Oncology Nurse-APN/PA®* logo is a registered trademark of Green Hill Healthcare Communications, LLC. No part of this publication may be reproduced or transmitted in any form or by any means now or hereafter known, electronic or mechanical, including photocopy, recording, or any informational storage and retrieval system, without written permission from the Publisher. Printed in the United States of America.

EDITORIAL CORRESPONDENCE should be addressed to **EDITORIAL DIRECTOR**, *The Oncology Nurse-APN/PA®*, 1249 South River Road, Suite 202A, Cranbury, NJ 08512. E-mail: editorial@greenhillhc.com. **YEARLY SUBSCRIPTION RATES:** United States and possessions: individuals, \$105.00; institutions, \$135.00; single issues, \$17.00. Orders will be billed at individual rate until proof of status is confirmed. Prices are subject to change without notice. Correspondence regarding permission to reprint all or part of any article published in this journal should be addressed to **REPRINT PERMISSIONS DEPARTMENT**, Green Hill Healthcare Communications, LLC, 1249 South River Road, Suite 202A, Cranbury, NJ 08512. The ideas and opinions expressed in *The Oncology Nurse-APN/PA®* do not necessarily reflect those of the Editorial Board, the Editorial Director, or the Publisher. Publication of an advertisement or other product mentioned in *The Oncology Nurse-APN/PA®* should not be construed as an endorsement of the product or the manufacturer's claims. Readers are encouraged to contact the manufacturer with questions about the features or limitations of the products mentioned. Neither the Editorial Board nor the Publisher assumes any responsibility for any injury and/or damage to persons or property arising out of or related to any use of the material contained in this periodical. The reader is advised to check the appropriate medical literature and the product information currently provided by the manufacturer of each drug to be administered to verify the dosage, the method and duration of administration, or contraindications. It is the responsibility of the treating physician or other healthcare professional, relying on independent experience and knowledge of the patient, to determine drug dosages and the best treatment for the patient. Every effort has been made to check generic and trade names, and to verify dosages. The ultimate responsibility, however, lies with the prescribing physician. Please convey any errors to the Editorial Director.



To obtain a digital version, download a free QR code app on your SmartPhone and then scan this code.

This special issue has been funded by Takeda Oncology.

Survivorship Care: Planning for Action

Oncology nurses, advanced practitioners, and oncology nurse navigators gathered at the Navigators Exploring Xtra Tracks lunch session, “Survivorship Care: Planning for Action,” hosted by the Academy of Oncology Nurse & Patient Navigators West Coast Regional Meeting in Seattle, Washington, May 19-20, 2015. Supported by Takeda Oncology and presented by Deborah Cook, RN, BSN, OCN, the lunch session helped participants gain insight on the importance of survivorship care for patients with cancer after undergoing active treatment.

The program covered the following topics:

- Survivorship and its importance in the lives of patients living with cancer
- Basic requirements and additional elements for building a survivorship care plan
- Use of a survivorship care plan in various practice settings
- Long-term burdens of cancer and cancer treatment.

According to the American Cancer Society, approximately 1,658,370 new cancer cases will be diagnosed in 2015.¹ As of January 2015, nearly 14.5 million Americans were living with a history of cancer,¹ and an estimated 18 million Americans will be living with cancer by 2020.²

Despite these grim statistics, early diagnosis and advances in treatment have resulted in a substantial increase in the survival of patients with cancer in the past 4 decades. Data from the American Cancer Society reveal that the 5-year relative cancer survival rates have

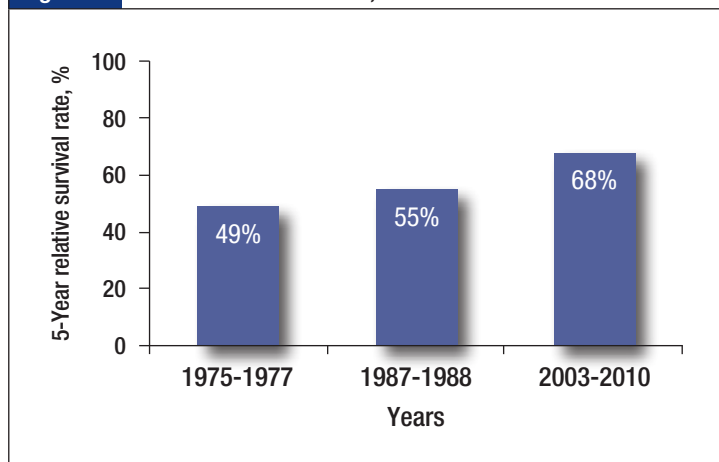
increased from 49% in 1975-1977 to 68% in 2003-2010 (Figure 1),¹ and with the advent of novel cancer drugs and technology, cancer survival rates are projected to continue to improve.²

The History of Cancer Survivorship

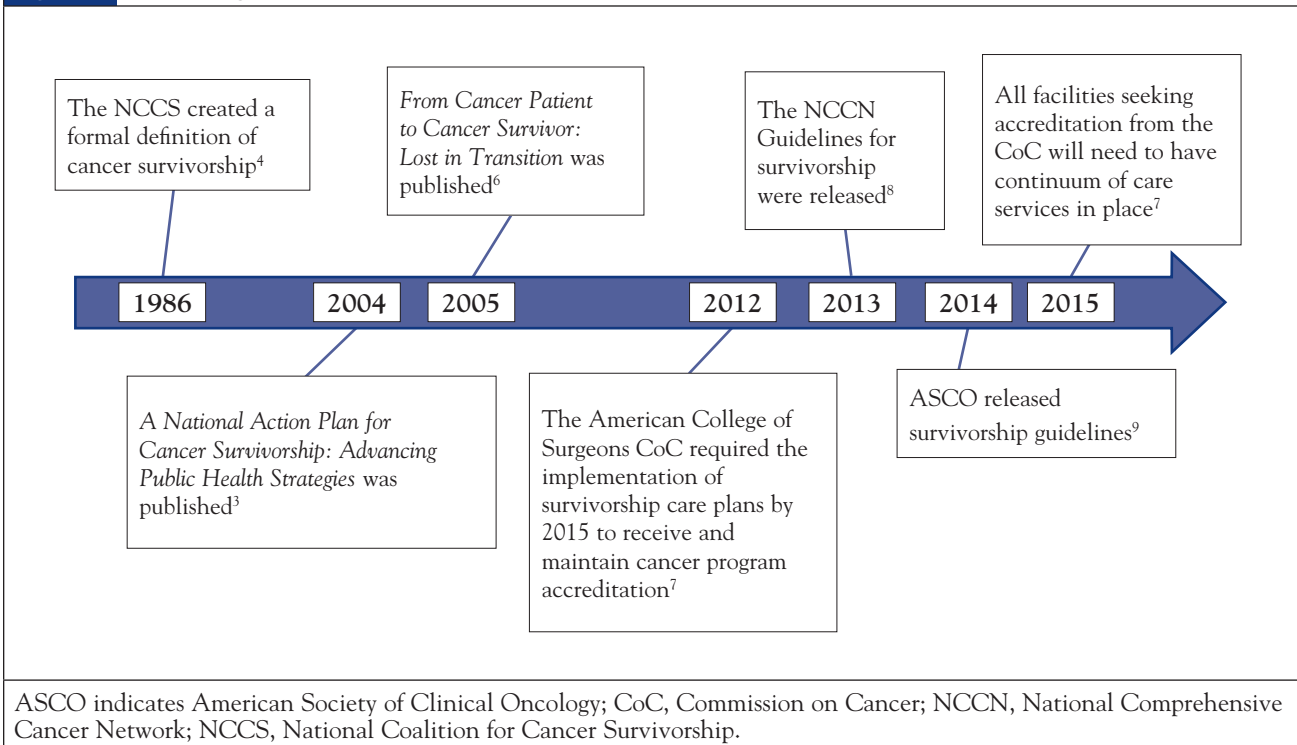
The term “cancer survivor” was originally used to describe family members who survived the loss of a loved one to cancer when cancer was considered incurable.³ The definition of “survivor” was soon modified to include patients with cancer whose disease did not recur in the 5 years after their diagnosis or treatment.³ In 1986, the National Coalition for Cancer Survivorship (NCCS) aimed to redefine cancer survivorship to capture the broad patient experience after cancer diagnosis and throughout the disease trajectory.⁴ As such, cancer survivorship was defined as a unique phase that begins from the moment of diagnosis and lasts for the remainder of life; this definition is now widely adopted throughout the oncology community.⁴

Established in 1986, the NCCS sought to address the full spectrum of survivorship issues related to living with a cancer, including the psychologic, physiologic, psychosocial, economic, and spiritual issues associated with a cancer diagnosis.⁵ Between 1986 and 2004, the NCCS vehemently lobbied for different organizations and institutions to educate government agencies and policymakers about the need for quality cancer care across the survivorship continuum (Figure 2).³⁻⁹ It was not until 2004, however, that the Centers for Disease Control and Prevention, in partnership with the Lance Armstrong Foundation,

Figure 1 Cancer Survival Rates, 1975-2010



Source: American Cancer Society. Cancer Facts & Figures 2015. www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf.

Figure 2 The History of Survivorship

published *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* to inform the general public, policymakers, survivors, providers, and other stakeholders about cancer survivorship and public health.³ In 2005, the Institute of Medicine (IOM) released *From Cancer Patient to Cancer Survivor: Lost in Transition*, another instrumental report that underlined the importance of using survivorship care plans in healthcare settings.⁶

The publication of these 2 documents helped cancer survivorship care gain momentum in the oncology community and among policymakers. In 2012, the American College of Surgeons Commission on Cancer (CoC) released their cancer program standards in an effort to ensure that patients with cancer receive the highest quality of care.⁷ The CoC required all cancer programs to implement survivorship care plans by 2015 to receive and maintain cancer program accreditation.⁷

In 2013 and 2014, the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO), respectively, released their guidelines for survivorship care.^{8,9} Both organizations recognized the importance of survivorship care for effectively guiding patients with cancer through their cancer journeys.^{8,9}

The 4 Stages of Cancer Survivorship

Cancer survivorship comprises 4 stages—acute, transitional, extended survivorship, and permanent survivorship (Table 1).^{6,10,11} The acute stage includes the time of

diagnosis and active treatment. This stage is dominated by diagnostic and therapeutic efforts.^{6,10} Patients at this stage are overwhelmed by feelings of fear and anxiety, which may be more damaging to their health than the disease itself.¹⁰ Furthermore, patients are confronted with their mortality.¹⁰

Cancer survivorship comprises 4 stages—acute, transitional, extended survivorship, and permanent survivorship. The acute stage includes the time of diagnosis and active treatment.

The transitional stage is the period of change from active treatment to careful observation; patients have completed their active treatment and are no longer dominated by medical visits.¹¹ During this stage, it is common for patients to feel isolated, devastated, or depressed, because they have to gradually separate from their oncology healthcare professionals who have provided consistent care and guidance throughout their treatment period.¹¹ Unlike the acute stage, where patients were continuously monitored and treated, the transitional stage forces patients to lead more independent lives. Consequently, pa-

Table 1 Stages of Cancer Survivorship

Stage of survivorship	Characteristics
Acute	Dominated by diagnostic and therapeutic efforts; patients are overwhelmed by feelings of fear and anxiety and are confronted with their mortality
Transitional	Change from active treatment to careful observation; patients may feel isolated and depressed; fear of cancer recurrence is common
Extended	Period of watchful waiting; psychosocial problems are common and fear of cancer recurrence is prevalent; patients may turn to their oncology specialists for general health issues
Permanent	Long-term remission; patients face employment and insurance issues; secondary effects and malignancies associated with previous cancer treatment may become apparent

Sources: Institute of Medicine. Hewitt M, et al, eds. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press; 2005; Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313:270-273; Dana-Farber Cancer Institute. Cancer's 'Seasons of Survivorship.' www.dana-farber.org/Newsroom/Publications/Cancer-s--Seasons-of-Survivorship-.aspx.

tients may fear that their cancer will return if they are not being closely monitored by their oncology care providers.¹¹ In addition, patients may contact their oncology specialists about health concerns that are typically handled by primary care physicians, such as headaches or requests for antihypertensive medications.

The extended survivorship stage is characterized by a period of watchful waiting. The permanent survivorship stage encompasses long-term remission.

The extended survivorship stage is characterized by a period of watchful waiting.^{6,10} Psychosocial problems are a common feature of this phase as individuals resume their daily lives after a considerable hiatus. In addition, fear of cancer recurrence is prevalent during an extended survivorship, and patients may be physically limited by the impact of their cancer and/or its treatment.^{6,10} Furthermore, patients may continue to consult their oncology specialists about general health issues, because they worry that their primary care physician will not understand their cancer history.

The permanent survivorship stage encompasses long-term remission, with an increased likelihood of living cancer-free for long periods.⁶ During this stage, patients are faced with employment and insurance issues as they recommence their everyday routines. In addition, secondary effects and malignancies of cancer treatment become an added area of concern.^{6,10}

Survivorship Care

Although the rising cancer survival rates are a testament to the significant strides researchers and health-care professionals have made on the cancer treatment front, patients living with cancer often lack the necessary tools and resources to effectively navigate the healthcare system, particularly after they have completed their cancer treatment.¹²

After treatment, many cancer survivors experience physical, emotional, and practical concerns, but they do not always receive the help they need.¹² Fitzhugh Mullan, MD, expressed this dilemma best when he said, "It is as if we have invented sophisticated techniques to save people from drowning, but once they have been pulled from the water, we leave them on the dock to cough and splutter on their own in the belief that we have done all that we can."¹⁰

The increased survival rates among patients with cancer have prompted healthcare professionals to recognize the healthcare needs of these individuals and offer management via survivorship care—the key to minimizing disease- and treatment-related effects on a patient's quality of life.¹²

Elements of Survivorship Care

According to the IOM and the NCCN, the central components of survivorship care include (1) prevention of new and recurrent cancers and other late effects; (2) surveillance for cancer spread, recurrence, or second cancers; (3) assessment of late psychosocial and physical effects; (4) intervention for consequences of cancer and treatment; and (5) coordination of care between primary care providers and specialists to ensure that all of the survivor's health needs are met.^{6,13}

One of the greatest challenges facing the cancer survivorship community is how best to design and deliver high-quality survivorship care.¹² Because there is little agreement on what providers should include in their approach to survivorship care, building consensus is important to effectively respond to the myriad challenges cancer survivors face during the post-treatment period.¹²

In 2011, LIVESTRONG assembled the Essential Elements of Survivorship Care Meeting in an effort to delineate the necessary elements of survivorship care that any survivorship program must provide to patients with cancer during the posttreatment period.¹² The meeting in-

Table 2 The Essential Elements of Cancer Survivorship Care

Tier 1: All medical settings must provide direct access or referral to the following elements of care:	Tier 2: All medical settings should provide direct access or referral to the following elements of care:	Tier 3: All medical settings should strive to provide direct access or referral to the following elements of care:
<ul style="list-style-type: none"> • Care coordination strategy addressing care coordination with primary care physicians and primary oncologists • Health promotion education • Screening for new cancers and surveillance for recurrence • Survivorship care plan, psychosocial care plan, and treatment summary • Symptom management and palliative care 	<ul style="list-style-type: none"> • Comprehensive medical assessment • Family and caregiver support • Information about survivorship and program offerings • Late-effects education • Nutrition services, physical activity services, and weight management • Patient navigation • Psychosocial assessment • Psychosocial care • Rehabilitation for late effects • Transition visit and cancer-specific transition visit 	<ul style="list-style-type: none"> • Continuing medical education • Counseling for practical issues • Ongoing quality improvement activities • Referral to specialty care • Self-advocacy skill training
<p>Source: Rechis R, et al. Wisconsin Comprehensive Cancer Control Program. The essential elements of survivorship care: a LIVESTRONG brief. December 2011. www.wicancer.org/uploads/pub_64120.pdf.</p>		

cluded more than 150 community leaders, stakeholders, experts, cancer survivors, and cancer survivor advocates.¹² The meeting participants identified 20 essential elements of survivorship care, which were grouped into 3 tiers based on their ranking scores.¹²

As shown in **Table 2**, tier 1 includes elements of care that all medical settings must provide; tier 2 comprises elements that all medical settings should provide; and tier 3 includes elements that all medical settings should strive to provide.¹²

CoC Standards of Survivorship Care

The IOM's report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, laid the foundation for the CoC to delineate their standards for cancer program accreditation.⁷ In their 2012 report, *Cancer Program Standards 2012: Ensuring Patient-Centered Care*, the CoC defined 3 criteria for continuum of survivorship care services, including (1) patient navigation services, (2) psychosocial distress screening, and (3) survivorship care plans.⁷

Patient navigation. Patient navigation services are offered to patients, families, and caregivers to help overcome healthcare system barriers and facilitate timely access to quality medical and psychosocial care; patient navigation can start before a cancer diagnosis and continue through all phases of the disease trajectory.⁷

Patients who have difficulty navigating the healthcare system are likely to experience lower quality patient-clinician communication and shared decision-making, 2 factors that may contribute to underutilization of quality care, overuse of suboptimal care, and accrual of higher costs.¹⁴

The CoC specifies that before launching the navigation process, the cancer committee should conduct a community needs assessment to identify the needs of the population, the potential to improve cancer health disparities, and gaps in resources—the results of which will help lay the groundwork for program development, implementation, and evaluation.⁷

Psychosocial distress. Patients with cancer often experience a myriad of psychosocial issues throughout their disease course, including psychological, financial, social, and behavioral problems, all of which can have a profound effect on patients' health and on their treatment plan.⁷ In an effort to address the psychosocial issues experienced by patients with cancer, the CoC requires that cancer programs develop a process to incorporate distress screening into the standard of care and provide resources and/or referrals for psychosocial needs to patients with distress.⁷

One of the greatest challenges facing the cancer survivorship community is how best to design and deliver high-quality survivorship care.

According to the CoC, distress screening should be performed at least once per patient during a pivotal medical visit, such as at time of diagnosis, presurgical and postsurgical visits, and first visit to discuss chemotherapy.⁷ The CoC does not specify the use of a particular distress

assessment tool (eg, patient questionnaire, clinician-administered questionnaire) and leaves it up to the cancer program to choose; however, the CoC gives preference to standardized, validated distress assessment instruments with established clinical cutoffs.⁷

Survivorship care plan. The third standard of survivorship care includes developing and implementing a process to disseminate a survivorship care plan to patients with cancer who are completing their cancer treatment.⁷ The survivorship care plan should include a comprehensive care summary and a follow-up plan, and should be administered to patients after they complete their treatment.⁷ The CoC stipulates that the survivorship care plan be prepared by the principal provider who coordinated the patient's oncology treatment, incorporating input from the other care providers of the patient.⁷

Survivorship Care Plans

The concept of a survivorship care plan was first introduced in the 2005 IOM report.⁶ By providing patients with a comprehensive care summary and a follow-up plan, survivorship care plans can help to preserve the continuity of care between primary care providers and oncologists.^{6,13} Given that primary care providers also care for cancer survivors, it is essential that patient information is seamlessly transferred between oncologists and primary care providers.¹³

By providing patients with a comprehensive care summary and a follow-up plan, survivorship care plans can help to preserve the continuity of care between primary care providers and oncologists.

In addition to improving the continuity of patient care, survivorship care plans can help clinicians identify psychosocial distress, detect cancer recurrence and secondary cancers in a timely manner, manage bothersome symptoms, avoid preventable conditions, and avert potentially fatal late effects.⁶

According to the IOM, the following components should be included in the comprehensive care summary of a survivorship care plan⁶:

- Dates of treatment initiation and completion
- Diagnostic tests performed and their results
- Full contact information on treating institutions and key individual providers
- Identification of a key point of contact and coordinator of continuing care

- Psychosocial, nutritional, and supportive services provided
- Surgery, chemotherapy, radiotherapy, transplant, hormonal therapy, or gene or other therapies provided, including agents used, treatment regimen, total dosage, identifying number and title of clinical trials (if any), indicators of treatment response, and toxicities experienced during treatment
- Tumor characteristics.

In addition, the following components should be included in the follow-up portion of a survivorship care plan⁶:

- Likely course of recovery from treatment toxicities, as well as the need for health maintenance or adjuvant therapy
- Recommended cancer screenings and other periodic examinations, the schedule on which they should be performed, and who should conduct them.

Survivorship Care Models

Various models of survivorship care have been developed to help deliver high-quality care to cancer survivors during the posttreatment period.¹³ Each model has advantages and disadvantages, and no one model is best suited for all healthcare settings.¹³ For example, some survivorship care models focus on treating the disease and emphasize care for long-term and late effects of cancer treatment, whereas other models center on wellness and highlight the importance of psychological support.⁹

The patient population and the level and type of resources available in the practice setting should be the 2 chief considerations when selecting a survivorship care model.⁹ The experiences of patients with cancer and their needs may vary throughout their disease trajectory, ranging from patients who have a few treatment-related long-term effects to patients with chronic conditions or significant treatment-related health issues.⁹ Many survivorship care models are used in oncology today, as discussed below.

Multidisciplinary Care Model

The multidisciplinary care model is provided in a clinic outside of the oncology setting and was developed for patients with a complex diagnosis who require an extensive follow-up for long-term effects of treatment.⁹ In this survivorship care model, clinicians help patients to improve their knowledge of long-term and late effects of cancer treatment, as well as provide psychological support to accompany medically focused oncology care.⁹ This model, however, is available to a limited number of patients, and it can be difficult to coordinate all the specialists on the team.⁹ In addition, the multidisciplinary clinic may inadvertently discourage patients from reestablishing care or from initiating care with primary care providers, which can potentially result in unmet primary care needs.⁹

Shared-Care Model

The shared-care model combines care delivered by the primary care physician, the oncologist, and other health-care specialists with varying levels of involvement, depending on the needs of the patient.⁹ The shared-care model is well-suited for patients with a limited risk for late effects, and the focus is on wellness rather than on the disease; however, this model is resource-intensive, requiring time, expertise, and ongoing communication between the specialist and the primary care physician.⁹

Consultative Clinic Model

In this model, the initial follow-up is provided in the oncology setting with an eventual transition to a primary care physician. Patients may be directed back to the cancer center for needed services by the primary care physician.⁹ The consultative clinic model requires few resources, allows for the continuity of oncology care, and helps to educate patients; however, this model calls for providers who can bill for their services, because not all types of providers may be reimbursed for this service.⁹

Integrated Clinic Model

Care is provided in an oncology setting, and may be delivered by a physician or an advanced practice provider.⁹ Overall, patient care is coordinated with the primary care physician and with other specialists. In this model, oncologists are readily available to patients, when needed. Consequently, it may be difficult to transition patients to primary care, and patients may expect oncology providers to deliver primary care services.⁹

Disease/Treatment-Specific Survivor Clinic Model

In this model, the type and intensity of follow-up care that patients receive is determined by their cancer treatment.⁹ One of the advantages of this model is that providers have an expertise in one area; however, this model may concentrate resources away from other survivor groups, as well as unintentionally discourage patients from seeing primary care physicians.⁹

General Survivorship Clinic Model

A physician or an advanced practice provider delivers care at a cancer center, a community hospital, or a private practice.⁹ The general survivorship clinic model is financially more efficient than the disease-specific model; however, similar to the multidisciplinary clinic model, a general survivorship clinic may discourage patients from visiting primary care providers.⁹

Community Generalist Model

Care is provided by the primary care physician, an advanced practice nurse, or an internist within the community.⁹ This model promotes patient independence and

reintegrates the survivor into primary care, but the provider often has limited knowledge about the long-term and late effects of cancer and its treatment.⁹

Oncology Specialist Care Model

Survivorship care is provided as a continuation in the oncology center setting.⁹ This survivorship model is particularly beneficial for patients, their families, and their caregivers who have developed a relationship with the treating oncologist. However, this model focuses on the disease rather than on patient wellness, and the patient's primary care needs may be unmet.⁹

Regardless of the specific survivorship care model that is chosen, effective communication remains the cornerstone of patient-centered care and can help providers identify patients with needs that are likely to affect their health or their care.

Patient–Clinician Communication Essentials

Regardless of the specific survivorship care model that is chosen, effective communication remains the cornerstone of patient-centered care and can help providers identify patients with needs that are likely to affect their health or their care; support patients in managing their disease; refer patients to appropriate psychosocial services; coordinate psychosocial and biomedical healthcare; and follow-up on care delivery to monitor the effectiveness of services and to determine whether any changes are needed.^{13,15} According to the National Cancer Institute, the key aspects of effective patient–clinician communication include (1) fostering healing relationships, (2) exchanging information, (3) responding to emotions, (4) managing uncertainty, (5) making decisions, and (6) enabling patient self-management.¹⁶

Because family members are often the primary caregivers for patients with cancer, effective communication between caregivers and clinicians is equally important, especially if the caregiver cares for an individual with limited communication skills, including language barriers or cognitive deficits.¹⁵

Evidence indicates that effective clinician–patient communication is associated with favorable patient outcomes.¹⁵ Multiple studies have shown that physicians who involve patients in their treatment decisions during office visits have better health outcomes than physicians who do not.^{15,17,18}

To set the stage for effective communication, clinicians must prepare themselves for optimal exchange,

Table 3 Quality-of-Life Domains in Survivorship Care

Physical well-being	Psychological well-being	Social well-being	Spiritual well-being
Control or relief of symptoms Fertility Functional activities Overall physical health Pain Sleep and rest Strength and fatigue	Anxiety Cognition and attention Control Depression Distress of diagnosis and control of treatment Enjoyment and leisure Fear of recurrence	Affection and sexual function Appearance Enjoyment Family distress Finances Independence Isolation Roles and relationships Work	Hope Inner strength Meaning of illness Religiosity Transcendence Uncertainty

Source: Ferrell BR, Hassey Dow K. Quality of life among long-term cancer survivors. *Oncology (Williston Park)*. 1997;11:565-568, 571; discussion 572, 575-576.

create an environment that enhances true connection, provide feedback and confirm understanding, and ask for feedback about their communication style.¹⁹ Establishing a connection with patients from the beginning allows patients to open up, be less frightened, and concentrate on the clinician-provided information.¹⁹

Although many patients can function normally after completing treatment, cancer and its treatment often result in long-term and late effects.

Addressing Quality-of-Life Issues

Maintaining quality of life for cancer survivors is an important component of survivorship care, especially for patients who experience long-term and late effects of cancer and cancer treatment.²⁰ As it pertains to cancer care, “quality of life” is defined as a personal sense of well-being, encompassing physical, psychological, social, and spiritual domains; a disruption in one domain can impact other domains.²⁰

According to Ferrell and colleagues, quality-of-life issues in cancer survivorship comprise physical, psychological, social, and spiritual well-being (Table 3). Physical well-being involves the control or relief of symptoms and the maintenance of function and independence. Psychological well-being is the attempt to maintain a sense of control in the face of a life-threatening illness that is characterized by emotional distress, altered life priorities, and fear of the unknown, as well as by positive life changes. Social well-being is the effort to deal with the impact of cancer on individuals, their roles, and relationships; and spiritual well-being is the ability to maintain hope and derive meaning from the cancer experience, which is characterized by religiosity, hope, uncertainty, inner strength, and feelings of transcendence.²⁰

Long-Term and Late Effects of Cancer Treatment

Although many patients can function normally after completing treatment, cancer and its treatment often result in long-term and late effects.²¹ Long-term effects emerge during or after treatment and persist for long durations, whereas late effects may become apparent only months or years after patients have completed their treatment.²¹

The types of long-term and late effects that patients experience vary, depending on the type of treatment they received.²² For example, patients who have undergone surgery to remove their lymph nodes may experience lymphedema, and patients with Hodgkin lymphoma who had their spleen removed have an increased risk for contracting serious infections compared with patients who did not undergo this surgery.²²

Heart and lung problems are frequently reported in patients who receive chemotherapy and radiation therapy to the chest, whereas learning, memory, and attention deficits are common in patients who receive chemotherapy and high doses of radiation therapy to the head.²² In addition, dental, oral health, and vision problems may be attributed to chemotherapy, high-dose radiation therapy, and steroid medications.²² Other common long-term and/or late effects of cancer treatment include fatigue, sexual dysfunction, and pain.²³⁻²⁵

Cancer-related fatigue is the most common side effect of cancer and cancer treatment, with 40% to 100% of patients reporting fatigue.

Fatigue

Cancer-related fatigue is the most common side effect of cancer and cancer treatment, with 40% to 100% of patients reporting fatigue.²³ Cancer-related fatigue can be attributed to various causes, including the cancer itself

and cancer treatment.²³ Many patients with cancer say that fatigue is the most distressing side effect of cancer and its treatment, and has a significant impact on their quality of life (eg, mood, employment, daily routine, self-care, recreation, and relationships).²³ Yet physicians and nurses rarely focus on fatigue, and patients and caregivers rarely report it, possibly because they may have difficulty broaching the topic.²³

Sexual dysfunction issues are among the most common and distressing side effects of cancer treatment. The highest rates of sexual dysfunction have been reported in patients whose pelvic nerves, blood vessels, and organ structures have been damaged by cancer treatments.

Nevertheless, because fatigue cannot be diagnosed with standard diagnostic tools, it is crucial that patients and physicians have an open dialogue about cancer-related fatigue.²³ Patients are encouraged to describe their fatigue level using descriptive or numerical scales (ie, “none” to “severe,” or “0” to “10”), and clinicians are encouraged to ask interrogative-led questions.²³

Managing cancer-related fatigue depends on the type and length of treatment, how likely the treatment is to cause fatigue, and the patient’s response to treatment.²³ To ameliorate cancer-related fatigue, the American Cancer Society advises that patients with cancer maintain a healthy sleep routine, stay active, save energy, get help and support, and eat well.²³

Sexual Dysfunction

Sexual dysfunction issues are among the most common and distressing side effects of cancer treatment.²⁴ The highest rates of sexual dysfunction have been reported in patients whose pelvic nerves, blood vessels, and organ structures have been damaged by cancer treatments; however, even treatments for lung cancer, hematologic cancers, and head and neck tumors can result in sexual dysfunction.²⁴

Female sexual issues comprise a lack of sexual desire and arousal, lack of orgasm, and pain, whereas male sexual dysfunction issues manifest as loss of desire for sex and erectile dysfunction.^{13,24} Clinicians should assess and evaluate male and female cancer survivors for sexual function at regular intervals by asking them about their sexual function before cancer treatment, their present sexual activity, and impact of the cancer treatment on their sexual function and intimacy.¹³

The NCCN guidelines recommend that healthcare

professionals who treat female sexual issues adopt a multidimensional treatment approach that addresses the underlying issues, such as physiologic, disease-induced, medication-induced, psychological, and interpersonal.¹³ The treatment of erectile dysfunction includes modification of risk factors, such as smoking cessation, weight loss, increased physical activity, and avoidance of excessive alcohol consumption.¹³ Addressing psychosocial problems can also help to improve the symptoms of erectile dysfunction.¹³

Lack of patient–clinician communication regarding sexual dysfunction remains a major unmet need in survivorship care.²⁴ Although the majority of patients prefer that healthcare providers initiate discussions about sexual dysfunction, as well as educate them about sexual issues relating to cancer treatment, they rarely receive that information.²⁶ Some healthcare providers say the barriers to effective communication about sexual dysfunction include limited time, sex not being perceived as a concern of patients, and a lack of expertise in discussing sexual issues.²⁶

Cancer Pain

Cancer pain is a consequence of cancer and its treatment; approximately 1 in 3 patients undergoing cancer treatment experiences cancer pain.²⁵

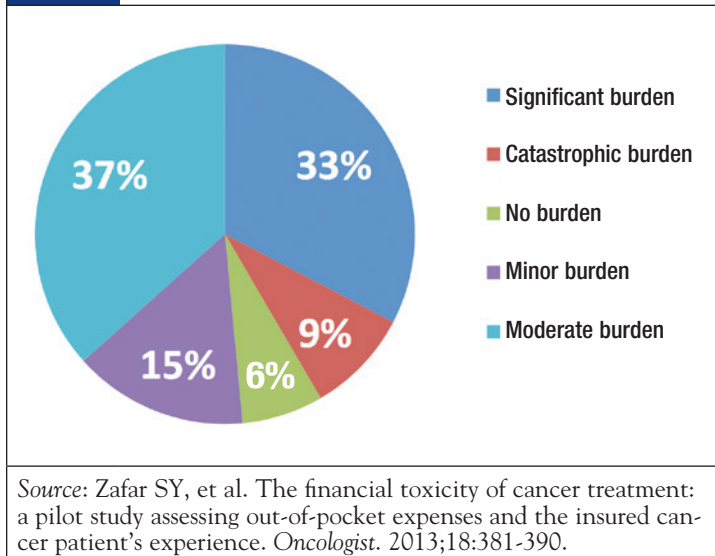
Patients may report pain as a result of destroyed tissue near the tumor.²⁵ In addition, cancer pain can come from other areas where the cancer has metastasized; as a tumor grows, it may put pressure on nerves, bones, or organs, causing pain.²⁵ Furthermore, cancer treatments, such as chemotherapy, radiation, and surgery, can result in burning sensations or painful scars and are often accompanied by unpleasant side effects, including mouth sores, diarrhea, and nerve damage.²⁵

Patients with cancer pain may be reluctant to discuss pain for fear of being perceived as complainers. In addition, anxiety over becoming addicted to pain medications may also deter patients from discussing this.

Although cancer-related pain has a significant impact on patients’ quality of life, it is undertreated, possibly because patients and clinicians do not initiate discussions about pain often enough.²⁵ Some clinicians are not sufficiently knowledgeable about pain management, whereas others are concerned that prescribed pain medications will be abused.²⁵

Patients with cancer pain may be reluctant to discuss pain for fear of being perceived as complainers. In addition, anxiety over becoming addicted to pain medications, such as opioids, and side effects related to pain

Figure 3 Financial Burden Resulting from Cancer-Related Out-of-Pocket Expenses



medication, may also deter patients from discussing pain with their clinicians.²⁵

The NCCN guidelines recommend that clinicians screen all survivors for pain at regular intervals, using numeric rating scales to assess the intensity of pain, as well as patients' own descriptions of pain.¹³ According to the NCCN, the management of pain requires a multidisciplinary approach, including pharmacologic treatments (eg, opioids, adjuvant analgesics, muscle relaxants), psychosocial and behavioral interventions, physical therapy and exercise, and interventional procedures (eg, transcutaneous electrical nerve stimulation, dorsal column stimulation).¹³

The appropriate management of these cognitive issues is necessary and should include pharmacologic interventions (eg, stimulants, cognition-enhancing drugs, antidepressants, and opiates), occupational therapy and vocational rehabilitation, and cognitive training.

Cognitive Issues

Defined as difficulty processing information, cognitive issues are common during and after cancer treatment.²⁷ In fact, up to 75% of patients with cancer report cognitive problems during treatment, and as many as 35% of patients continue to experience cognitive issues for months after treatment has ended.²⁷

Symptoms of cognitive dysfunction are manifested in various ways. For example, some patients may have trouble concentrating, performing multiple tasks, or difficulty remembering things.²⁷ Other patients may experience difficulty with spatial orientation, issues with comprehension or understanding, or behavioral and emotional changes (eg, irrational behavior, mood swings).²⁷ Patients with cancer are advised to discuss these symptoms with their healthcare providers, including any new symptoms or a change in symptoms.²⁷

Although chemotherapy and radiation are often cited as the major causes of cognitive issues in patients with cancer, other factors can also contribute to cognitive issues, including brain surgery; hormone therapy, immunotherapy, and other medications; infections; and a deficiency of vitamins and minerals.²⁷

Whereas cognitive issues associated with the use of certain medications or with reversible conditions (eg, anemia, electrolyte imbalance) are transient, cognitive issues related to chemotherapy and radiation are not likely to resolve.²⁷ Therefore, the appropriate management of these cognitive issues is necessary and should include pharmacologic interventions (eg, stimulants, cognition-enhancing drugs, antidepressants, and opiates), occupational therapy and vocational rehabilitation, and cognitive training.²⁷ In addition, patients are encouraged to adopt various strategies to help cope with cognitive problems, such as keeping a checklist of daily reminders, completing a task at a time, and exercising to improve mental sharpness.²⁷

Financial Implications of Cancer Treatment

The rising cost of cancer care is taking a considerable toll on patients' finances and can affect patients' well-being. According to Bernard and colleagues, approximately 13% of patients with cancer spend more than 20% of their income on healthcare and on insurance premiums.²⁸

Cancer care is one of the fastest growing components of the US healthcare costs, estimated to reach nearly \$158 billion by 2020—a 39% increase in cost from 2010.² ASCO attributes the rising cost of cancer care to the overall aging of the population; the introduction of costly new drugs and innovative surgery and radiation techniques; and the adoption of more expensive diagnostic tests.²⁹ Although emerging technology continues to revolutionize cancer care, there are cases when the use of expensive novel agents, the latest treatment techniques, and diagnostic tests do not yield sufficient evidence to warrant their use, resulting in increased costs without improved patient outcomes.³⁰

Whereas years ago patients with health insurance were, for the most part, protected from the exorbitant costs of cancer treatment, the recent focus on cost-sharing via high deductibles and larger copayments has forced

patients and their families to confront cancer treatment costs head-on, with some patients potentially compromising their health for the sake of saving money.^{29,31}

A 2013 survey by Zafar and colleagues revealed that the increased out-of-pocket cost burden for cancer care has a considerable impact on patients' well-being and on their quality of care.³¹ For example, of the 254 patients surveyed, 46% reported spending less on food and clothing, 24% did not fill their prescription, 9% did not undergo a recommended test, 7% avoided a recommended procedure, and 4% skipped clinic or chemotherapy appointments—all of which were attributed to cancer-related out-of-pocket expenses.³¹

This study further revealed that 46% of patients used all or a portion of their savings, and 35% of patients borrowed money or used credit cards to pay for cancer care.³¹ Overall, 42% of patients surveyed reported a significant or catastrophic financial burden resulting from cancer-related out-of-pocket costs.³¹

Sources of Financial Assistance for Cancer Care

Many financial assistance programs exist to help patients offset their significant cancer-related costs, including health insurance, government programs, public and nonprofit hospitals, copayment relief programs, patient assistance programs, voluntary organizations, fundraising, and personal financial planning.³²

Health insurance. Health insurance should help to cover various cancer-related costs.³² In many cases, the insurance company can assign a case manager to help patients with cancer answer any questions they may have. Patients have the right to appeal if their insurance company denies coverage for any aspect of their cancer care.³²

Government programs. The federal government offers several programs that provide assistance with medical and living expenses, including Medicare, Medicaid, and Social Security.³² These programs are designed for individuals who are disabled or elderly, or those who have low incomes. Many state governments also have programs to assist qualified state residents with medical and living expenses.³²

Public and nonprofit hospitals. Hospitals that are run by state or local government, as well as certain nonprofit hospitals, provide care to anyone who may need it, regardless of their ability to pay.³² Social workers or local health departments may help patients locate charity care or indigent care programs that are available in patients' communities.³²

Copayment relief programs. Many voluntary organizations offer financial assistance to patients with cancer who cannot afford their insurance premiums, copay-

ments, deductibles, and other out-of-pocket costs.³² Each organization offers different kinds of assistance and has its own eligibility rules; for example, some programs may be available only to people with specific types of cancer. Funds are limited, and the amount of funding available can change.³²

Patient assistance programs. Many pharmaceutical companies offer patient assistance programs to help patients with insurance reimbursement, referrals to copayment relief programs, and applications for assistance.³² In addition, these companies may offer medications at little or no cost to patients who do not qualify for other help.³²

Of the 254 patients surveyed, 46% reported spending less on food and clothing, 24% did not fill their prescription, 9% did not undergo a recommended test, 7% avoided a recommended procedure, and 4% skipped clinic or chemotherapy appointments—all of which were attributed to cancer-related out-of-pocket expenses.

Voluntary organizations. Voluntary organizations may offer assistance with practical needs, such as help with child care and transportation. Each organization offers different kinds of assistance and may have its own eligibility rules.³²

Fundraising. Fundraising is a widely used approach to help patients pay for cancer care.³² Before raising funds, however, patients should ensure that fundraising will not disqualify them from receiving other financial benefits, such as Medicaid or Social Security.³² Patients should consider working with an organization that has experience raising funds for medical treatment. In addition, patients should follow Internal Revenue Service guidelines for using tax-exempt donations.³²

Personal financial planning. Seeking advice from an accountant or a financial advisor may help patients save money on their income taxes.³² For example, some patients may qualify for tax credits that will reduce their taxes; if patients have many out-of-pocket medical expenses, they may be able to reduce their taxes by deducting those expenses from their income.³² In addition, financial planners may help patients manage their finances and plan their financial future. Organizations such as the American Association of Retired Persons or investment management companies offer free or low-cost financial planning talks.³²

Conclusion

With an increasing number of patients living longer after their cancer diagnosis, the need for survivorship planning has become apparent. Equipping patients with survivorship care plans, discussing long-term and late effects of cancer treatment, and navigating patients through the healthcare system can empower them to take control of their cancer journey.

With an increasing number of patients living longer after their cancer diagnosis, the need for survivorship planning has become apparent. Equipping patients with survivorship care plans can empower them to take control of their cancer journey.

When discussing survivorship care with your patient, it is important to consider several points. First, patients are living longer after their cancer diagnosis and are in need of survivorship care to help maintain their quality of life; therefore, every patient with cancer should receive a plan that is customized to his or her individual needs. In addition, all healthcare team members caring for patients with cancer should be actively involved in maintaining open lines of communication internally and externally.

Furthermore, patients should be informed about the various financial programs that help to offset the rising cost of cancer care. Finally, potential long-term burdens and late effects of cancer treatment should be addressed at diagnosis and throughout the care continuum and survivorship.

References

- American Cancer Society. Cancer Facts & Figures 2015. www.cancer.org/acs/groups/content/@editorial/documents/document/acspc-044552.pdf. Accessed July 15, 2015.
- Mariotto AB, Yabroff KR, Shao Y, et al. Projections of the cost of cancer care in the United States: 2010-2020. *J Natl Cancer Inst*. 2011;103:117-128.
- Centers for Disease Control and Prevention. A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. www.cdc.gov/cancer/survivorship/pdf/plan.pdf. Accessed July 15, 2015.
- National Coalition for Cancer Survivorship. Defining cancer survivorship. July 24, 2014. www.canceradvocacy.org/news/defining-cancer-survivorship/. Accessed July 15, 2015.
- National Coalition for Cancer Survivorship. The National Coalition for Cancer Survivorship. www.canceradvocacy.org/about-us/our-history/. Accessed July 15, 2015.
- Institute of Medicine. Hewitt M, Greenfield S, Stovall E, eds. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: The National Academies Press; 2005.
- American College of Surgeons Commission on Cancer. Cancer Program Standards 2012: Ensuring Patient-Centered Care. V1.2.1. www.facs.org/~media/files/quality%20programs/cancer/coc/programstandards2012updates.ash. Accessed July 15, 2015.
- National Comprehensive Cancer Network. NCCN presents new guidelines for survivorship. www.nccn.org/about/news/newsinfo.aspx?NewsID=333. Accessed July 15, 2015.
- American Society of Clinical Oncology. *Providing High Quality Survivorship Care in Practice: An ASCO Guide*. 2014. www.asco.org/sites/www.asco.org/files/survivorshipcompendium2014_web.pdf. Accessed July 15, 2015.
- Mullan F. Seasons of survival: reflections of a physician with cancer. *N Engl J Med*. 1985;313:270-273.
- Dana-Farber Cancer Institute. Cancer's 'Seasons of Survivorship'. www.dana-farber.org/Newsroom/Publications/Cancer-s-Seasons-of-Survivorship.aspx. Accessed July 16, 2015.
- Rechis R, Beckjord EB, Arvey SR, et al. Wisconsin Comprehensive Cancer Control Program. The essential elements of survivorship care: a LIVESTRONG brief. December 2011. www.wicancer.org/uploads/pub_64120.pdf. Accessed July 15, 2015.
- National Comprehensive Cancer Network. NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines): survivorship. Version 1.2015. February 27, 2015. www.nccn.org/professionals/physician_gls/pdf/survivorship.pdf. Accessed July 15, 2015.
- Institute of Medicine. *Delivering High-Quality Cancer Care: Charting a New Course for a System in Crisis*. Washington, DC: National Academies Press; 2013. www.nap.edu/catalog/18359/delivering-high-quality-cancer-care-charting-a-new-course-for. Accessed July 15, 2015.
- Institute of Medicine. *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: National Academies Press; 2008. www.nap.edu/catalog/11993/cancer-care-for-the-whole-patient-meeting-psychosocial-health-needs. Accessed July 15, 2015.
- Epstein RM, Street RL Jr. Patient-Centered Communication in Cancer Care: Promoting Healing and Reducing Suffering. Bethesda, MD: National Cancer Institute; 2007. NIH Publication No. 07-6225. http://appliedresearch.cancer.gov/areas/pcc/communication/pcc_monograph.pdf. Accessed July 15, 2015.
- Gattellari M, Butow PN, Tattersall MH. Sharing decisions in cancer care. *Soc Sci Med*. 2001;52:1865-1878.
- Hack TF, Degner LF, Watson P, Sinha L. Do patients benefit from participating in medical decision making? Longitudinal follow-up of women with breast cancer. *Psychooncology*. 2006;15:9-19.
- Planetree, Inc. and Picker Institute. Patient-Centered Care: Improvement Guide. October 2008. <http://planetree.org/wp-content/uploads/2015/03/Patient-Centered-Care-Improvement-Guide-10.10.08.pdf>. Accessed July 15, 2015.
- Ferrell BR, Hassey Dow K. Quality of life among long-term cancer survivors. *Oncology (Williston Park)*. 1997;11:565-568, 571; discussion 572, 575-576.
- Stein KD, Syrjala KL, Andrykowski MA. Physical and psychological long-term and late effects of cancer. *Cancer*. 2008;112(11 suppl):2577-2592.
- Cancer.net. Long-Term Side Effects of Cancer Treatment. www.cancer.net/survivorship/long-term-side-effects-cancer-treatment. Accessed July 15, 2015.
- American Cancer Society. Fatigue in people with cancer. 2014. www.cancer.org/acs/groups/cid/documents/webcontent/002842.pdf. Accessed July 15, 2015.
- Schover LR, van der Kaaij M, van Dorst E, et al. Sexual dysfunction and infertility as late effects of cancer treatment. *EJC Suppl*. 2014;12:41-53.
- Moynihan T; for Mayo Clinic staff. Cancer pain: relief is possible. October 18, 2014. www.mayoclinic.org/diseases-conditions/cancer/in-depth/cancer-pain/art-20045118. Accessed July 15, 2015.
- Lindau ST, Surawska H, Paice J, Baron SR. Communication about sexuality and intimacy in couples affected by lung cancer and their clinical-care providers. *Psychooncology*. 2011; 20:179-185.
- Cancer.net. Attention, thinking, or memory problems. June 2013. www.cancer.net/navigating-cancer-care/side-effects/attention-thinking-or-memory-problems. Accessed August 3, 2015.
- Bernard DS, Farr SL, Fang Z. National estimates of out-of-pocket health care expenditure burdens among nonelderly adults with cancer: 2001 to 2008. *J Clin Oncol*. 2011;29:2821-2826.
- Schnipper LE, Davidson NE, Wollins DS, et al. American Society of Clinical Oncology statement: a conceptual framework to assess the value of cancer treatment options. *J Clin Oncol*. 2015 Jun 22. Epub ahead of print.
- Shih YC, Ganz PA, Aberle D, et al. Delivering high-quality and affordable care throughout the cancer care continuum. *J Clin Oncol*. 2013;31:4151-4157.
- Zafar SY, Peppercorn JM, Schrag D, et al. The financial toxicity of cancer treatment: a pilot study assessing out-of-pocket expenses and the insured cancer patient's experience. *Oncologist*. 2013;18:381-390.
- Cancer Financial Assistance Coalition. Sources of financial assistance. www.cancerfac.org/reading/sources.php. Accessed July 15, 2015.

