Advancing Survivorship Care Through the National Cancer Survivorship Resource Center

Developing American Cancer Society Guidelines for Primary Care Providers

Rebecca Cowens-Alvarado, MPH1; Katherine Sharpe, MA2; Mandi Pratt-Chapman, MA3; Anne Willis, MA4; Ted Gansler, MD, MBA, MPH5; Patricia A. Ganz, MD6; Stephen B. Edge, MD7; Mary S. McCabe, RN, MA8; Kevin Stein, PhD9

The National Cancer Survivorship Resource Center (The Survivorship Center) began in 2010 as a collaboration between the American Cancer Society and the George Washington University Cancer Institute and was funded by the Centers for Disease Control and Prevention. The Survivorship Center aims to improve the overall health and quality of life of posttreatment cancer survivors. One key to addressing the needs of this ever-growing population is to develop clinical follow-up care guidelines that emphasize not only the importance of surveillance for cancer recurrence, but also address the assessment and management of the physical and psychosocial long-term and late effects that may result from having cancer and undergoing cancer treatment as well as highlight the importance of healthy behaviors that can reduce the risk of cancer recurrence, second primary cancers, and other chronic diseases. Currently, The Survivorship Center is coordinating the work of experts in oncology, primary care, and other health care professions to develop follow-up care guidelines for 10 priority cancer sites. CA Cancer J Clin 2013;63:147-150. ©2013 American Cancer Society.

Keywords: survivorship, primary care, public health, guidelines

Introduction

Cancer survival rates have improved over the past several decades due to advances in treatment and screening.1 Nearly 13.7 million Americans are cancer survivors, and that number is expected to grow to almost 18 million by 2022.2 This increase can be attributed, in part, to an increased risk of cancer among the large, aging population of baby boomers. Continued improvements in cancer detection and treatment contribute further to the ever-growing population of cancer survivors,3 with research demonstrating that these individuals face many challenges even after treatment ends.4 These challenges may be physical, psychosocial, practical, spiritual, or informational and can begin during treatment and persist beyond treatment (long-term effects) or occur months or years after treatment ends (late effects).5 Unfortunately, many cancer survivors and their primary care providers6 are often unaware of these issues and may not recognize the need for coordinated, comprehensive follow-up care. As a result, many survivors do not receive appropriate clinical care and support, which may negatively impact their long-term health outcomes and quality of life.

1Director of Cancer Control Mission Strategy, Health Promotions Department, American Cancer Society, Atlanta, GA; 2Managing Director of Prevention and Survivorship Strategy, Health Promotions Department, American Cancer Society, Atlanta, GA; 3Associate Director, Community Programs, George Washington University Cancer Institute, Washington, DC; 4Director, Division of Cancer Survivorship, George Washington University Cancer Institute, Washington, DC; 5Director of Medical Content, Health Promotions Department, American Cancer Society, Atlanta, GA; 6Professor, University of California at Los Angeles Schools of Medicine and Public Health, Division of Cancer Control and Prevention Research, Jonsson Comprehensive Cancer Center, Los Angeles, CA; 7Alfiero Foundation Endowed Chair in Breast Oncology, Roswell Park Cancer Institute, Buffalo, NY; 8Director, Survivorship Program, Memorial Sloan-Kettering Cancer Center, New York, NY; 9Managing Director, Behavioral Research Center, American Cancer Society, Atlanta, GA.

Corresponding author: Rebecca Cowens-Alvarado, MPH, Director of Cancer Control Mission Strategy, Health Promotions Department, American Cancer Society, 250 Williams St, NW, Suite 600, Atlanta, GA 30303; rowens@cancer.org

DISCLOSURES: Supported by Cooperative Agreement SU55DP003054 from the Centers for Disease Control and Prevention. The contents of this article are solely the responsibility of the authors and do not necessarily represent the official views of the Centers for Disease Control and Prevention. The American Cancer Society is funded through Cooperative Agreement 1U55DP003054 with the Centers for Disease Control and Prevention to create the National Cancer Survivorship Resource Center (The Survivorship Center). The American Cancer Society provides a subgrant to the George Washington University Cancer Institute to collaborate on The Survivorship Center objectives. Staff from both the American Cancer Society and the George Washington University Cancer Institute contributed to the development of this article and the clinical care guidance.

©2013 American Cancer Society, Inc. doi:10.3322/caac.21183. Available online at cacancerjournal.com
In 2006, the Institutes of Medicine (IOM) published *From Cancer Patient to Cancer Survivor: Lost in Transition*, which focused on the specific needs of adult cancer survivors as they transition from cancer treatment to the posttreatment survivorship phase. This report was followed by a second IOM report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, which further emphasized the importance of assessing and treating the psychological, social, and spiritual issues experienced by many cancer survivors. Both reports recommended that survivors receive a detailed care plan to assess and treat the potential long-term and late effects specific to their cancer diagnosis and treatment. In addition, these reports emphasized the need to develop clinical guidelines for survivorship care and recognized the importance of primary care providers (PCP) as partners in the care of cancer survivors. The increasing emphasis on the need to address the long-term and late effects of cancer and its treatment has led to more attention being given to making changes at the individual, community, system, and societal levels. These efforts, however, have not been without significant challenges.

There are numerous barriers to the delivery of quality, comprehensive, posttreatment care. The growing number of individuals requiring posttreatment follow-up care is increasingly difficult for many practices to manage. This is compounded by a lack of agreement among health care providers at both the local and national level on who should manage the follow-up care of cancer survivors and a lack of comprehensive clinical guidelines to inform this care, as well as the limited evidence base to support these guidelines. In addition, there are challenges when coordinating care among various providers. When care management shifts from treatment to the management of side effects and long-term survivorship, PCPs and nonphysician PCPs can participate in and even deliver this care. However, the PCP may not be fully knowledgeable in this area, and may not have been fully informed about the scope of the cancer care.

One possible solution to improve care coordination among providers and ensure a smooth transition from active to posttreatment care is to provide each patient completing treatment, and all of his or her primary and specialty providers, with a survivorship care plan, which includes a summary of treatment and a specific detailed plan for surveillance follow-up and symptom management. While many health care systems are moving toward the goal of delivering a survivorship care plan for every cancer patient, there are many barriers to the widespread implementation and use of such tools. The best evidence is that fewer than 15% of patients receive such a plan and that fewer than one-half of the National Cancer Institute-designated cancer centers consistently deliver care plans to their cancer survivors.

Lack of reimbursement for the time it takes to complete a care plan is a key barrier to widespread implementation. In addition, there are variations and inconsistencies with regard to the extent of information provided in the care plans used to date. Often, these plans do not include recommendations for health promotion or assessment and the management of long-term and late effects. Furthermore, oncology professionals lack training in delivering these plans as well as tools to make these plans easy to complete, including linkages to relevant information on the impact of therapy with relevant resources that providers can share with patients.

An additional barrier to care coordination is related to the comfort and confidence that PCPs express regarding the follow-up care of cancer survivors. Only about one-half of PCPs report feeling comfortable and confident in their knowledge and skills in providing follow-up care for cancer survivors and cite uncertainty regarding the type, frequency, and duration of surveillance testing for cancer recurrence. While new care delivery models are emerging, there are no established standards for providing follow-up care. More research is needed on survivorship models of care to definitively determine how to effectively and efficiently coordinate follow-up care. However, although the evidence is limited to patients with early-stage breast cancer, it has been demonstrated that PCPs can deliver posttreatment care with patient outcomes measured in terms of both cancer recurrence and quality of life that are similar to those resulting from oncology provider follow-up care when equipped with adequate information about the cancer diagnosis, treatment, surveillance guidelines, and potential long-term or late effects. Currently, there is a lack of consensus on the role of each provider in caring for survivors. With education and guidelines, PCPs can share care and eventually take over the follow-up care for some cancer survivors. Engaging the PCP in caring for posttreatment survivors can facilitate the prevention and management of not only the long-term and late effects of cancer treatment, but also of other chronic comorbid conditions that may be overlooked by oncology specialists.

One initial step toward systematic changes to improve the quality of survivorship care began in 2010 with the creation of the National Cancer Survivorship Resource Center (The Survivorship Center). The Survivorship Center is a collaboration between the American Cancer Society and the George Washington University Cancer Institute, and is funded through a cooperative agreement with the Centers for Disease Control and Prevention. The Survivorship Center was established to advance the recommendations made in *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies*. In 2011, The Survivorship Center convened an Expert Panel composed of
more than 100 multidisciplinary cancer survivorship experts representing not only oncology specialists, but also experts in cancer rehabilitation, psychosocial and behavioral issues, health promotion, primary care, health systems, and public policy. The Expert Panel was tasked with developing strategic recommendations for increasing knowledge and awareness of the issues faced by cancer survivors and improving access to quality survivorship care. The Expert Panel recognized the importance of developing clinical survivorship care guidelines as a fundamental element to advancing survivorship care as outlined in the aforementioned IOM reports. Despite the lack of long-term survivorship data and limited evidence regarding the long-term and late effects associated with many cancers and their associated treatment, The Survivorship Center is currently developing follow-up care guidelines to bridge the gap until additional evidence is available.

The Survivorship Center began by identifying 10 priority cancer sites based on survivor prevalence and the severity of long-term or late effects, building on earlier publications designed to provide guidance to PCPs. These 10 cancer sites are: breast, colorectal, prostate, lung, gynecologic (cervix, ovarian, endometrial, and uterine), and head and neck cancers, and melanoma. The process is a hybrid design that leverages practice-based evidence and expert consensus while incorporating a systematic review of existing evidence as emphasized in the American Cancer Society’s process for developing prevention and early detection guidelines. Site-specific guidelines will be updated as additional evidence emerges. While follow-up care should be individualized based on the type of cancer, the type of treatment received, and the individual’s overall health, including possible cancer treatment-related problems, the guidelines will facilitate follow-up care for cancer survivors that addresses critical elements of care necessary to achieve optimal health and quality of life.

The follow-up care guidelines content was structured to align with work previously conducted by leaders in survivorship care. It parallels the IOM recommendations for critical components of survivorship care detailed in the 2006 report, From Cancer Patient to Cancer Survivor: Lost in Transition that focused on survivors of adult cancer during the phase of care that follows primary treatment.4 In late 2011, with sponsorship from The Survivorship Center, LIVESTRONG convened the Essential Elements of Survivorship Care meeting to “build consensus among key stakeholders on the essential elements of survivorship care that any effective cancer survivorship provider must provide (directly or via referral) to post-treatment cancer survivors.” The LIVESTRONG Tier 1 Consensus Elements are consistent with the prior recommendations set forth in the IOM report. The American Cancer Society’s follow-up care guidelines will include these essential elements: routine health promotion to reduce the risk of cancer and other chronic conditions such as diabetes and cardiovascular disease (nutrition, physical activity, smoking cessation); screening for new cancers and surveillance for recurrent cancers; assessment and management of potential cancer-related or treatment-related long-term and late effects, including recommendations for psychosocial support and physical rehabilitation; and implications for practice with an emphasis on PCP communication with other health care professionals responsible for caring for the cancer survivor (eg, oncology team, mental health professionals, etc).

Currently, The Survivorship Center has drafted follow-up care guidelines for patients with colorectal and breast cancer. Work is also underway to develop follow-up care guidelines for survivors of head and neck and prostate cancer. These guidelines should be available in CA during the latter part of 2013.

In addition to the work of The Survivorship Center, both the National Comprehensive Cancer Network (NCCN) and the American Society of Clinical Oncology (ASCO) are working to develop survivorship guidelines that address common long-term and late effects experienced by many survivors. The NCCN survivorship guideline incorporates information related to wellness as well as common long-term and late effects such as anxiety, depression, cognitive function, fatigue, sleep disorders, chronic pain, and sexual function. ASCO guidelines will focus on providing guidance for the clinical management of survivors, with an emphasis on the management of long-term and late effects such as treatment-related neuropathy. The NCCN also publishes guidelines for the management of most cancers that include surveillance for recurrent disease that can help guide follow-up care. ASCO previously published follow-up guidelines for patients with breast and colorectal cancer that largely focus on surveillance for recurrent disease. The Survivorship Center is coordinating with the NCCN and ASCO to ensure that the American Cancer Society’s follow-up care guidelines complement the work of the NCCN and ASCO to meet the needs of the variety of providers caring for cancer survivors.

The American Cancer Society’s follow-up care guidelines will build upon available evidence, surveillance guidelines, and standard clinical practice and are designed to facilitate the provision of high-quality, standardized, clinical care by PCPs (including physicians, physician assistants, and nurse practitioners), nurses, and others who are increasingly playing a key role in the management of follow-up care for cancer survivors. While these groups are a priority audience, oncologists caring for cancer survivors may also find these guidelines valuable as it is a step toward comprehensive and standardized follow-up care.
References

1. Siegel R, Naishadham D, Jemal A. Cancer statistics, 2013. CA Cancer J Clin. 2013;63:3–30.
2. Siegel R, DeSantis C, Virgo K, et al. Cancer treatment and survivorship statistics, 2012. CA Cancer J Clin. 2012;62:220-241.
3. Parry C, Kent EE, Mariotto AB, Alfano CM, Rowland JH. Cancer survivors: a booming population. Cancer Epidemiol Biomarkers Prev. 2011;20:1996-2005.
4. Hewitt M, Greenfield S, Stoval E, eds. From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: National Academies Press; 2006.
5. Baker F, Denniston M, Smith T, West MM. Adult cancer survivors: how are they faring? Cancer. 2005;104(suppl 11):2565-2576.
6. Potosky AL, Han PK, Rowland J, et al. Differences between primary care physicians’ and oncologists’ knowledge, attitudes and practices regarding the care of cancer survivors. J Gen Intern Med. 2011;26:1403-1410.
7. Adler NE, Page AEK, eds. Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs. Washington, DC: National Academies Press; 2008.
8. Cooper JM, Loeb SJ, Smith CA. The primary care nurse practitioner and cancer survivorship care. J Am Acad Nurse Pract. 2010;22:394-402.
9. Blaseg K, Kile M, Salner A. Survivorship & Palliative Care: A Comprehensive Approach to a survivorship care plan. nxtbook.com/nxtbooks/accc/ncccp_monograph/index.php?startid=49#50. Accessed February 13, 2013.
10. Salz T, Oeffinger KC, McCabe MS, Layne TM, Bach PB. Survivorship care plans in research and practice. CA Cancer J Clin. 2012;62:101-117.
11. Nissen MJ, Beran MS, Lee MW, Mehta SR, Pine DA, Swenson KK. Views of primary care providers on follow-up care of cancer patients. Fam Med. 2007;39:477-482.
12. Salz T, Oeffinger KC, Lewis PR, Williams RL, Ryne RL, Yeazel MW. Primary care providers’ needs and preferences for information about colorectal cancer survivorship care. J Am Board Fam Med. 2012;25:635-651.
13. McCabe M, Baker KS, Huffman C, Miller K. Optimizing survivorship care: academic and community clinic models. In: Feuerstein M, Ganz PA, eds. Health Services for Cancer Survivors Practice, Policy, and Research. New York: Springer; 2011:223-238.
14. Lavis JN, Montesanti S. Evidence Brief: Enhancing Patient Transitions From Treatment in a Regional Cancer Centre to Survivorship in the Hamilton Niagara Haldimand Brant Community. Hamilton, Ontario, Canada: McMaster Health Forum; 2011.
15. Grunfeld E, Earle CC. The interface between primary and oncology specialty care: treatment through survivorship. J Natl Cancer Inst Monogr. 2010;2010:25-30.
16. Department of Health and Human Services, Centers for Disease Control and Prevention. Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC: National Academies Press; 2006.
17. American Cancer Society, George Washington University Cancer Center. National Cancer Survivorship Resource Center Executive Summary: Year One Overview. cancer.org/acs/groups/content/@editorial/documents/document/acspc-031407.pdf. Accessed February 13, 2013.
18. Kattlove H, Winn RJ. Ongoing care of patients after primary treatment for their cancer. CA Cancer J Clin. 2003;53:172-196.
19. Sunga AY, Eberl MM, Oeffinger KC, Hudson MM, Mahoney MC. Care of cancer survivors. Am Fam Physician. 2005;71:699-706.
20. Brawley O, Byers T, Chen A, et al. New American Cancer Society process for creating trustworthy cancer screening guidelines. JAMA. 2011;306:2495-2499.
21. LIVESTRONG. The LIVESTRONG Essential Elements of Survivorship Care: Definitions and Recommendations. livestrong.org/pdfs/3-0/Essential-Elements-Definitions-Recommendations. Accessed February 13, 2013.
22. National Comprehensive Cancer Network. National Comprehensive Cancer Network Clinical Practice Guidelines in Oncology. Fort Washington, PA: National Comprehensive Cancer Network; 2012. nccn.org/clinical.asp. Accessed February 13, 2013.
23. McCabe MS, Bhatia S, Oeffinger KC, et al. American Society of Clinical Oncology Statement: Achieving High-Quality Cancer Survivorship Care. J Clin Oncol. 2013;31:631-640.
24. Khatcheressian JL, Hurley P, Bantug E, et al. Breast Cancer Follow-Up and Management After Primary Treatment: American Society of Clinical Oncology Clinical Practice Guideline Update [published online ahead of print January 14, 2013]. J Clin Oncol.
25. Desch CE, Benson AB 3rd, Somerfield MR, et al; American Society of Clinical Oncology. Colorectal cancer surveillance: 2005 update of an American Society of Clinical Oncology practice guideline. J Clin Oncol. 2005;23:8512-8519.