

Cancer Survivorship: A New Challenge in Delivering Quality Cancer Care

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“After my very last radiation treatment for breast cancer, I lay on a cold steel table hairless, half-dressed and astonished by the tears streaming down my face. I thought I would feel happy about finally reaching the end of treatment, but instead I was sobbing. At the time, I wasn’t sure what emotions I was feeling. Looking back, I think I cried because this body had so bravely made it through 18 months of surgery, chemotherapy, and radiation. Ironically, I also cried because I would not be coming back to that familiar table where I had been comforted and encouraged. Instead of joyous, I felt lonely, abandoned and terrified. This was the rocky beginning of cancer survivorship for me.”—Elizabeth D. McKinley, MD, MPH¹

The year 2006 represents an important landmark for cancer survivorship. First, it marks the 20th anniversary of the founding of the National Coalition for Cancer Survivorship (NCCS).² When NCCS’s 23 founding members met in Albuquerque, NM, in October of 1986, they rejected the historic definition of a cancer survivor as someone who had remained disease-free for 5 years. They embraced instead the right for an individual to label him or herself a cancer survivor from the moment of diagnosis and for the balance of life, regardless of whether death was ultimately due to cancer or some unrelated cause or event. Their intent in adopting this new language was not merely to provide hope to those newly diagnosed, but also to foster a change in the nature of doctor-patient communication in the context of cancer. If it was recognized from the outset that the majority of people diagnosed with cancer could expect to live years beyond this history, then discussion about the potential long-term and late costs of cancer treatments, and the different choices affecting these, needed to be part of the early dialogue. The coalition also recognized that there were different needs experienced by survivors across the course of their illness and recovery, eloquently described by one of their founding members, Fitzhugh Mullan as “seasons of survival.”³ This notion and advocacy by NCCS members resulted in the concept of “survivorship,” or more specifically, the period of health and well-being experienced by survivors after active cancer treatment (and before diagnosis of recurrence or a new malignancy), as a distinct phase on the cancer control continuum being added to the language of oncology.

Second, 2006 marks the 10th anniversary of the establishment of the Office of Cancer Survivorship (OCS) at the National Cancer Institute.⁴ The OCS was created in direct response to compelling and articulate consumer advocacy for more attention to the unique and

poorly understood needs of the growing population of cancer survivors across the United States. The mandate of the OCS is to improve the length and quality of life of all those diagnosed with cancer. The OCS achieves its mission by pursuing activities in three areas: first, by directing and supporting research; second by underwriting or advocating for the training of researchers and clinicians dedicated to studying and treating or caring for survivors; and third, by participating in the development of educational materials and outreach programs designed to equip cancer survivors and their caregivers with the information they need to achieve optimal health after cancer.

Third, in recognition of the importance of survivorship issues, the American Society of Clinical Oncology (ASCO) introduced a “Patient and Survivor Care” track to its Annual Meeting this year. This addition to the meeting agenda recognized the expanding number of cancer survivors and the critical role of oncologists in meeting the health care needs of patients following the completion of treatment. The addition of “survivors” to the patient care track further serves to highlight the rapid maturation that has occurred in the field of cancer survivorship both with respect to the science of survivorship research and the art of survivor care. Reviews of the progress made, and the challenges that remain, in these respective domains form the basis of this special issue.

As Meadows rightfully notes in her reflective article,⁵ some of the great success stories in our ability to cure and control cancer have occurred in pediatric cancer. As a consequence, childhood cancer survivors were among the first subjects of cancer survivorship research. Critically, they have also served as the proverbial ‘canaries in the mineshaft,’ their documented experience of survivorship warning of the at times considerable price that may be paid for added years of life due to the toxic and life-altering effects of aggressive cancer treatments. While Meadows notes that there are a number of unique challenges inherent to the follow-up of survivors of cancer treated as children, versus those treated as adults, there are many lessons to be learned from the pediatric arena in how best to monitor cancer and deliver post-treatment care.⁶

Efforts to translate this knowledge and develop appropriate care models for adult cancer survivors are just beginning to take off. Like childhood cancer survivors, we know that adult survivors face a host of challenges to their long-term psychosocial functioning⁷ and economic well being⁸ post-treatment. Appreciating these adverse sequelae and finding means to prevent or ameliorate them are important challenges

for clinicians and researchers. However, a critical key to success in achieving this goal will depend on the development and, importantly, routine use of tools that enable clinicians to effectively and efficiently assess survivors' health-related quality of life and functioning.⁹ Further, reducing the psychosocial morbidity of cancer will depend on how quickly we can develop interventions to address these and when identified, make them broadly available to all sectors of our diverse society.^{7,10}

Our evolving knowledge about the lingering consequences of cancer survival has implications for how survivors are evaluated in the medical setting and for the delivery of post-treatment follow-up care and surveillance. As articulated by Ganz,¹¹ in addition to addressing psychosocial sequelae, the ability to evaluate the long-term effects and screen for and treat the late medical and physiologic consequences of cancer and its treatments are skills that those caring for survivors must acquire. Further, as part of this role, understanding what survivors are currently doing to promote their health and well-being and building on this may be critical to health care professionals' ability to reduce the risk for morbidity and mortality after cancer.^{12,13} Cancer treatments are constantly changing; as a result, toxicity profiles are a moving target. While the development of new molecularly targeted cancer agents holds great promise for reducing damage to healthy tissues and organs, they may introduce unanticipated risks that only become apparent over time.^{14,15}

Questions related to how best to deliver optimal follow-up care, who should deliver it, in what settings, and according to which guidelines or best practice models represent a new focus of research.¹⁶ Some insights on the delivery of quality care may be gained from the more than two dozen programs designed to follow childhood cancer survivors that have sprung up across the country.¹⁷ However, the challenges associated with providing comprehensive follow-up medical services to adult cancer survivors—who are usually treated in the community, are rarely on clinical trials, and often present with comorbid conditions that compete for attention and may restrict therapeutic options—likely demand new models for care.¹⁸ Finding ways to train the next generation of health care providers about survivorship issues, and attracting and supporting future generations of clinicians and researchers invested in caring for an aging population of survivors and advancing the science of survivorship research pose a significant challenge.¹⁹

The pressure to find rapid solutions to all of these challenges is building; particularly in the wake of new figures that show a decline in cancer deaths, but only a modest decrease in the numbers of those being diagnosed.²⁰ Already estimated as including more than 10 million adults in the United States alone, the number of cancer survivors is expected to grow as new advances in cancer screening and treatment diffuse into the community, and with the aging of the population. If we count in these figures family members and caregivers, who are also included in the definition of survivors adopted by NCCS² and embraced by the National Cancer Institute⁴ as being affected by cancer in a loved one, the number of individuals whose lives will be altered by cancer rises to the tens of millions.²¹ Attention to this future challenge is not unique to the United States as illustrated by Grunfeld's²² review of international cancer control efforts. Across all of this new focus on survivorship, it is clear that a driving force has been and will continue to be survivors themselves.²³ Understanding what survivors need in terms of care and support, and leveraging their collective voice and

advocacy is necessary if we are to truly achieve quality cancer care across the cancer trajectory.

This JCO special issue builds not only on a significant body of work that has developed in the last two decades but also on several recently released high-profile national reports addressing issues in cancer survivorship. These include two volumes produced by the Institute of Medicine, *Childhood Cancer Survivorship: Improving Care and Quality of Life*,²⁴ which appeared in August 2003, and *From Cancer Patient to Cancer Survivor: Lost in Transition*,²⁵ released November 2005, a report published April 2004, by the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation, *A National Action Plan for Cancer Survivorship to Advance Public Health Strategies*,²⁶ and two from the President's Cancer Panel, *Living Beyond Cancer: Finding a New Balance*,²⁷ released June 2004 with recommendations for consideration, and a follow-up report delivered June 2006, *Assessing Progress: Advancing Change*.²⁸

Many of the authors (as well as the editors) were involved in a number of these reports, in particular the series of studies undertaken by the Institute of Medicine (IOM) addressing cancer survivorship. All of the IOM's survivorship-related work followed from the IOM's seminal document, *Ensuring Quality Cancer Care*,²⁹ that recommended strategies to promote evidenced-based, comprehensive, compassionate, and coordinated care throughout the cancer care trajectory. Another of the IOM's earlier reports, *Improving Palliative Care for Cancer*,³⁰ addressed the need for quality care at the end of life for those who die from cancer. However, it also conceptualized and endorsed the philosophy that palliation, or symptom management, must start at diagnosis and continue across the course of care, including that delivered post-treatment. It should be noted that work on survivorship issues continues at the IOM with in-depth examination of psychosocial care provided to cancer survivors currently underway. This study itself follows a 2004 report *Meeting the Psychosocial Needs of Women with Breast Cancer*.³¹

Finally, this special issue of the *Journal* reflects the culmination of a year of concentrated focus on cancer survivors by ASCO, specifically on those who are post-treatment for their disease. A Survivor Task Force, originally created under the leadership of past ASCO President David Johnson, and co-chaired by 2005-2006 ASCO President Sandra Horning and Patricia Ganz, championed the development of the 2006 meeting Patient and Survivor Care Track. The logo for this meeting, where Tour de France winner Lance Armstrong received ASCO's 2006 Special Recognition Award (a video of the speech is available at www.asco.org), also featured survivorship (Advocating Survivorship, Clinical Science, and Oncology Quality Care). A special panel was created to revisit the evidence base for, and content of guidelines for follow-up care for survivors. In addition, following the release of the IOM's authoritative report on adult cancer survivors, already endorsed by several major cancer advocacy organizations, ASCO cosponsored with IOM, an all-day Scientific Symposium on November 8, 2005, to call attention to the report. The organization issued a press release in support of its recommendations³² and coedited (Dr Ganz) the symposium report.³³

Taking direction from this watershed report (Table 1), ASCO has moved quickly to implement a number of the outlined recommendations. ASCO assumed a leadership role in developing and piloting the use of survivor treatment summaries and care plans, with the intent of having versions for individuals treated for the most common cancers, available in early 2007. These documents will be important in activities

Table 1. Recommendations From the Institute of Medicine Report
From Cancer Patient to Cancer Survivor: Lost in Transition²⁵

Recommendation 1

Health care providers, patient advocates, and other stakeholders should work to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care.

Recommendation 2

Patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained. This "Survivorship Care Plan" should be written by the principal provider(s) that coordinated oncology treatment. This service should be reimbursed by third-party payors of health care.

Recommendation 3

Health care providers should use systematically developed evidence-based clinical practice guidelines, assessment tools, and screening instruments to help identify and manage late effects of cancer and its treatment. Existing guidelines should be refined and new evidence-based guidelines should be developed through public-and private-sector efforts.

Recommendation 4

Quality of survivorship care measures should be developed through public/private partnerships and quality assurance programs implemented by health systems to monitor and improve the care that all survivors receive.

Recommendation 5

The Centers for Medicare and Medicaid Services, National Cancer Institute, Agency for Healthcare Research and Quality, Department of Veterans Affairs, and other qualified organizations should support demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.

Recommendation 6

Congress should support the Centers for Disease Control and Prevention, other collaborating institutions, and the states in developing comprehensive cancer control plans that include consideration of survivorship care, and promoting the implementation, evaluation, and refinement of existing state cancer control plans.

Recommendation 7

The National Cancer Institute, professional associations, and voluntary organizations should expand and coordinate their efforts to provide educational opportunities to health care providers to equip them to address the health care and quality-of-life issues facing cancer survivors.

Recommendation 8

Employers, legal advocates, health care providers, sponsors of support services, and government agencies should act to eliminate discrimination and minimize adverse effects of cancer on employment, while supporting cancer survivors with short-term and long-term limitations in ability to work.

Recommendation 9

Federal and state policy makers should act to ensure that all cancer survivors have access to adequate and affordable health insurance. Insurers and payors of health care should recognize survivorship care as an essential part of cancer care and design benefits, payment policies, and reimbursement mechanisms to facilitate coverage for evidence-based aspects of care.

Recommendation 10

The National Cancer Institute, Centers for Disease Control and Prevention, Agency for Healthcare Research and Quality, Centers for Medicare and Medicaid Services, Department of Veterans Affairs, private voluntary organizations such as the American Cancer Society, and private health insurers and plans should increase their support of survivorship research and expand mechanisms for its conduct. New research initiatives focused on cancer patient follow-up are urgently needed to guide effective survivorship care.

designed to mobilize efforts to standardize care of survivors, as evidenced by discussions held as part of "Implementing Survivorship Care Planning," a May 2006 workshop cosponsored by the National Coalition for Cancer Survivorship and the IOM, in partnership with the Lance Armstrong Foundation and the National Cancer Institute.³⁴

The first recommendation of the report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, calls on health care providers, patient advocates, and other stakeholders to raise awareness of the needs of cancer survivors, establish cancer survivorship as a distinct phase of cancer care, and act to ensure the delivery of appropriate survivorship care. With the publication of this special issue, the *JCO* seeks to meet this first recommendation. Specifically, this issue is intended to raise awareness among the *Journal's* readership, and prompt actions to improve clinical care, and importantly enhance what is known of the cancer experience post-treatment.

These and other efforts underway at ASCO are a clear indication of the organization's commitment to quality cancer care; they also reflect the organization's acknowledgment that quality of survivorship care and the transition from patient to survivor needs our attention. Not all individuals diagnosed with cancer choose to embrace or even welcome the label of "cancer survivor." But no individual with a cancer history should be treated as though his or her illness never happened; and many of them, along with their health care providers and family members, will need to be educated about what implications their illness has for their future health care and decision making.

It is hoped that the content of this volume will enhance ASCO's pioneering effort in this area.

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REFERENCES

- McKinley ED: Under toad days: Surviving the uncertainty of cancer recurrence. *Ann Intern Med* 133:479-480, 2000
- Hoffman B: *A Cancer Survivor's Almanac: Charting Your Journey* (ed 3). Hoboken, NJ, John Wiley & Sons Inc, 2004
- Mullan F: Seasons of survival: Reflections of a physician with cancer. *N Engl J Med* 313:270-273, 1985
- National Cancer Institute: Cancer Survivorship Research Web site. <http://dcccps.nci.nih.gov/ocs/>
- Meadows AT: Pediatric cancer survivorship: Research and clinical care. *J Clin Oncol* 24:5160-5165, 2006
- Rowland JH: Foreword: Looking beyond cure—Pediatric cancer as a model. *J Pediatr Psychol* 30:1-3, 2005
- Stanton AL: Psychosocial concerns and interventions for cancer survivors. *J Clin Oncol* 24:5132-5137, 2006
- Short PF, Vargo MM: Responding to employment concerns of cancer survivors. *J Clin Oncol* 24:5138-5141, 2006
- Ayanian JZ, Jacobsen PB: Enhancing research on cancer survivors. *J Clin Oncol* 24:5149-5153, 2006
- Alfano CM, Rowland JH: Recovery issues in cancer survivorship: A new challenge for supportive care. *Cancer J* 12:432-443, 2006
- Ganz PA: Monitoring the physical health of cancer survivors: A survivorship focused medical history. *J Clin Oncol* 24:5105-5111, 2006
- Demark-Wahnefried W, Pinto BM, Gritz ER: Promoting health and physical function among cancer survivors: Potential for prevention and questions that remain. *J Clin Oncol* 24:5125-5131, 2006
- Ganz PA: A teachable moment for oncologists: Cancer survivors, 10 million strong and growing! *J Clin Oncol* 23:5458-5460, 2005
- Smith KL, Dang C, Seidman AD: Cardiac dysfunction associated with trastuzumab. *Expert Opin Drug Saf* 5:619-629, 2006
- Glabbeke MV, Verweij J, Casali PG, et al: Predicting toxicities for patients with advanced gastrointestinal stromal tumours treated with imatinib: A study of the European Organisation for Research and Treatment of Cancer, the Italian Sarcoma Group, and the Australasian Gastro-Intestinal Trials Group (EORTC-ISG-AGITG). *Eur J Cancer* 42:2277-2285, 2006
- Earle CC: Failing to plan is planning to fail: Improving the quality of care with survivorship care plans. *J Clin Oncol* 24:5112-5116, 2006
- Aziz NM, Oeffinger KC, Brooks S, Turoff AJ: Comprehensive long-term follow-up programs for pediatric cancer survivors. *Cancer* 107:841-848, 2006
- Oeffinger KC, McCabe MS: Models for delivering survivorship care. *J Clin Oncol* 24:5117-5124, 2006

19. Ferrell BR, Winn R: Medical and nursing education and training opportunities to improve survivorship care. *J Clin Oncol* 24:5142-5148, 2006
20. Ries LAG, Harkins D, Krapcho M, et al: SEER Cancer Statistics Review, 1975-2003. National Cancer Institute, Bethesda, MD, 2006. http://seer.cancer.gov/csr/1975_2003
21. Lewis FM: The effects of cancer survivorship on families and caregivers. *Cancer Nurs* 29:20-25, 2006 (suppl 2)
22. Grunfeld E: Looking beyond survival: How are we looking at survivorship? *J Clin Oncol* 24:5166-5169, 2006
23. Hoffman B, Stovall E: Survivorship perspectives and advocacy. *J Clin Oncol* 24:5154-5159, 2006
24. Hewitt M, Weiner SL, Simone JV: Childhood Cancer Survivorship: Improving Care and Quality of Life. Washington, DC, The National Academies Press, 2003
25. Hewitt M, Greenfield S, Stovall E: From Cancer Patient to Cancer Survivor: Lost in Transition. Washington, DC, The National Academies Press, 2005
26. Centers for Disease Control and Prevention and the Lance Armstrong Foundation: A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies. Atlanta, GA, Centers for Disease Control and Prevention, 2004
27. President's Cancer Panel 2003/2004 Annual Report: Living Beyond Cancer: Finding a New Balance. Bethesda, MD, National Cancer Institute, 2004
28. President's Cancer Panel 2005/2006 Annual Report: Assessing Progress, Advancing Change. Bethesda, MD, National Cancer Institute, 2006
29. Hewitt M, Simone JV: Ensuring Quality Cancer Care. Washington, DC, The National Academies Press, 1999
30. Foley KM, Gelband H: Improving Palliative Care for Cancer. Washington, DC, The National Academies Press, 2001
31. Hewitt M, Herdman R, Holland J Meeting Psychosocial Needs of Women with Breast Cancer. Washington, DC, The National Academies Press, 2004
32. ASCO Press Release, November 7, 2005: Symposium on Cancer Survivorship to Focus on Long-Term Care Plans for Survivors After Treatment Ends. <http://www.asco.org/portal/site/ASCO/menuitem.c543a013502b2a89de912310320041a0/?vgnextoid=34a82071d0658010VgnVCM100000ed730ad1RCRD>
33. Hewitt M, Ganz P: From Cancer Patient to Cancer Survivor - Lost in Transition: An American Society of Clinical Oncology and Institute of Medicine Symposium. Washington, DC, The National Academies Press, 2006
34. Hewitt M, Ganz P (eds): Implementing Cancer Survivorship Care Planning. Washington, DC, The National Academies Press (in press)

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