Cancer Survivors: A Look Backward and Forward

By Patricia A. Ganz, MD

Introduction

There are few of us practicing oncology today who remember what cancer care was like in the 1960s, when the American Society of Clinical Oncology (ASCO) was founded. From my knowledge of cancer care history, the first trials of single-agent chemotherapy for childhood acute lymphoblastic leukemia (ALL) were just getting organized in the 1960s. It was not until the 1970s that great strides occurred in the treatment of ALL, with the introduction of prophylactic cranial radiation therapy, new drugs with standardized protocols, and prolonged maintenance therapy—pediatricians were on the long march toward demonstrating extended survival and cure for patients with childhood ALL.[1] The rest is history, with the rapid and systematic development of clinical trials for treatment of a wide variety of childhood cancers—cancer clinical trials were the standard of care for the universe of children diagnosed with cancer, and off-protocol treatment was rare. Fifty years of progress in the treatment of children with cancer has led us to the current expectation of cure among almost all children diagnosed with cancer today.[1] Of course, there has been a price to pay, as we have learned about many late effects of cancer treatment in children.[2]

At the time I began my medical oncology fellowship in the mid 1970s, we were in the early years of combined-modality chemotherapy for Hodgkin lymphoma[3] and use of multiagent therapy for advanced metastatic breast cancer.[4] A new investigational agent (cisplatin) in phase II trials was showing promise in the treatment of advanced testes cancer. New drugs, such as doxorubicin, were making their way into the clinic, being tested in a variety of cancers (breast cancer, lymphoma, and sarcoma). There was great hope that adult malignancies would now capitulate and yield significant cures such as we had seen in children. At that time, we marked survival by attaining 5 years free of disease, and there were approximately 3 million individuals in the United States who were thought to be alive and disease free. It is not clear how those survival rates were calculated (more complex methods are in place today to obtain such estimates), but this was used as a benchmark, as Nixon's war on cancer was declared, and increased funding was applied to cure cancer.

To further set the stage, I would like to remind you that the radical mastectomy for breast cancer was the standard of surgical care, including extensive axillary nodal dissection; staging laparotomy and total nodal irradiation with or without chemotherapy were standard for Hodgkin lymphoma; estrogen receptor assays on breast tumors were just being developed for clinical use and required that a gram of frozen tissue be submitted at the time of surgery; diethylstilbestrol and oophorectomy were the main endocrine therapies for advanced metastatic breast cancer; the concept of adjuvant chemotherapy was in its infancy, being tested in clinical trials for breast cancer and osteosarcoma; mammography and prostate-specific antigen screening did not exist as part of routine primary care. Clinical care has changed dramatically over these past decades, with much earlier detection of a variety of cancers (breast, cervical, prostate, and colorectal cancers), along with the advent of organ-preserving treatments (laryngeal, bladder, breast, and prostate cancers and sarcoma) relying on use of multimodal combined therapies (surgery, radiation therapy, and chemotherapy). Neoadjuvant therapy was unheard of (how could the tumor not be removed first?) but is now common for many cancers (breast and rectal cancers and sarcoma). Fortunately, we have seen a parallel rise in the number of adult survivors of cancer, with nearly 14 million estimated in 2012 and an expected 18 million by 2022.[5]

Given this tremendous success story, how is the current health care system coping with the large number of cancer survivors as well as the more than 1.6 million new patient cases diagnosed each year? There have been relatively few modifications in the practice of oncology in the past 25 years, when there was a great expansion of well-trained oncology providers (surgeons, medical oncologists, and radiation oncologists) practicing in the community, where most cancer care is now delivered. There are many community cancer programs certified by the American College of Surgeons Commission on Cancer, and this program has done much to ensure that patients in the community can receive many of the effective treatments delivered at National Cancer Institute–designated Comprehensive Cancer Centers and other academic centers. However, none of the existing settings of care—academic institutions, community cancer centers, or clinical oncology practices—have determined how to address the growing number of cancer survivors. In the discussion that follows, I will review and summarize a series of efforts that emerged identifying the critical need to provide better coordination of care for all patients with cancer, but especially the growing numbers of cancer survivors. The current efforts focus on developing new models of care and more research to prepare the health care system to more efficiently and effectively provide care for cancer survivors.

Seminal Events

In 1985, a young physician, Fitzhugh Mullan, penned an article for the *New England Journal of Medicine*,[6] describing the seasons of survival and reflecting on his own personal experience as a patient with cancer with a mediastinal germ cell tumor receiving combined-modality therapy and experiencing cure and its consequences (toxicity, psychological sequelae, and uncertainty about the future). Shortly thereafter, in 1986, working with a local Albuquerque, New Mexico, cancer support group, he invited 25 individuals to come for a 2-day meeting to discuss the issues related to the long-term survival experience after cancer and whether there was a space for a new movement or organization that might be the voice for the growing numbers of cancer survivors. Among those attending were several cancer survivors and their partners, representatives of several psychosocial support communities, nurses, social workers, a young lawyer, and one medical oncologist. Among the patients and their family members, there was a genuine passion for recognition of the burden of illness they bore, even though they were cured, and of the apparent lack of knowledge of the medical care system about how their persistent symptoms and secondary complications should be managed. Their primary care physicians felt helpless in advising them on their post-treatment care, and they looked to their oncologists as the major source of guidance, but even there, they came up short.

The product of that meeting was a new organization: the National Coalition for Cancer Survivorship (NCCS), whose founders declared that “from the moment of diagnosis and for the balance of life, an individual diagnosed with cancer is a survivor” (Figure 1). This definition would go on to be accepted as the standard in the cancer community. The goal of the fledgling organization was imagined to be a confederation of grassroots organizations (a coalition) and individual members who would begin to champion the health care needs and expectations of the growing number of cancer survivors. Strategies proposed included affecting health care policy and research so that survivors and their health care providers would be better prepared for what to expect in the aftermath of cancer treatment, and that this information could be infused into the training of clinicians and enhance the quality of care for patients with cancer and survivors. These laudable goals were challenging to implement from an organizational office in New Mexico, and after a few years, NCCS relocated to the Washington, DC, area and was staffed by individuals with greater experience in the policy arena, who could lobby for the important issues on which the organization was founded. There were national meetings of the NCCS where these issues were discussed among all stakeholders (patients, survivors, care givers, and health professionals), and in 1996, NCCS published a white paper on the quality of cancer care, “Imperatives for Quality Cancer Care: Access, Advocacy, Action and Accountability,”[6a] calling for more research, clinical trials, and better services for long-term survivors.

At the same time, ASCO became aware of this nascent movement and began to work with a number of patient advocacy groups. You may recall the early activities of the AIDS activists; this was paralleled by the substantial activities of patients with breast cancer and advocates, with the emergence of funding for breast cancer research by the Department of Defense, resulting from the actions of the breast cancer community. ASCO had a Patient Advocacy Committee in the early 1990s, first led by Nicholas Vogelzang and then me. We did not quite know how ASCO should be engaging with these organizations, because patient advocacy organizations were novel and not as ubiquitous as today. Similar to the present, it was a time of turmoil in health care reform, with the recent election of President Clinton and Hillary Clinton’s task force on health care. Although nothing emerged from the lengthy policy discussions in Washington, DC, patient advocates and oncology physicians were concerned that health care as we knew it was threatened, and our relationships became solidified over time as we saw the benefits of collaboration. At my recommendation, the ASCO Patient Advocacy Committee was disbanded, and the role of interacting with these organizations became a part of the newly established ASCO organizational leadership at headquarters in Alexandria, Virginia, under the leadership of John Durant. This was the beginning of the formal and informal strong and productive relationships ASCO has had with

Figure 1. Founding meeting of the National Coalition for Cancer Survivorship, Albuquerque, New Mexico, 1986.

diverse stakeholders in the patient advocacy and survivorship movement.

The NCCS continued to push its policy agenda under the able leadership of Ellen Stovall and a board of directors that included many ASCO clinicians and other community stakeholders. Ultimately, at their behest, in 1996, the director of the National Cancer Institute (NCI), Richard Klausner, established the Office of Cancer Survivorship at NCI to shepherd and stimulate a scientific research agenda to expand the knowledge base on the long-term and late effects of cancer treatment, about which so little information was available. Initially led on a part-time basis by Anna Meadows, a pioneer in the study of the late effects of childhood cancers, the leadership position of director of the Office of Cancer Survivorship was subsequently filled by my friend and research colleague, Julia Rowland. Under her leadership, we now have accurate statistics on the number of cancer survivors, their diversity, and the expected growth in their numbers over the next decade. She and her program staff at NCI have fostered new research initiatives and have championed cancer survivorship research across NCI as well as other National Institutes of Health and federal organizations. They have hosted a wonderful scientific conference, the Biennial Cancer Survivorship Research Conference, in collaboration with the American Cancer Society, LIVESTRONG, and other partners, for more than a decade. Survivorship research is now considered a mainstream component of cancer research (description of outcomes for many common cancers and some interventions), and the portfolio across NCI and the National Institutes of Health is extensive; however, there is much less known about how to achieve implementation and care delivery improvements for cancer survivors.

Finally, there were several critical policy activities in the early years of the 21st century that reinvigorated the clarion call of the NCCS founders, who longed for a better care delivery system for cancer survivors. Several reports had strong recommendations and common themes, including one developed by the Centers for Disease Control and Prevention and the Lance Armstrong Foundation in 2004, a report from the President's Cancer Panel on Cancer Survivors in 2003 to 2004, and the 2005 Institute of Medicine (IOM) report on the health care delivery needs of adult cancer survivors, who were described as being lost in transition, finally putting the health care challenges of the more than 10 million cancer survivors front and center.

ASCO Response to Challenges Associated With Cancer Survivorship Care Delivery

ASCO was a sponsor of the 2005 IOM survivorship report[7] and had several of its members represented on the consensus study committee, including the late Roger Winn, Craig Earle, Sarah Donaldson, and me. ASCO also played an important role in disseminating the report findings, including holding a workshop that was held immediately after the report was released and acting as a cosponsor of a subsequent workshop on implementation of survivorship care planning—a high-profile recommendation from the report.[8,9] As a member of the ASCO Board of Directors, I was tasked to work with staff to develop several ASCO templates that could be used by our members to try to implement the recommendation on end-of-treatment summaries and survivorship care plans, and we were able to assemble several disease-specific committees that produced one-page treatment plan/treatment summary documents that could be used by our members. Unfortunately, the uptake of these templates was limited. As a member of the Electronic Health Record Working Group, I worked with the vendors to get them to develop these templates in their emerging products, but we had little traction. Even today, the large electronic health record vendors have not provided a solution for easy extraction of key treatment elements that can be folded into a summary document to be shared with patients and their nononcology health care providers.

Also spurred by the 2005 IOM report, there was an incomplete effort by ASCO to develop guidelines for survivorship care, because patients and their clinical care providers needed to know how follow-up care should be provided, especially surveillance for recurrence as well as the late effects of cancer treatment. Although some high-quality evidence for surveillance is available for a few cancers (ie, breast and colon cancers) and is part of extant ASCO guidelines, efforts to develop more high-level guidelines faltered. An exception was one for fertility preservation, which was issued in 2006[10] and has recently been updated.[11] For a short time, Sandra Horning and I led the ASCO Cancer Survivorship Task Force, but the activities of this effort diminished over time. Cancer.net, the ASCO Web portal for patients with cancer and cancer survivors did develop some materials for survivors, hoping to fill some of the gaps in information.

It was not until the recent ASCO presidency of Michael Link that cancer survivorship re-emerged as an important focus for ASCO. There is now a Cancer Survivorship Committee (established in 2011), the role of which is to ensure that the research, clinical care, and educational needs related to cancer survivorship are championed in all the activities of ASCO, as well as directly addressed by the committee. To this end, the committee published a policy statement from ASCO in 2013, outlining the goals of achieving high-quality care for cancer survivors.[12] This comprehensive document outlines a robust agenda of activities for the committee and ASCO to improve potential outcomes for the growing number of cancer survivors. This includes developing models of care in a variety of settings where cancer survivors receive care and broadening the education of all health care providers about the needs and concerns of cancer survivors. To this end, the committee has created several task forces addressing key issues and promulgated and published its first guidelines with detailed and practical recommendations for common symptoms and problems faced by cancer survivors and their health care providers.[13-15] These much-needed guidelines with high-quality management recommendations should facilitate the post-treatment management of cancer survivors and improve their quality of care, as strongly requested in the 2005 IOM report. There are various dissemination products that accompany these guidelines, and it is hoped that these will facilitate education among providers as

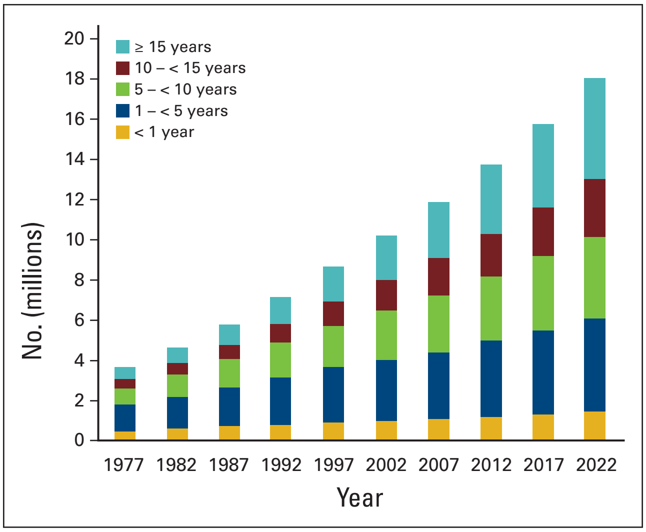

Figure 2. Anticipated growth in the number of cancer survivors by 2022. Reprinted with permission.[5]

well as individual patient interactions. In addition, the Cancer Survivorship Committee is about to release the Cancer Survivorship Care Toolbox, which will provide information and resources for clinicians and health care organizations to use in developing care delivery programs for the cancer survivors in their practices.

Where Are We Now in Cancer Survivorship Care Delivery, and Where Are We Going?

It has been almost a decade since the 2005 IOM report.[7] The first recommendation, that cancer survivorship be recognized as a distinct phase of cancer care, has been widely accepted. Around the globe, not just in North America, the needs of cancer survivors are being recognized. However, we are far away from achieving the goals and aspirations reflected in many of the other recommendations. Among them, the need for post-treatment coordination of care, has become even more critical, as communicated extensively in the 2013 IOM report on delivery of high-quality cancer care.[16] Given the fact that more than 18 million cancer survivors are expected in the United States by 2022 (Figure 2), and that the vast majority of these cancer survivors will be age > 65 years, it is imperative that better coordination of care be achieved among oncology specialists, as well as among clinicians who care for older adults (primary care and various medical subspecialists).[17] The looming shortage of oncology professionals, as well as other health care professionals more generally,[16] will make this even more critical. We must develop efficient and coordinated ways to transition patients at low risk for cancer recurrence back to their primary care clinicians and prepare these providers and patients with plans for follow-up. Team-based care needs to be promoted, and nurses and other clinicians are important members of these teams.

Any new model for care delivery will need to have well-informed and engaged patients at the center of care,[18] and this is an area of important opportunity for ASCO and other professional organizations to develop better information and decision-support tools for oncology clinicians to use at the point of care with their patients (Figure 3). Survivors must be engaged in their follow-up care for the remainder of their lives. They need to be concerned about recurrence, late effects of treatment, and second cancers, while often experiencing lingering physical and emotional effects of their prior treatments.[19,20] They often find themselves educating their nononcology clinicians about their cancer treatments and follow-up needs. It would be much more valuable for each patient/survivor to have his or her primary treating oncologist act as a partner in this process, so the patient/survivor is not the sole individual responsible for designing and communicating a post-treatment plan.

This also means that we have to increase our knowledge base regarding optimal surveillance and follow-up strategies, as well as monitor for and intervene in the late effects of cancer treatment. We are all hopeful that a learning health care system,

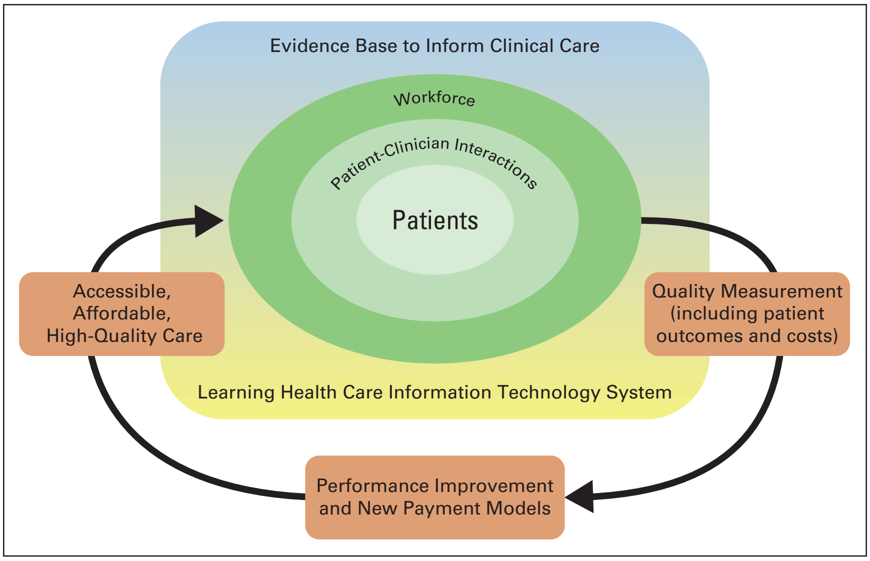

Figure 3. Conceptual framework figure from Institute of Medicine report on delivery of high-quality cancer care.[16]

made possible by advances in computing and health information technology, will make it more feasible for us to learn about survivor experiences and outcomes in the real world.[16,21,22] In this regard, the development of CancerLinQ by ASCO as a prototype for aggregation and analysis of data collected in routine clinical practice is a forward-looking step that may be useful in understanding the true magnitude of long-term and late effects of cancer treatment, especially if patient-reported outcomes are included.

In conclusion, the oncology community should be proud of what has been accomplished in the past 50 years in terms of understanding the fundamental genetic basis of cancer, along with many advances in early detection of cancer, the development of multimodal treatment strategies that have increased survival, and now the development of targeted therapies that may avoid some of the indiscriminant harmful effects of chemotherapy and radiation treatments. Today is an exciting time to be an oncologist. However, we cannot forget about the nearly 14 million cancer survivors in the United States and more than 25 million worldwide who are looking to us for guidance about how their post-treatment care should be organized and how we can mitigate or diminish some of the symptoms and concerns that they still have even though cancer is no longer with them. Following the recommendations of the 2005 IOM report,[7] we need to ensure that these survivors are receiving the essential components of survivorship care, including efforts to prevent cancer recurrence and late effects of treatment, appropriate surveillance for cancer recurrence or second cancers and medical and psychosocial late effects, intervention for the consequences of cancer and its treatment (eg, lymphedema, sexual dysfunction, pain, and fatigue), and coordination of care between cancer specialists and primary care providers. There is still much more to be done in the next 50 years.

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