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Adult Cancer Survivorship: Evolution, Research, and Planning Care

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Abstract

Increases in the number of adult cancer survivors and other issues have forced the oncology community to examine, evaluate, and alter the cancer care paradigm. Pediatric oncologists are grappling with the task of transitioning a growing population of adult survivors of childhood cancer to adult medicine, while oncologists caring for adult cancer survivors are seeking models of follow-up care that are acceptable to patients and providers. Workforce and access-to-care issues suggest that primary care providers will see more cancer survivors in their practices across time, although it is unclear how prepared they are for this task. Translational research is needed to develop evidence-based clinical care and survivorship care plans. A broad picture of the evolving field of adult cancer survivorship is presented. The recent focus on young adult survivors of childhood cancer, an overview of translational research needed to inform the physical and psychosocial care of cancer survivors, and the roles of primary and specialty care providers managing this population is examined. Finally, an overview of evolving treatment summary and care plan initiatives is presented. *CA Cancer J Clin* 2009;59:391-410. ©2009 American Cancer Society, Inc.



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Introduction

Concern for cancer survivors and their long-term care developed initially as a result of significant improvements in curing children and adolescents with cancer. During the last 3 decades, a population of young adult cancer survivors has emerged, many with special needs that require ongoing care and surveillance. Some of these childhood cancer survivors have continued to receive follow-up care in pediatric oncology settings well into adulthood, despite the fact that the likelihood of their primary cancer recurring is remote. At this phase of care,

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the focus for them, as well as for the much larger number of survivors of adult cancers, turns to surveillance for and management of long-term and late effects that occur as a result of cancer and its treatment, as well as routine health promotion and prevention of disease.

More than 40% of people born today in the United States will be diagnosed with cancer at some point in their lives.¹ Advances in screening and treatment have contributed to lengthening the survival period for many of these individuals, and long-term survival is now a possibility for many patients. The need for cancer care to more fully address survivorship issues has been the subject of numerous conferences, workshops, and symposia sponsored by such groups as the National Cancer Institute (NCI), the National Coalition for Cancer Survivorship (NCCS), and most recently, the Institute of Medicine (IOM). The NCCS, founded in 1986, was responsible for adding the term “survivorship” to cancer care^{2,3} and for heightening awareness of the importance of looking beyond cancer treatment to the survivorship phase of care. However, the adult oncology community has been slow to embrace the notion that this phase warrants significant and separate attention.

In 1997, the Lance Armstrong Foundation was founded and with additional support from influential groups such as the NCI and the American Cancer Society (ACS) has contributed to bringing survivorship to the forefront of the oncology community.⁴ In 2006, a committee established by the IOM published a seminal report, *From Cancer Patient to Cancer Survivor: Lost in Transition*, which examined a broad range of medical and psychosocial issues faced by cancer survivors as a consequence of their diagnosis and its treatment

TABLE 2. IOM Recommendations for Survivorship Care

	RECOMMENDATIONS FOR SURVIVORSHIP CARE
1	Raise awareness of cancer survivorship
2	Provide a care plan for survivors
3	Develop clinical practice guidelines for cancer survivors
4	Define quality health care for cancer survivors
5	Overcome health care system challenges
6	Address survivorship as a public health concern
7	Provide survivorship education and training of health care professionals
8	Address employment concerns of cancer survivors of all ages
9	Improve access to adequate and affordable health insurance
10	Invest in research

IOM indicates Institute of Medicine.

Hewitt M, Greenfield S, Stovall E, eds. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.

and has probably been most responsible for drawing attention to the survivorship phase of care.²

The IOM report identified cancer survivorship as a distinct phase of care that has been neglected in areas such as advocacy, education, clinical practice, and research. The report recognized 4 essential components of patient-centered survivorship care (Table 1), and 10 recommendations for improving the care provided to survivors were made (Table 2).² These recommendations are far-reaching and broad, requiring cooperation among health care providers, researchers, advocacy groups, professional organizations, government bodies, and policy makers. Since 2006, there have been numerous publications outlining and discussing the report, with many focusing on the recommendation that patients completing primary cancer treatment “be provided with a comprehensive summary of their treatment together with a

TABLE 1. Essential Components of Survivorship Care

	ESSENTIAL COMPONENTS OF SURVIVORSHIP CARE
1	Prevention of recurrent and new cancers, and other late effects
2	Surveillance for cancer spread, recurrence, or second cancers; assessment of medical and psychosocial late effects
3	Intervention for consequences of cancer and its treatment
4	Coordination between specialists and primary care providers to ensure that all of the survivor's health needs are met

Hewitt M, Greenfield S, Stovall E, eds. *From Cancer Patient to Cancer Survivor: Lost in Transition*. Washington, DC: National Academies Press; 2006.

survivorship follow-up care plan written by the treating health care provider(s).²

This is a challenging task for reasons that include workforce and reimbursement issues and a lack of empirical guidelines on which to base recommendations and develop survivorship care plans. Pediatric oncology has taken the lead in developing treatment summaries and guidelines for follow-up care plans for patients and their families and in communicating this information to other health care providers. These guidelines have been written and managed by the Children's Oncology Group (COG).⁵ Although generally consensus-based rather than data-driven, these recommendations provide consistency for follow-up care of childhood cancer survivors, a feature lacking in long-term follow-up care provided to adult cancer survivors. There has been considerable debate about how to approach the development of survivorship care plans for adult cancer survivors. The IOM report acknowledged that survivorship plans "have strong face validity and can reasonably be assumed to improve care unless and until evidence accumulates to the contrary."² However, the adult oncology community has been hesitant to make consensus-driven recommendations for follow-up care of adult cancer survivors.

Oncology workforce issues are another factor to be considered when examining the broad topic of adult cancer-survivorship care delivery. The IOM examined the workforce issue in the recent *Ensuring Quality Cancer Care through the Oncology Workforce: Sustaining Care in the 21st Century* workshop and publication.⁶ They noted that the current crisis in the cancer-care workforce will worsen because of the aging and retiring of health care providers in oncology and primary care and because of the increasing number of cancer survivors. The long-term follow-up care needs of cancer survivors combined with the increasing focus on health promotion will further tax the resources of available oncology practitioners and place new and significant demands on primary care providers who do not feel adequately prepared to care for cancer survivors.⁶⁻¹³ Yet, as survivors increase and the oncology workforce diminishes, primary and specialty care practices will be caring for more long-term cancer survivors, and these cancer-care providers must be prepared to do so.

Treatment summaries and survivorship care plans serve as effective communication tools between on-

cology practitioners and primary care physicians, and these tools improve the confidence with which non-oncological physicians practice. They provide a focus for the evolving field of adult survivorship that includes clinical care, research, and education. Survivorship care plans engage survivors and cancer-care providers alike and help to guide clinicians in their clinical care of cancer survivors. Although data-driven surveillance guidelines have not been established for most adult cancers, clinically derived and consensus recommendations are arising from a variety of sources. As models are developing for the care of adult cancer survivors, thoughtfully designed evaluative research must be conducted that can truly inform clinical care and guide evolving models of care.

This article explores the emerging field of adult cancer survivorship. It is not easy to change a paradigm in which providers have historically focused on cancer treatment and cure. The field of adult cancer survivorship is growing and demands are being placed on providers who lack adequate training, data, or practice standards to guide care for a rapidly growing number of patients. As mentioned earlier, many articles have been published that outline the IOM recommendations, the essential components of care, and the barriers to providing that care, including oncology and primary care workforce issues.^{2,14-16} In addition, professional and advocacy groups have focused on the need for and development of care plans for cancer survivors despite a paucity of survivorship research.¹⁸ We will attempt to bring these issues together, providing the reader with a broad picture of the evolving field of adult cancer survivorship. The ongoing work in the field of pediatric cancer survivorship care will be presented including the more recent focus on the population of survivors of pediatric cancer who are now adults. Adult cancer-survivorship issues, including the what, why, and how of translational research that will inform the physical and psychological care of this population, and the roles of primary care and specialty practitioners who are caring for adult survivors at a time when there are significant workforce issues in oncological and primary care will also be examined. Finally, we will present an overview of available treatment-summary and care-plan templates, an in-depth view of a patient-focused Internet-based treatment summary, and a care-plan initiative that has an integrated re-

search component driving the evolution of the product. Examination of these topics will provide the reader with a picture of the multifaceted scope of the challenges faced by clinicians, researchers, administrators, and adult cancer survivors themselves.

Pediatric Oncology Survivorship Care

Prompted by IOM reports, medical oncologists, surgeons, radiation oncologists, and other oncology care providers now recognize that cancer survivors who have completed therapy and have no evidence of disease are, nevertheless, at risk for problems that are likely to reduce the quality and length of their survival.^{2,18-21} Focus on survivorship care began with pediatric oncology in the 1970s as clinical trials were prolonging the lives of more and more children with cancer. It was noted that normal tissues of growing children were especially likely to suffer from the deleterious effects of radiation therapy and certain chemotherapeutic agents, and studies of selected cohorts of survivors continued into the decades of the 1980s and 1990s.²¹⁻³¹ This led to the recognition that second cancers, cardiac disease, neurocognitive dysfunction, infertility, and other late complications could be attributed to specific therapies.^{22-24,32} Studies of the late effects of treatment led to clinical trials that tested the efficacy of reducing the offending agent(s) and also led to the elimination or reduction in dose of radiation for Wilms tumor, lymphomas, acute lymphocytic leukemia, and brain tumors.³³⁻³⁵

It was during the 1990s that the relation between dose and outcome began to be studied, and efforts were made to inform survivors of their future risks.³⁶⁻⁴⁰ These initial reports of late effects in childhood cancer survivors came from single institutions or from multicenter consortia. In 1994, with funding from the NCI, a multicenter cohort of long-term survivors of childhood cancer was assembled to address and overcome the limitations of earlier studies that had fewer subjects and shorter follow-up.⁴¹ The Childhood Cancer Survivor Study (CCSS) published the many aspects of survival in 14,000 children and adolescents who were characterized demographically by treatment from 1970 to 1986 and who survived for at least 5 years after diagnosis.⁴²⁻⁴⁵ As treatments evolved during the subsequent decades, the CCSS embarked on studies of children diagnosed from 1987 to 1999 by using the same eligibility criteria and

seeking to address changes in quality of survival and long-term and late complications.⁴¹

Caring for children who are likely to be cured of cancer (approximately 90% of those who survive for 5 years from diagnosis are in that group) involves understanding that many of the late effects of therapy do not become apparent until childhood cancer survivors are no longer a part of the pediatric follow-up system. The expertise of any one or more of the following specialists is often necessary to address late complications: cardiologist, pulmonologist, gynecologist, neurologist, or gastroenterologist. This need for specialists to address the myriad of late effects associated with cancer treatments led to the emergence of long-term follow-up clinics where many specialists are available to returning survivors. Rather than monitoring for a recurrence of the original cancer, these programs are designed to educate and counsel survivors on the treatment they received and their potential late effects. They also serve as wellness centers, where recommendations for healthy life practices can be reinforced and referrals can be made to appropriate specialists for the management of issues related to treatment.

How institutions provide appropriate follow-up care for these survivors of childhood cancer has always been a question. In 1999, to address this need, and by using the expertise available in the COG, guidelines for follow-up based on therapy were developed; the third revision is online and may be accessed by providers and survivors (<http://www.survivorshipguidelines.org>).⁵ Despite the availability of these guidelines and the increasing number of specialized clinics, it is estimated that fewer than 30% of survivors 20 years from diagnosis return for follow-up care, and many do not receive appropriate surveillance.^{5,46,47}

Children and adolescents who survive cancer grow into adulthood and then require care that focuses on their needs as adults. Many childhood cancer survivors are lost to follow-up care as they mature, leave the oversight of their parents, and take responsibility for their own medical care. As young adults, they seek care on an “as-needed” basis and, for some of them, their providers pay little clinical attention to their history of cancer and to the potential risks these young adults face as a consequence of their previous treatment.⁴⁸⁻⁵²

For this population of survivors, there is a critical need to address the following questions: How can that majority of survivors of childhood cancers who have been lost to risk-based follow-up be identified and recovered? How can we identify those adolescents and young adults who are ready to manage their care in an adult setting? How can the COG guidelines be adapted to provide guidance for the care of adult survivors of childhood cancer? What is the best way to transmit information to survivors and their providers? What is the best venue for follow-up care of adult survivors of childhood cancer? How can we evaluate whether our counseling and surveillance have been effective in preventing or ameliorating late effects that are of significant concern for this group of survivors?^{49,53}

There are many obstacles to achieving a timely and smooth transition from pediatrics to adult-focused care.^{48-52,54} Patients and families are sometimes reluctant to leave institutions and caregivers in whom they have confidence and with whom they have developed a dependent relationship. Pediatric caregivers are reluctant to relinquish the satisfaction that comes from seeing young adult patients who have overcome cancer. Survivors themselves are often not confident that they can manage their own care because many report that they are often unable to recall information on the treatment they received that is necessary to inform other caregivers and guide their care.⁴⁹⁻⁵³ In addition, there are too few caregivers of adults who are confident and capable of understanding the needs of survivors treated for cancer as children; consequently, many young adult survivors receive less than optimal care.⁵⁵ When treatment intensity is limited and not complex, referrals can confidently be made to primary and/or specialty care providers.⁵⁶ However, in the case of survivors whose treatment involved multiple modalities and who have many potential or actual late complications, a specialized program designed for young adult survivors can provide support for managing and possibly transitioning the care of these patients to nononcological providers.

Pediatric cancer centers across the country have developed programs that deliver care to pediatric cancer survivors, and many of these programs include young adult survivors in the populations they follow. These programs are based in pediatric settings, and survivors are followed by providers focused on care within a

designated survivorship or late-effects clinic. These programs provide ongoing care to pediatric cancer survivors, and some of these programs, when appropriate and/or at a certain age, refer young adult survivors back to the community to be followed by adult oncology specialty and/or primary care providers. An excellent example of this is the St. Jude After Completion of Therapy (ACT) Clinic. This program is designed to assist young adults in transitioning their follow-up care to outside providers, as well as to provide survivors and their families with information and access to a wide array of services available in their communities. A comprehensive list of pediatric programs that care for children after completion of treatment, including St. Jude's, can be found on the Ped-Onc Resource Center Web site (<http://www.acor.org/ped-onc/treatment/surclinics.html>).

Given the relatively new focus on survivorship within the adult oncology community, it is not surprising that adult oncology has not been quick to establish a mechanism for providing care that would address the unique needs of adult survivors of childhood cancer within an adult cancer care setting. The Transition Program at the Abramson Cancer Center (ACC) of the University of Pennsylvania, established by Anna Meadows, MD, in 2002 as a collaborative effort between The Children's Hospital of Philadelphia (CHOP) and the ACC, is one of the few programs in the country that is based in an adult cancer care setting. This program focuses on transitioning young adult survivors of childhood cancer to an adult medical setting where appropriate risk-based follow-up care can be provided. The family and survivor receive considerable support during the transition process in order to attenuate the difficulties that can arise when survivors move from the protective environment of a pediatric setting to what is perceived as the more difficult-to-navigate world of adult care. The Dana Farber Cancer Institute, the University of Colorado Cancer Center, and the University of California at Los Angeles are examples of other institutions that have recently developed similar programs in adult oncology (personal communications).

Caring for Adult Cancer Survivors

The number of adult cancer survivors in the United States has grown to approximately 12 million⁵⁷ and is

likely to double by 2050.⁵⁸ Survivorship follow-up care is an essential component of cancer care.¹⁷ Cancer can represent a “teachable moment” for many individuals,⁵⁹ and behavioral modifications, psychosocial adjustments, detection of late effects, and management constitute important issues in follow-up care.^{2,17,59,60} However, research necessary to understand and frame these concerns and to structure a plan of care for adult cancer survivors has not been adequate, and follow-up recommendations have been based primarily on consensus in the absence of Level I evidence.⁶¹ In recognition of this phenomenon, both the National Institutes of Health Office of Cancer Survivorship and philanthropic groups, such as the Lance Armstrong Foundation, have supported research initiatives in cancer survivorship that hope to provide evidence that will guide the care and follow-up of adult cancer survivors. Such research spans many areas, including behavioral, health service, and translational investigation.

Translational Research to Inform Clinical Survivorship Care

Translational survivorship research is key to understanding the specific risks and late effects for individuals who have developed and been treated for cancer. For example, what is the incidence of cardiac dysfunction after anthracycline-based chemotherapy, and who is at risk? What is the risk of a second primary cancer after radiation to the chest? What are the fertility issues faced by the large cohort of adult survivors treated as children as well as young adults diagnosed and treated in their childbearing years? Does the provision of care for survivors by oncology, primary care, and specialty care providers influence the uptake of health-promoting behaviors among cancer survivors? Such questions are at the heart of personalized cancer care.

More questions are likely to arise as more patients survive for longer periods following chemotherapy and radiation. Large patient cohorts or case-control approaches are necessary to accurately estimate incidence or prevalence rates and to evaluate multiple risk factors for developing late and long-term effects. The use of databases linked to cancer outcomes, such as the SEER-Medicare linked databases, is one approach to a research design. However, this approach has limitations, including findings that most patients

in the database are older than age 65 years and that detailed treatment information or outpatient therapies are not well characterized. Claims databases may not be accurate in capturing all outcomes of interest apart from the primary event that led to hospitalization. Thus, there is a need for coordinated efforts to assemble large patient cohorts that are well annotated and have long follow-up histories. Ongoing clinical care for cancer survivors is crucial to the collection of information on subsequent lifestyle, medication, and other exposures, as well as the development of second cancers and other medical conditions over time.

Another challenge to translational research is that, as oncologists who treat adults learned from their colleagues who treat pediatric patients, outcomes of interest often occur years to decades from the time of exposure to treatment. Thus, development of surrogate biomarkers is essential to identifying patients at risk and for monitoring development of late effects. Such biomarkers would ideally provide the opportunity to identify susceptible patients at a time when interventions can be most effective at preventing or ameliorating late effects. These markers can also provide an opportunity for screening. Important surrogate markers of processes, such as late pulmonary, cardiac, hepatic, or renal effects, require collection of serum or urine.⁶² Genetic markers require the collection of blood for polymorphonucleic cells, cheek swabs, or other sources of germline DNA. Collection of tumor, premalignant, and normal tissue at the time of diagnosis can provide important resources for research on cancer susceptibility, the development of second cancers, and strategies for intervening at a premalignant stage. Optimally, biological specimens should be collected at diagnosis as well as periodically over the course of follow-up. Specimen banks that use standardized collection procedures are essential to the forward movement of the field of cancer survivorship practice, as the development of assays and platforms advance over time and new hypotheses are developed.

One area in which research has been performed is the area of second cancers. Second cancers account for a significant proportion of new cancers diagnosed annually and can reflect late effects of treatment, influence of lifestyle, environmental exposures, host factors, and combinations of influences that include gene-environment and gene-gene interactions. In 2004, the NCI hosted a workshop entitled, *Cancer*

*Survivorship: Genetic Susceptibility and Second Primary Cancers.*⁶³ This conference brought together a multinational group of experts on epidemiology, oncology, and survivorship research to address “research issues, priorities, resources, and infrastructure requirements needed to advance the field.”⁶³ Key recommendations included the development of research infrastructure for studies of cancer survivorship, including multicenter adult cancer survivor cohorts culled from individual treatment centers; clinical trial cooperative groups; population-based cancer registries; a coordinated system of biological specimen collection; development of new technology, biomarkers, and bioinformatics; and development of new epidemiological study designs and methods. Although these recommendations were formulated with the goal of expanding and facilitating research on second cancers, they are critical components necessary to all translational research in cancer survivorship.

Health Behavior Research to Inform Clinical Survivorship Care

As cancer has become as much a chronic health condition as an acute health crisis, it is imperative that care of survivors and research focus on psychosocial as well as physiological consequences of cancer treatment. Much behavioral research to date has emphasized psychological and social sequela of cancer survivorship. This research has focused on issues such as emotional distress and psychiatric disturbance, informational and knowledge needs, and more biological-behavioral areas such as fatigue, pain, and cognitive-impairment complaints. Social concerns such as finances, employment, and insurance have also been examined. These areas of clinical research have been well-described in a recent IOM report, *Cancer Care for the Whole Patient: Meeting Psychosocial Health Needs*, which outlines psychosocial concerns among cancer survivors and provides models of care and recommendations for addressing these.⁶⁴ Although a thorough recapitulation of this report is beyond the scope of the present article, it is worth noting that the report described a set of 5 components common to effective intervention programs (Table 3).

An area of research that has received less attention concerns health behaviors practiced by cancer survivors, including behaviors that enhance their quality of life,

TABLE 3. Essential Components of Psychosocial Survivorship Care

	ESSENTIAL COMPONENTS OF PSYCHOSOCIAL SURVIVORSHIP CARE
1	Identify psychosocial difficulties and develop care plans with patients.
2	Connect patients with appropriate services.
3	Support patients in managing their illnesses.
4	Coordinate psychosocial and biomedical care.
5	Provide follow-up assessment to monitor and evaluate outcomes and to make appropriate alterations in care plans.

Adler N, Page A, eds. *Cancer Care For The Whole Patient: Meeting Psychosocial Health Needs*. Washington, DC: The National Academies Press; 2008.

seeking screening for new and secondary malignancies, and pursuing reduction of late effects of treatment. This is especially important given the aging population of adult cancer survivors whose health is disproportionately impaired by normal aging processes.⁶⁵ Although health-promoting behaviors are important for the health of any individual, they are even more crucial among cancer survivors given the potential for treatment that leads to organ dysfunction, tissue damage, and future morbidities.⁶⁶ Engagement in health-promoting behaviors such as cancer screening, sun safety, nutritional intake, exercise, and avoidance of smoking, drugs, and alcohol may minimize the risk of many poor-health outcomes.

Unfortunately, little is known about how the experience of survivorship and risk-based care influence use of preventative services. Furthermore, the processes leading survivors to engage in health-promoting or risk-avoidance behaviors are not well understood. These issues are important as long-term cancer survivors report poorer health and greater role interference than matched controls; these effects are amplified by the presence of chronic comorbidities.⁶⁷ An overview of findings from both single-institution and large-scale epidemiological studies is presented along with limitations and suggestions for future directions.

Health Behavior Research in Adult Survivors of Childhood Cancers

As summarized by Clarke and Eiser,⁶⁸ survivors of childhood cancers engage in health-risk behaviors at the same or lower rates as comparison groups. Although

not worse than the general population, these rates are somewhat concerning based on survivors' increased risk for new cancer diagnoses (30-year cumulative risk for second neoplasm is 9.3%)²⁰ and other health problems (62.3% have at least 1 chronic condition).⁵¹ For example, whereas rates of smoking among childhood cancer survivors are generally found to be the same or less than the general population, any smoking is too much given its exacerbation of already existing risk for cardiac and pulmonary disease and second cancers.⁶⁶ Survivors are also less likely to meet recommendations for physical activity, and they report engaging in fewer leisure activities than their siblings.⁶⁹ Demark-Wahnefried et al⁷⁰ reported that only 21% of a sample of 200 adolescent and young-adult survivors met guidelines for fruit and vegetable consumption, 32% met guidelines for calcium intake, 48% met guidelines for exercise, and 42% were overweight or obese. These findings are similar to those reported in the Youth Risk Behavior Surveillance (YRBS) survey⁷¹ concerning guideline-congruent fruit and vegetable consumption (21.4%) and slightly below the proportion of those aged 19-30 years in the National Health Interview Survey (NHIS) who are exceeding calcium-intake guidelines (38.8%).⁷² However, they reflect a much higher rate of obesity and overweight status than reported in the YRBS (28.8%), likely resulting, at least in part, from decreased physical activity seen among adolescent and young adult (AYA) cancer survivors.^{73,74}

Screening practices, as well, fall below optimal levels for survivors of childhood cancers. Yeazel⁷³ reported that although survivors tended to perform screening behaviors at a higher rate than siblings, only 28% of females regularly performed breast self-examination, and only 17% of males performed testicular self-examinations. Although 80% of females had received a Pap smear within the previous 3 years, and 62% had had a clinical breast exam, only 21% had received a mammogram. Receipt of mammography was higher (57%) among those women at highest risk (older than age 30 years and those who had received chest or mantle radiation) but remains less than optimal. Similarly, among women who received chest radiation, 64% of those ages 25-39 and 24% of those ages 40-50 had not received screening mammography within the previous 2 years, despite guidelines that these women should receive annual mammograms.⁷⁴

Such health behaviors may be deemed suboptimal on the basis of lack of survivor awareness of their

risks and lack of risk-based follow-up care.⁶⁶ Moreover, differences exist in how health-risk management behaviors among survivors of childhood cancer are acquired and maintained compared with their peers. This is exemplified by findings that suggest that survivors who smoke are less likely to attempt or to successfully quit smoking⁷⁵ and by findings that psychological sequela of cancer, such as post-traumatic stress, depression, and worries about illness, relate to poor health behaviors.^{32,76-79}

Behavioral Research in Survivors of Adult Onset Cancers

A few large-scale studies of the preventative and health behaviors of adult cancer survivors have now been published. In a study of more than 9000 cancer survivors, Blanchard et al⁸⁰ reported that these survivors comprised 6 different tumor locations and that 8.4% to 17.4% were current smokers, which is on the low end and may reflect absence of survivors of lung, head and neck, and other cancers in which smoking is more prevalent. Large population-based studies from the United States and Australia^{67,81,82} have estimated the rate of smoking among survivors to be at least 20%. Of particular importance to providers of care to cancer survivors is a consistent finding that young adult cancer survivors are smoking at a rate above that of their comparison groups^{67,81} with rates among those survivors younger than age 40 years as high as 38% according to NHIS data.⁸³ Alcohol use appears common in this population as well, with Coups and Ostroff⁸³ and Bellizzi et al⁸¹ reporting moderate to heavy use by 15% to 16% of cancer survivors. This is not substantially different from noncancer controls.

Rates of self-reported dietary adherence and physical activity are also less than ideal. Coups and Ostroff⁸³ found that across age-stratified survivor groups, at least 45% were meeting 5-a-day recommendations for fruit and vegetable consumption. Similarly, adherence to physical activity recommendations ranged from 30% to 52% of survivors.⁸⁰⁻⁸³ Not surprisingly, this is reflected in rates of body-mass-index-determined categories of overweight and/or obese survivors that range from 52% to 69%, although again, these rates for survivors are not substantially different from those in the general population. Survivors appear to be meeting recommenda-

tions for surveillance and screening, and, overall, are reporting adherence rates that are at least as high as noncancer controls. By using NHIS data, we find that 99% of female survivors appear to have *ever* had a Pap smear, and more than three-fourths are currently meeting screening recommendations.^{81,84,85} Mammography recommendations are met by 75% to 88%, with 92% reporting *ever* having had a mammogram. Similarly, between 56% and 76% of survivors for whom prostate-specific antigen tests are discussed have had them performed. Although these data are promising, it should be remembered that they are based on self-reports of health behaviors rather than on examination of medical records, and, therefore, may be somewhat biased toward adherence to positive behaviors and denial of risk behaviors.

Next Steps in Advancing the Field of Adult Cancer Survivorship Care

Until recently, studies that examine health behaviors among adult cancer survivors have been predominantly small, cross-sectional, or retrospective, and from single institutions and primarily tertiary-care cancer centers. Additionally, the focus, more often than not, has been on short-term (ie, less than 5 years) breast cancer survivors. Consequently, much of this work has been performed with selected groups of patients who may or may not represent all survivors in these settings. More recent population or large data-based studies have emerged, such as the CCSS and the NHIS, and data are accumulating from the American Cancer Society's Studies of Cancer Survivors.⁴ These studies have described prevalence of health behaviors among survivors and have identified a need for prevention and intervention to enhance health outcomes for survivors. However, significant shortcomings include reliance on self-reports of both cancer history and health behaviors with brief, not-validated indices and a lack of well-described and documented treatment exposures.

For example, the NHIS has been used numerous times to gather data on survivors but is not specifically designed to assess cancer-related variables. In the NHIS survey, cancer history and health behaviors are self-reported, important contextual information (eg, prevalence of referrals, use of behavioral supports) is absent, and sampling does not represent survivors-at-large. In particular, although adults

older than age 65 years represent more than 62% of current cancer survivors, this age group is seldom adequately represented. Furthermore, those who reside in institutional settings and, thus, may be expected to have the greatest morbidity burden are not represented at all in the NHIS. In addition, these data remain cross-sectional and retrospective, allowing little insight into changes that occur in health behaviors across the cancer trajectory. Our understanding of health behaviors and how they change over time will be greatly enhanced with better documentation from physicians and access to medical databases that capture comparable data and allow multi-institutional data to be linked to larger networks. In addition, providing mechanisms and funding opportunities for follow-up of clinical trial participants would allow for long-term survivorship data to be collected on very well-characterized samples.

Adoption of recommendations such as those made by the President's Cancer Panel 2005-2006⁸⁶ that all clinical trials collect psychological risk-factor data could do much to advance our understanding of predictors of adaptation and to allow early identification of those at risk for long-term difficulties. Unfortunately, the rate of participation of adult cancer patients in clinical trials is low and selective. For example, it was recently estimated that only 1.7% of the incident cases of breast, colorectal, lung, or prostate cancer were enrolled onto NCI Cooperative Group trials, with significantly lower accrual among African Americans, Hispanics, and the elderly.⁸⁷ Absolute numbers of participants, however, is high enough for very meaningful data to be generated by such an endeavor. Additionally, research across the spectrum needs to include improvements in measurement that provide standardized assessments of health behaviors and linkages to quality-of-life and objective health outcomes.

Acknowledging deficiencies in research that examines cancer-related health behaviors may be considered a first step toward developing care plans with surveillance recommendations for which efficacy and compliance have been tested. Although intervention projects have been developed, they have not been widely disseminated beyond academic medical centers. This process is complicated by the finding that many patients transition their care from a tertiary center to geographically more accessible centers or primary care providers who are better able to meet

their long-term needs. Thus, interventions to improve the health behaviors of survivors must be able to be generalized to a range of settings, able to be implemented by various health care providers, and willing to take patient preferences into account.

Despite inroads made into the fields of, mainly, pediatric cancer survivorship, research, and care, evidence-based surveillance guidelines are not available to guide the care of any adult cancer survivors, including young adult survivors of childhood cancers, and considerable research is still needed as this population ages. Research in this population will likely provide data and recommendations for comprehensive clinical care of adult cancer survivors of all ages.

Clinical Care Providers for Adult Cancer Survivors

A shortage of oncologists recently reported by the American Society of Clinical Oncology (ASCO)⁸⁸ is occurring at the same time as the demand for oncology services is expected to rise. This will require that oncologists work with primary care providers to play a major role in caring for survivors across the cancer trajectory. However, the shortage and inadequate preparation of primary care physicians to address the complex concerns of cancer survivors are also well-documented.^{10,11,14,15,89,90} These issues pose a concern to the oncology community.^{2,6}

Whereas a significant number of cancer survivors continue to receive cancer follow-up care from oncologists in the United States, many are cared for by primary care and other specialty care providers.⁹¹ In a study among breast cancer survivors aged 65 years or older, only 27% of survivors saw their oncologists annually for 3 years following active treatment.⁹² These survivors have more health care encounters with their primary care providers than with their oncologists.^{10,11,14,15,89,90} In addition, as cancer survivors age, they face managing late effects of cancer therapies (eg, accelerated cardiovascular-, pulmonary-, and bone-health decline),⁹³ as well as other ongoing comorbid illnesses (eg, diabetes, arthritis, recurring pain, and distress).⁹⁴ The complexity of the health issues faced by survivors requires coordinated, patient-centered care and a paradigm shift from disease-focused to wellness-centered comprehensive care. Survivorship care focuses on restoring health and preventing recurrence; therefore, care of cancer

survivors needs to be personalized, preventative, and participatory. Thus, an essential component of health care for cancer survivors is active involvement of primary and specialty care providers.⁹⁵

Traditionally the role of primary care providers in cancer control was screening and prevention. However, because the overall 5-year survival rate for cancer now exceeds 65%, many cancer survivors return to their primary care providers for follow-up and routine care, and some see their primary care provider exclusively for cancer and other follow-up care.⁹⁶ Studies suggest that primary care providers are more willing to participate in the care of survivors^{96,97} than has been perceived by survivors and oncologists. Although adequate resources, communication among providers, and access to information have been identified as important in the care of survivors,⁹⁶ primary care providers have identified poor communication with the oncology team as a factor making transition of care more difficult.⁹⁷ Inadequate knowledge of cancer care and treatments have also been identified as barriers for nononcology providers^{7,96} as has the current workload of primary care providers.⁹⁶ Patients have reported that although they endorse their primary care providers' ability to provide general care, they had concerns about these providers' ability to provide survivorship-specific care.¹⁰

Studies that used large administrative databases have noted that older survivors followed by primary care tend to receive inadequate screening for cancer recurrence, although they receive comprehensive preventative services, including screening for other cancers.^{10,98-100} Survivors who received care from oncologists tended to receive cancer-specific follow-up but fewer preventative health services, whereas those who received care from both received cancer-specific and other preventative health services.^{91,101} Recent clinical trials suggest that with education and a treatment algorithm, primary care providers can deliver care similar to that of oncologists with respect to cancer-recurrence detection for breast and colorectal cancers.^{102,103}

The care of survivors needs to be negotiated among providers and the patient, and one size probably won't and shouldn't fit all when it comes to developing a plan for post-treatment care. Patients often build strong relationships with their oncology team and, in many cases, use the oncology team for primary health care. Survivors may view their oncol-

ogist as the one who saved their life and, consequently, trust only the oncology team with the comprehensive management of their care.

Health care providers should actively engage patients in formulating a care plan¹⁰⁴ that includes the expected frequency of follow-up visits with all providers, including a clear designation of the role each provider will play (eg, screening for specific cancers, screening for other cancers, other preventative measures, and ongoing comorbidity management). A formal care plan can be an important tool to facilitate communication and to outline required surveillance.¹⁰⁵

Because cancer survivors have an increased risk of treatment-related comorbid conditions, there is the potential to involve virtually every medical specialty in long-term cancer care. Ideally, specialists with an interest in care of survivors and a basic understanding of chemotherapy and radiation side effects should be identified. As noted, long-term management of cancer survivors is hampered by the lack of surveillance guidelines, including those that would be specialty-specific. Research that identifies long-term treatment-related effects could foster and contribute to guideline development and lead to improved overall care for cancer survivors.

Organizing and Communicating Health Information

Templates for organizing treatment data and creating a written survivor care plan at the end of treatment have been developed by a number of sources. These plans are based on a combination of the best available clinical information, evidence-based standards, and in some cases, institutional practices. The IOM has suggested a list of elements to be included in a care plan; however, lack of research makes it impossible to determine, with any certainty, what should be included in a care plan. It has been noted that care plans are only as good as their contents, and there is considerable debate among the oncology care team as to who should be responsible for developing a personalized plan for post-treatment care and what should be considered when developing that plan.

The development of a treatment summary and a care plan for survivors is challenging because it requires time and resources, 2 commodities that are hard to come by for busy oncology clinicians in the

current practice environment. One strategy would be the adoption of electronic medical record (EMR) systems within institutions that would allow health care providers to communicate across specialties. Systems that interface across institutions would significantly improve communication among medical providers.

The EMR allows easy exchange of notes among providers and eliminates the need for every provider to document extensive medical information because this information is placed in the record at the initial encounter with a health care provider in the system, and needs only to be verified and updated at each subsequent encounter. The easy and efficient exchange of information among providers allows primary, specialty, and oncology care providers to share the management of these patients and will hopefully improve confidence among patients that they are receiving optimal care.

Although it has been years since numerous groups called for the continuum of cancer care to include survivorship, it is evident that the adult oncology community has been slow to embrace the concept. However, in recent years, several things have contributed to catapulting this phase of cancer care to the level of a medical specialty. The implementation of the EMR in many institutions has cleared a number of barriers to providing seamless care to survivors by revolutionizing communication among specialties, organizing patient data, educating patients and providers, and billing more efficiently for services provided. Advocacy groups and patients are demanding that cancer care include the survivorship phase, and many medical issues encountered by cancer survivors that were once considered normal comorbidities associated with aging are now considered possible late effects of cancer treatment, and these must be addressed by oncology, specialty, and primary care providers.

Ideally, treatment summaries and survivorship care plans should serve as conduits between active cancer care and survivorship care and also between survivors and providers. In our current health care system, the question of responsibility for the care of cancer survivors among health care providers remains unclear. Is the medical oncologist, the primary care provider, the gynecologist, the surgeon, the radiation oncologist, or another provider responsible for ensuring that cancer survivors receive comprehensive medical care

[Insert Practice Name/Info Here]					
The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.					
Patient name:			Patient ID:		
Medical oncology provider name:			PCP:		
Patient DOB: (/ /)		Age:		Patient phone:	
Support contact name:					
Support contact relationship:			Support contact phone:		
BACKGROUND INFORMATION					
Symptoms/signs:					
Family history/predisposing conditions:					
Major co-morbid conditions:					
Tobacco use: <input type="checkbox"/> No <input type="checkbox"/> Yes, past <input type="checkbox"/> Yes, current (If current, cessation counseling provided?: <input type="checkbox"/> Yes <input type="checkbox"/> No)					
Cancer type/location:			Diagnosis date: (/ /)		
Is this a new cancer diagnosis or recurrence?: <input type="checkbox"/> New <input type="checkbox"/> Recurrence (date: / /)					
Surgery: <input type="checkbox"/> None <input type="checkbox"/> Diagnosis only <input type="checkbox"/> Palliative resection <input type="checkbox"/> Curative resection					
Surgical procedure/location/findings:					
Tumor type/histology/grade:					
STAGING					
Study	Date	Findings			
T stage: <input type="checkbox"/> T1 <input type="checkbox"/> T2 <input type="checkbox"/> T3 <input type="checkbox"/> T4 <input type="checkbox"/> Not applicable			N stage: <input type="checkbox"/> N0 <input type="checkbox"/> N1 <input type="checkbox"/> N2 <input type="checkbox"/> N3 <input type="checkbox"/> Not applicable		
M stage: <input type="checkbox"/> M0 <input type="checkbox"/> M1 <input type="checkbox"/> Not applicable			Tumor markers:		
Stage: <input type="checkbox"/> I <input type="checkbox"/> II <input type="checkbox"/> III <input type="checkbox"/> IV <input type="checkbox"/> Recurrence			Alternative staging system:		
Location(s) of metastasis or recurrence (if applicable):					
TREATMENT PLAN			TREATMENT SUMMARY		
White sections to be completed prior to chemotherapy administration, shaded sections following chemotherapy					
Height: in/cm	Pre-treatment weight: lb/kg	Post-treatment weight: lb/kg			
Pre-treatment BSA:	Treatment on clinical trial: <input type="checkbox"/> Yes <input type="checkbox"/> No				
Name of chemotherapy regimen:					
Chemotherapy start date: (/ /)			Chemotherapy end date: (/ /)		
Chemotherapy intent: <input type="checkbox"/> Curative, adjuvant or neoadjuvant <input type="checkbox"/> Disease or symptom control					
ECOG performance status at start of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4			ECOG performance status at end of treatment: <input type="checkbox"/> 0 <input type="checkbox"/> 1 <input type="checkbox"/> 2 <input type="checkbox"/> 3 <input type="checkbox"/> 4		
Chemotherapy Drug Name	Route	Dose mg/m ²	Schedule	Dose reduction	# cycles administered
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
				<input type="checkbox"/> Yes _____% <input type="checkbox"/> No	
Major side effects of this regimen: <input type="checkbox"/> Hair loss <input type="checkbox"/> Nausea/Vomiting <input type="checkbox"/> Neuropathy <input type="checkbox"/> Low blood count <input type="checkbox"/> Fatigue <input type="checkbox"/> Menopause symptoms <input type="checkbox"/> Cardiac <input type="checkbox"/> Other					

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Important caution: this is a summary document whose purpose is to review the highlights of the cancer treatment for this patient. This does not replace information available in the medical record, a complete medical history provided by the patient, examination and diagnostic information, or educational materials that describe strategies for coping with cancer and cancer therapies in detail. Both medical science and an individual's health care needs change, and therefore this document is current only as of the date of preparation. This summary document does not prescribe or recommend any particular medical treatment or care for cancer or any other disease and does not substitute for the independent medical judgment of the treating professional.

FIGURE 1. American Society of Clinical Oncology (ASCO) Care Plan Template. HCP indicates health care provider; PCP, primary care provider. *Reflects number of users for whom data is available according to version implementation. Reprinted with permission. (c) 2008 American Society of Clinical Oncology. www.asco.org

[Insert Practice Name/Info Here]			
The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.			
TREATMENT PLAN (CONTINUED)			TREATMENT SUMMARY (CONTINUED)
Non-chemotherapeutic Agents	Route	Purpose/Goal	Comments
Reason for stopping treatment: <input type="checkbox"/> Completion <input type="checkbox"/> Toxicity <input type="checkbox"/> Progression <input type="checkbox"/> Other:		Response to treatment: <input type="checkbox"/> Complete <input type="checkbox"/> Partial <input type="checkbox"/> No response <input type="checkbox"/> Progression <input type="checkbox"/> Not measurable	
Treatment-related hospitalization required: <input type="checkbox"/> Yes <input type="checkbox"/> No		Serious toxicities during treatment (list all):	
Ongoing toxicity at completion of treatment: <input type="checkbox"/> Yes (enter type(s) and grade(s) _____) <input type="checkbox"/> No			
ADDITIONAL THERAPIES PLANNED			
Drug name	Comments		Date started (or to start)
			(/ /)
			(/ /)
			(/ /)
Radiation therapy: <input type="checkbox"/> Not planned <input type="checkbox"/> Planned <input type="checkbox"/> Administered Region treated: _____ Radiation dose: _____ Date initiated: (/ /) Date completed: (/ /)			
ONCOLOGY TEAM MEMBER CONTACTS		SURVIVORSHIP CARE PROVIDER CONTACTS	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	
Provider:		Provider:	
Name:		Name:	
Contact Info:		Contact Info:	

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FIGURE 1. (Continued)

<p>[Insert Practice Name/Info Here]</p> <p><i>The Treatment Plan and Summary is a brief record of major aspects of cancer treatment. This is not a complete patient history or comprehensive record of intended therapies.</i></p>		
FOLLOW-UP AND SURVIVORSHIP CARE		
Follow up care	When/How Often?	Coordinating Provider
Medical oncology visits		
Lab tests		
Imaging		
Potential late effects of treatment(s):		
Call your doctor if you have any of these signs and symptoms:		
Needs or concerns: <input type="checkbox"/> Prevention and wellness: _____ <input type="checkbox"/> Genetic risk: _____ <input type="checkbox"/> Emotional or mental health: _____ <input type="checkbox"/> Personal relationships: _____ <input type="checkbox"/> Fertility: _____ <input type="checkbox"/> Financial advice or assistance: _____ <input type="checkbox"/> Other: _____	Referrals provided: <input type="checkbox"/> Dietician <input type="checkbox"/> Smoking cessation counselor <input type="checkbox"/> Physical therapist or exercise specialist <input type="checkbox"/> Genetic counselor <input type="checkbox"/> Psychiatrist <input type="checkbox"/> Psychologist <input type="checkbox"/> Social worker <input type="checkbox"/> Fertility specialist or endocrinologist <input type="checkbox"/> Other: _____	
Comments		

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FIGURE 1. (Continued)

that attends to both screening for recurrent and/or progressive disease and the management of routine health care and screening? Unfortunately, more than half of primary care providers rate the transition process from oncology to primary care as fair or poor,⁸ and up to one-third of cancer survivors are unsure of who among their physicians is in charge of their follow-up care.¹⁰⁶ Although intended to assist in the care of survivors, treatment summaries and survivorship care plans also empower survivors to guide their own care and to ensure that they receive recommended screening.

In the current health care environment of shrinking resources, questions about the time and cost surrounding care plan development and implementation are important. Care plans must be individualized and detailed in order to be comprehensive. However, most health care providers have little time to devote to their creation, even when much of the information and language can be obtained from existing sources. In a recent survey-based study, most oncologists reported that a survivor care plan tool should require no more than 20 minutes per patient.⁷

Furthermore, no method of reimbursement currently exists for creation of survivorship care plans by individual centers. The IOM addressed this concern, recommending that survivorship care plan creation “be reimbursed by third-party payers of healthcare,”² but this concept has yet to be realized in practice.

Planning Care for Adult Cancer Survivors

In response to the call and to assist with the challenges of caring for adult cancer survivors, advocacy groups, professional organizations, and cancer centers have developed treatment summaries and survivor care plan templates, forms, and tools.¹⁰⁷ The following describes a few of these efforts.

ASCO offers survivor care plan templates specifically for survivors of breast and colorectal cancers and a general template that can be used for any cancer diagnosis. These templates can be completed online and saved as Word (Microsoft, Redmond, Washington) documents, which allow the user to integrate ASCO recommendations into the document to guide the care of cancer survivors.¹⁰⁴ In this way, the template can be adapted to the specific needs of an individual cancer survivor. The ASCO templates are available on the ASCO Web site at <http://www.asco.org>.

Journey Forward is a program designed for providers and patients who have recently completed active cancer treatment. This program was created through the collaborative efforts of the National Coalition for Cancer Survivorship, the UCLA Cancer Survivorship Center, WellPoint, Inc, and Genentech, and the plan that is generated by this program gives clear steps for providing care to survivors. It begins with a simple, yet complete, treatment summary and offers recommendations for monitoring future care. Journey Forward kits are available online at <http://www.JourneyForward.org>, and they are tailored to oncologists, patients, and primary care physicians. Journey Forward focuses on survivors of breast and colon cancers and has plans to expand to other cancer diagnoses.

The Cancer Survivor's Prescription for Living is a template developed by and for nurses in oncological practices. This template, printed in the April issue of the *American Journal of Nursing*¹⁰⁸ outlines cancer treatment history, significant problems related to or presenting as late effects of treatment, and other health issues. This survivor care plan includes guidelines for addressing persistent physical and psychosocial issues. It is recommended that health promotion and disease prevention measures, including recommended cancer screening activities, be outlined by the user on this template. However, this rather comprehensive template (available at <http://tiny.cc/SFA8e>) requires handwritten input of treatment and disease information and is not currently available in an electronic version that allows easy input and modification or saving of information entered.

A number of institutions are developing and implementing their own internal treatment summary and/or consensus-driven survivor care plan templates, including the Abramson Cancer Center at the University of Pennsylvania, Fred Hutchinson Cancer Research Center, Memorial Sloan-Kettering Cancer Center (<http://tiny.cc/rqgqxq>), the University of Colorado Cancer Center, and the Dana Farber Cancer Institute. These documents can be obtained by contacting individuals connected to the cancer survivor programs at each given institute (personal communications).

With the tremendous growth of Internet-based technology during the last decade, numerous cancer information Web sites and links to educational materials developed by professional organizations have been made available to cancer survivors and provid-

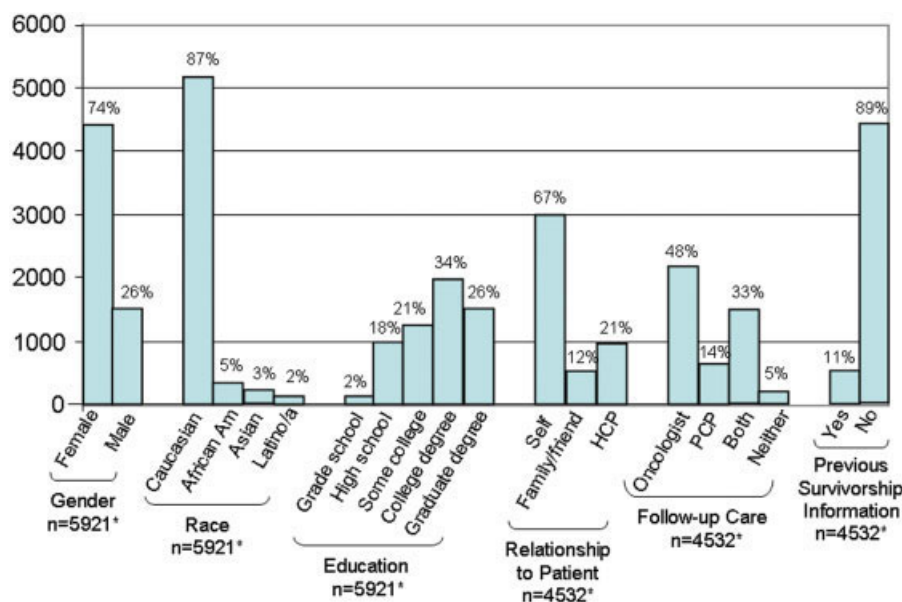


FIGURE 2. Demographics of LIVESTRONG Care Plan Users are listed.

ers. In May 2007, prior to the development of the templates described thus far, the first Internet-based tool for creation of individualized survivor care plans was launched. This plan tool was initially named *OncoLife*. Its developers recently partnered with the Lance Armstrong Foundation to release a revised version as the LIVESTRONG Care Plan powered by Penn Medicine's *OncoLink* (<http://www.livestrongcareplan.org>). This care plan was developed as a patient-oriented tool and has the potential to evolve into a multiversion mechanism that will allow the generation of several versions of a care plan that will more appropriately meet the differing needs of patients and providers. As end-users are expected to include patients, it is important to note that the care plan is not intended to replace provider recommendations, and users are advised on the Web site to discuss the information with their medical team.

The LIVESTRONG Care Plan can be completed by survivors, families, or providers, and a variety of user-specific questions are included and modified with each new version based on survivor and clinician feedback. After entry of demographic, disease, and treatment information, users receive a comprehensive, individualized list of recommendations specific to primary cancer diagnoses and treatments received. These recommendations are evidence- or consensus-based, whenever possible, and are in concordance with guidelines provided by the IOM, COG, NCI, and ASCO. In areas in which evidence- or consensus-based guide-

lines are not available, recommendations are based on practice at the developer's institution.

Questions regarding whether patients need to enter specific doses of chemotherapy agents and radiation received have arisen. Because, at this time, there is no evidence that knowledge of specific doses influences the risk of late effects or that this knowledge would lead to specific recommendations for screening,^{111,112} the *OncoLink* team that developed the tool decided that this information would not be required. Many institutions and providers choose to include this treatment information

in the cancer treatment summaries that they develop. Before the launch of the care plan program, the *OncoLink* team obtained permission from the University of Pennsylvania Institutional Review Board to collect data while maintaining user anonymity. The intent was for these data to guide the evolution and revisions of the LIVESTRONG Care Plan. To date, there is nothing in the literature that describes users of online care plans. Consequently, we report these descriptive data in figures 2, 3, and 4.

To date, almost 6000 users have completed the Internet care plan (Figure 1). Users identified themselves as survivors, friends or family of survivors, and health care providers (primarily nurses or nurse practitioners). Most respondents were Caucasian, female, and well-educated. The most common cancer diagnosis was breast cancer, followed by hematologic and gastrointestinal malignancies (Figure 2). Data from Internet utilization studies have demonstrated this demographic range to be the most likely to use the Internet for health information, including information about cancer.¹¹¹⁻¹¹⁴ Most LIVESTRONG Care Plan users reported some combination of having undergone surgery, chemotherapy, and radiation. One-third of these survivors reported that they receive follow-up care from oncologists and primary care providers, with approximately one-half receiving follow-up care solely from oncologists. It is noteworthy that few users reported receiving survivor information previously, being cared for at a cancer center with a dedicated survivor programs, or knowing whether such a program even existed.

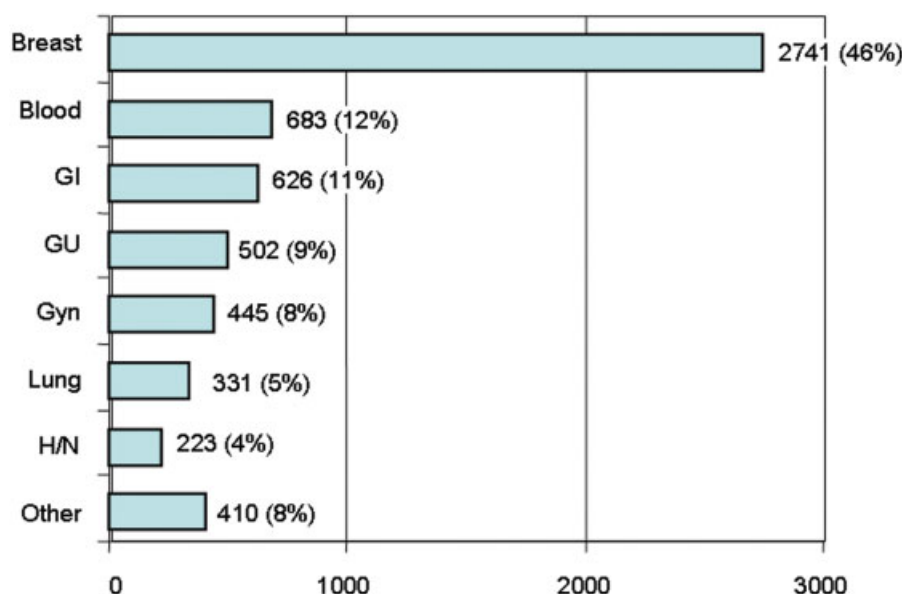


FIGURE 3. Cancer Diagnoses of LIVESTRONG Care Plan Users are shown.

Earle¹⁷ stated that it is crucial for the research community to evaluate each element of the survivorship care plan. He also recommends observational studies to determine the knowledge and desire demonstrated by cancer survivors for information about the elements of a proposed care plan. Level of satisfaction with the information provided, the transition from the treatment to the survivor phase of care, and other issues were included in Earle's suggestions for research that should be conducted in conjunction with widespread development and implementation of survivorship care plans.

In July 2008, an optional user-satisfaction survey was added to the LIVESTRONG Care Plan. Based on information from 747 users, care plan development required an average of 6.2 minutes. Overall, cancer survivors reported high satisfaction with the care plan. Most reported that they had the information needed to generate the care plan, that the information provided was helpful, and that they planned to share the care plan with their health care provider. Information overload did not appear to be a problem overall, although a substantial minority reported wanting somewhat more information. Most health care providers reported that they would use the program with

future patients (Figure 3). These data can be a useful resource for institutions and groups who are working to develop templates for survivors' treatment summaries and care plans.

As institutions struggle to develop templates and/or to adapt and use existing ones, it is important to remember that there is no perfect approach to the development of treatment summaries or care plans for cancer survivors. Institutions differ in their resources, and surveillance guidelines are only beginning to become available, creating reason for pause when putting resources into the

generation of formal care plans for cancer survivors. However, as Earle¹⁷ noted, "even informal plans can be sufficient to improve the quality of care for a survivor."

Conclusion

Oncology clinical practices focus on treatment and management of malignant diseases, and follow-up visits for patients who have completed treatment are generally directed toward surveillance for recurrent disease. Consequently, there is often inadequate assessment and management of symptoms reported by survivors that

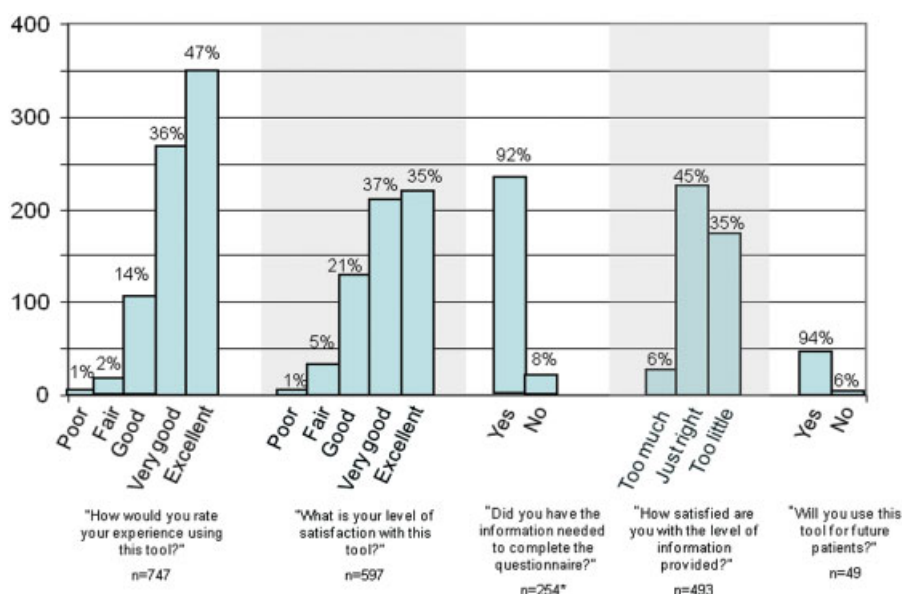


FIGURE 4. LIVESTRONG Care Plan Queries are illustrated. *Query posed to survivor/friends/family members. †Query posed to health care providers only.

may be related to the cancer treatment they received. In many cases, symptoms and medical issues that arise in this population are viewed as expected comorbidities of aging and subsequently referred to ill-prepared providers of primary and specialty care for management. Survivors may hesitate to present issues to their oncology care providers by thinking that they are nononcology problems and, to some extent, that their oncology providers are not willing or equipped to deal with these problems.¹³ Many survivors also report concern that their providers are too busy with patients in treatment to address a survivor's seemingly less significant issues.

The provision of survivor care as a component of cancer care, translational research that guides that care, and the education of patients, providers, and the public are critical to the development of the adult cancer survivor field. Numerous reports that examine the broad array of survivor issues outline recommendations for the development of treatment summaries and care plans, and models of care, as well as the need to change the education of professionals caring for cancer survivors. These reports also address the need for translational research that will inform and guide clinical care.

It seems that oncologists have been abruptly confronted with a population of patients whose demands differ from those of patients under treatment and whose numbers are out of control. For many years, the oncology community engaged in the treatment of adults chose to ignore or dismiss the need for care to include patients who were no longer being actively treated. Cancer survivor care requires a thoughtful, organized approach to address recommendations made by the IOM and other groups. However, the current number of survivors who require follow-up care poses significant and immediate challenges to the medical community as this population grows. Resources are

limited and shrinking at a time when patients and providers are demanding evidence-based guidelines for surveillance and the necessary care of cancer survivors. The IOM recognized that, despite the lack of data to support their use, care plans should be developed for every cancer survivor²; however, this is an added burden on the already overextended decreasing population of providers of oncology care. In addition, it is necessary to develop survivorship care plans by using surveillance and follow-up recommendations based on consensus and clinical evidence, but this will not be a feasible long-term solution.

The cancer survivor literature has exploded during the last few years, highlighting the broad scope of questions to be researched in this very young field. However, research opportunities for addressing some of the crucial questions that might have a direct bearing on the conduct of clinical care are still limited. The medical community is expected to provide care to cancer survivors without adequate data to make accurate and appropriate recommendations for follow-up, and although data to support these recommendations as well as studies to support the efficacy of providing survivor care in different settings by different providers is sorely needed, it is increasingly evident that it will be decades before the field of survivor research is mature enough to produce a body of literature that will guide clinical care as well as future research.

In the interim, clinical care will drive the initiation of research that examines the plethora of cancer survivor issues; however, in the long run, translational research must and will drive the clinical care of cancer survivors. A paradigm shift in cancer care requires that the survivorship phase of care be recognized as an essential and distinct phase in the continuum of cancer care. ■

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