

Survivorship Research: Past, Present, and Future

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Origins of Cancer Survivorship Research

In 1884, an official ceremony was held and the cornerstone laid for an ornate and turreted building in New York City that would for many years house the first cancer treatment center in the country. The site, located on the upper west side of Central Park, then a virtual wilderness area on the larger island of Manhattan, was selected because the belief at the time was that cancer was contagious. The rounded design of the towers, where patient beds were to be located, was intended to discourage the risk of germs, which were thought to lurk in corners. Named The New York Cancer Hospital, this institution would later be moved in 1948 to its current east side location where it was, until 1960, called the Memorial Hospital for Cancer and Allied Diseases. The history of this leading center for cancer care and research, known today as the Memorial Sloan-Kettering Cancer Center, a sprawling multisite enterprise, is illustrative of where we have come in viewing cancer.¹

At the turn of the 20th century, cancer was largely incurable, poorly understood, and associated with treatments that were often as dire as the disease itself. By midcentury, with the advent of anesthesia, antibiotics, and the introduction of multimodal cancer therapies, the number of individuals living longer (beyond 5 years) with cancer had slowly increased. However, it was not until the latter part of the 1900s that the nationally estimated 5-year cancer prevalence figures (prevalence being defined as the number of people alive at a given point in time with a history of cancer) reached 50%. From an evidence perspective, this event, which occurred between 1974 and 1976,² might in hindsight be considered a turning point in what would soon become the field of cancer survivorship. Arguably, without substantial numbers of survivors, issues of "survivorship" would never have become of interest; the focus of research would have remained, as it had in the past, largely on trying simply to enable an individual to become a survivor, not what the future of that person's life might be like.

The first glimpse at this new world came from pediatric oncology where, seemingly overnight, a death sentence was being converted into long-term cure. This point is well illustrated in the steady upward curve in pediatric cancer survival rates from 1950 to 1998 depicted in Figure 4.1. Introduction in the late 1960s of therapies to prevent central nervous system relapse in survivors of childhood lymphoblastic leukemia (ALL) was among several key treatment changes that would lead to a revised perspective on this disease (Figure

4.2). Because ALL is the most common form of childhood cancer, accounting today for approximately 30% of cancer cases diagnosed in children before the age of 14,³ the impact of this breakthrough produced a dramatic shift in 5-year survival rates for pediatric cancer as a whole. It also spawned the first generation of articles calling for attention by the medical community to issues that went beyond merely curing a child to those affecting his or her quality of life after treatment.⁴⁻⁶ This same process was slower to evolve in the adult cancer arena.

Development of Survivorship Researcher and Assessment Tools

Others, and most notably Jimmie Holland,^{7,8} have written in detail about the confluence of both medical and societal factors that led to the recognition of the field of psychosocial oncology. Three elements essential to the growth of the field were the change within the medical community toward disclosing a cancer diagnosis, training of a cadre of researchers to address posttreatment issues related to quality of life (QOL), and development of assessment tools to measure and describe the survivorship experience. Of these, the movement toward disclosing a cancer diagnosis was the most critical.

Throughout most of the 1960s, the practice in the United States was not to tell patients their diagnosis, "never tellers" constituting an estimated 90% of physicians surveyed in a report by Oken.⁹ A report published by Novack and colleagues revealed that this policy reversed in the course of a brief 10 years. By 1977, 97% of physicians stated that they told patients they had cancer at the time of diagnosis.¹⁰ This change in practice was important because it opened the door for researchers to approach and ask patients directly about their understanding of their illness and its impact on their lives. The shift in candor about a cancer diagnosis was consequent to growing attention in the United States to patients' rights, particularly in the health arena. However, physicians' willingness to adopt this practice was also a reflection of the greater optimism about survival prospects for those diagnosed with cancer. It should be noted that sharing the diagnosis is not a universal practice. In many countries around the world, including several industrialized nations, physicians still hide this information, sometimes at the request of family members.¹¹⁻¹³ In Third World countries, where access to curative therapies is more limited and hence prognosis is grim,

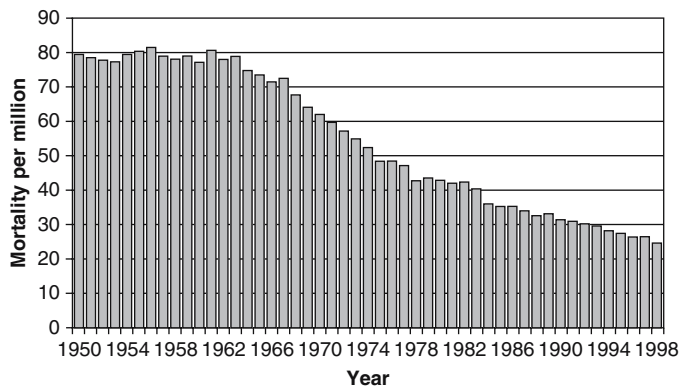


FIGURE 4.1. Remarkable past progress: childhood cancer mortality, 1950–1998.

protecting patients from learning their diagnosis is considered more humane.¹⁴ Even in many European countries, cancer still carries a significant social stigma. As part of its year-long study of cancer survivorship in the United States, the President's Cancer Panel held a meeting in Lisbon, Portugal, in May 2003. The purpose of this meeting was "to learn about the health services and survivorship activities in diverse European nations and health systems that might benefit survivors in this country".¹⁵ The Panel found that the term survivor was rarely used, and in some countries no linguistic equivalent existed. It was common for European survivors, the testimony from many of whom is included in transcripts and the final report from this meeting,¹⁵ to feel they could not publicly reveal their cancer history, or discuss their illness experience, even with family. In contrast to the situation in the United States, few prominent Europeans have disclosed their status as cancer survivors.

Early pioneers in the field of psychosocial oncology often came from mental health or nursing backgrounds. Few,

however, had formal training in psycho-oncology, as dedicated educational programs in this field did not appear until the late 1970s and early 1980s.^{7,16} Today, a number of the National Cancer Institute (NCI)-designated clinical and comprehensive cancer centers offer 2- to 3-year training programs for MDs and PhDs who wish to specialize in this area of research or care. Many also provide access to courses in psychosocial aspects of cancer research to a diversity of healthcare professionals. It also is increasingly common to see position openings for psychosocial oncology specialists announced on association-based online listserves, such as that supported by the American Psychological Association's Division 38 Health Psychology forum.

Paralleling the expertise of the early researchers, the tools used for QOL assessment of survivors' outcomes were drawn initially from the psychiatric or mental health field. Examples of frequently used instruments included the Hopkin's Symptom Checklist (better known to many as the SCL-90),¹⁷ the Profile of Mood States,¹⁸ and the Center for Epidemiologic Studies Depression Scale (CES-D).¹⁹ It quickly became apparent that these measures were not well suited to the cancer survivor population, which, although experiencing distress, generally did not report symptoms at psychiatric or pathologic levels. At the same time, teasing apart symptoms that might be caused by the effects of treatment (e.g., fatigue/lack of energy, sleep disruption, problems concentrating) from signs of emotional distress created a challenge to score interpretation.^{20–22} Further, many of the experiences of those treated were poorly captured by the questions asked in these tools. Frustration with the limits of these more-generic tools resulted in the birth of cancer-specific measurements, an enterprise that, although starting slowly, burgeoned in the 1980s to produce many of the QOL measures, or at least their sophisticated variants, most commonly used today.^{23–26}

Role of Advocacy in the Growth of the Field

DEFINING THE DOMAIN

The shift in focus and language to recognition of people with a history of cancer as "survivors" and their health and social outcomes as constituting "survivorship research" has its own history. In 1985, a young pediatrician working for the Public Health Service, Fitzhugh Mullan, wrote about his experience of living with cancer in a short piece for the *New England Journal of Medicine*. He referred to his journey as the "Seasons of Survival" and in his text first gave name to issues of survivorship.²⁷ In October 1986, he and an intrepid group of about two dozen fellow survivors, cancer healthcare providers and advocates, met in Albuquerque, New Mexico, and established the National Coalition for Cancer Survivorship (NCCS).²⁸ The standard medical definition of a survivor at the time of that gathering, and the only definition commonly applied, held that only those individuals who remained disease free for a minimum of 5 years could be labeled as survivors. At the founding NCCS meeting, the group declared that a person should be viewed as, and was entitled to call himself or herself, a survivor, "from the moment of diagnosis and for the balance of his or her life, regardless of the ultimate cause of death."

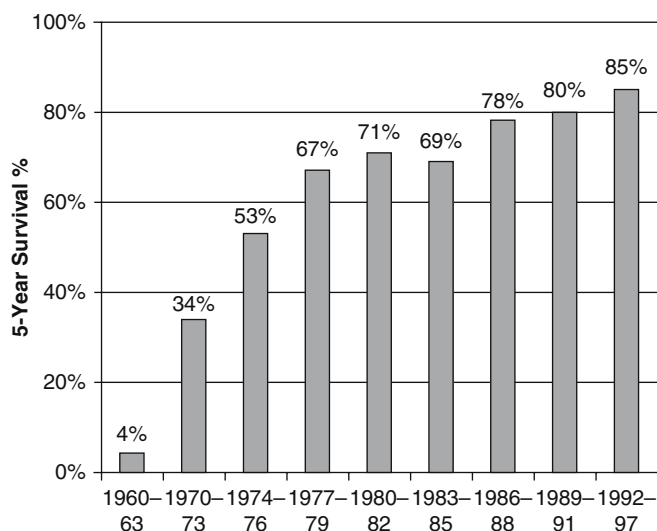


FIGURE 4.2. Remarkable past progress: childhood acute lymphoblastic anemia (ALL) survival rates, 1960–1997.

The group's argument for advancing this new definition was that it was only by endorsing such thinking that survivors would be able to significantly alter the prevailing medical culture. Specifically, they sought to encourage the cancer practitioner community to move away from its more narrow focus on starting treatment as quickly as possible to one that recognized that a person's unique needs, desires, and ultimate health and life outcomes must be acknowledged in this process. Ideally this would start on day 1, after diagnosis. Although controversial at the time, and certainly not uniformly embraced even today, this broader definition of a cancer survivor has taken hold, at least in the United States. In a search of *Pub Med* from 1981 to 1985, the 5-year period before the founding of the NCCS, 28 research articles (among humans, published in English), were identified using the terms cancer survivorship. Using the same approach to examine the "hits" in 5-year increments since then yielded the following: 1986–1990, 1,700 citations; 1991–1995, 8,417; 1996–2000, 10,574; 2001 to current (with 16 months still remaining to come during this 5-year period), 7,673. Although many of the citations identified would not be classified by many as addressing issues related to living with or beyond cancer (i.e., many still focus on survival, not survivorship), the numbers speak for themselves. On the public side, since 1987 the first Sunday in June has been celebrated as National Cancer Survivors' Day. Many of the large cancer centers in major cities now hold their own "Cancer Survivors Day" celebrations, often in association with special presentations by survivors, scientists, and advocates. The most significant evidence that the field of cancer survivorship had finally come into its own was the creation of an Office of Cancer Survivorship within the world's premier cancer research center, the U.S. National Cancer Institute.

A BRIEF HISTORY OF THE OFFICE OF CANCER SURVIVORSHIP

Had NCCS members decided to stop at endorsing a new definition of survivor, it is not clear how rapidly the broader field of survivorship research might have progressed. Fortunately, they were not content to merely draw attention to the needs of those living with a history of cancer. NCCS members began to advocate for specific resources to further identify and address these needs. In anticipation of what would become the first NCCS Congress, held in Washington, D.C., in November 1995, the Coalition sought the input of scores of researchers, clinicians, and survivors on what questions remained unanswered, who should be charged with addressing these, and how best were we going to achieve optimal cancer care for all. Response to this inquiry was combined in a white paper entitled *Imperatives for Quality Cancer Care: Access, Advocacy, Action & Accountability*. In spring 1996, Ellen Stovall, Executive Director for NCCS, gave a copy of this document to the director of the NCI, Dr. Richard Klausner. After reading this paper, Dr. Klausner called for the creation of the Office of Cancer Survivorship (OCS).

Formally inaugurated at a ceremony held in the Rose Garden of the White House in October 1996, the OCS was established in recognition of the growing population of cancer survivors and their unique and poorly understood needs.²⁹ The overall mission of the office is to enhance the length and quality of survival of all those diagnosed with cancer. The

OCS achieves this by serving as a focus for the support and direction of research that will lead to a clearer understanding of, and the ultimate prevention of, or reduction in, the adverse psychosocial, physical, and economic outcomes of cancer and its treatment. Survivorship research is seen as encompassing the medical, functional, and health-related QOL of children and adults diagnosed with cancer, as well as that of their families. It also includes within its domain issues related to healthcare delivery, access, and follow-up care as they relate to survivors. Because considerable work had been done in elucidating the needs and care of those newly diagnosed and in active treatment, particular emphasis in creating the OCS was placed on developing and supporting research that addresses the health and well-being of individuals who are posttreatment or in remission. The OCS also has as its purview a commitment to educating healthcare providers, as well as survivors themselves, about issues and practices critical to their patients (or in the case of survivors, their own) optimal well-being. Finally, the OCS works to foster and promote the training of the next generation of survivorship researchers and clinicians.

In 2001, members of the OCS, the NCI Director's Consumer Liaison Group, and a number of community researchers and advocates independently suggested that NCI leadership consider advancing cancer survivorship as an area for special focus along with other previously identified topics such as Genes and the Environment, Cancer Imaging, Research on Tobacco and Tobacco-Related Cancers, and Cancer Communications. This recommendation met with approval and elevated Cancer Survivorship to special status in NCI's Fiscal Year 2004 and 2005 budgets^{31,32} (pp 88–93 and 66–71, respectively). Successful adoption of cancer survivorship as an extraordinary opportunity for investment by the NCI was in significant measure due to the specific intercession of Dr. Andrew von Eschenbach. Dr. von Eschenbach's appointment as NCI Director by the President of the United States brought to the Institute in February 2002, for the first time, a cancer survivor as its director. Throughout his leadership, Dr. von Eschenbach has been outspoken about his own cancer experience as a three-time survivor and an unflagging champion for survivorship research.

The breadth of attention to cancer survivorship as an area of public health interest is reflected in a number of recent events at the national level. These events include the release in 2002 by the Institute of Medicine's National Cancer Policy Board of its report *Childhood Cancer Survivorship: Improving Care and Quality of Life* (and the adult companion *From Cancer Patient to Cancer Survivor: Lost in Transition*)³²; the decision by the President's Cancer Panel to pursue cancer survivorship as a theme for its planned hearings in 2003 and 2004, the report from which activities, *Living Beyond Cancer: Finding a New Balance*, was released at the annual meetings of the American Society of Clinical Oncology held in New Orleans in June 2004³³; and the publication in April 2004 of *A National Action Plan for Cancer Survivorship: Advancing Public Health Strategies* by the Centers for Disease Control and Prevention (CDC) and the Lance Armstrong Foundation.³⁴ The latter two initiatives bear the important contribution of Lance Armstrong. Lance, seven-time winner of the world's most grueling bicycle race, the Tour de France, an accomplishment achieved after his diagnosis with and treatment for metastatic testicular cancer, was nominated in 2002

by President Bush to serve as one of three members of the President's Cancer Panel. The foundation that bears his name underwrote the CDC effort to produce the *National Action Plan* document. During this same period, 2002–2004, five separate bills were introduced in Congress that included language identifying cancer survivorship as an area warranting more attention and funds from the U.S. Department of Health and Human Services (DHHS); one of these would have formally authorized the office by an act of Congress. None of these bills ultimately became law. However, the fact that they were put forward (with others of similar intent likely to follow) is strong evidence that the nation acknowledges that it is not enough for our scientists to find a cure for cancer; we must also, as a country, ensure the quality of the lives of those treated. In the Congressional appropriations document for 2003 (Senate Report 107-216; Department of Labor, Health and Human Services, and Education, and Related Agencies Appropriation Bill), members of the Senate wrote "... More must be done to improve the understanding of the growing cancer survivorship population, including determinations of the physiological and psychological late effects, prevalence of secondary cancers, as well as further development of effective survivorship interventions. The Committee supports an aggressive expansion of the NCI Office of Cancer Survivorship activities. . . ."

Function of Survivorship Research in Cancer Control and Care

The world of cancer survivorship research has expanded far beyond that originally envisioned. In the early 1970s, the function of such research was largely limited to describing the "terrain" of survival. By the early 1980s, researchers sought not simply to elucidate the impact of cancer on the lives of individuals and their families but to use this information to develop interventions to help survivors cope better with their illness.^{35,36} In the case of pediatrics, the findings from survivorship research were being used to refine cancer therapies so as to reduce their associated morbidity without diminishing the gains achieved in reduced mortality.³⁷ As we race into the new millennium, this vision, along with the approach to as well as application of survivorship research, has vastly expanded and come to encompass the entire cancer control continuum (Figure 4.3). Originally occupying just one part of the continuum, cancer survivorship research and care now have the potential to address and affect issues along the entire continuum. For example, with more young survivors expected to live full or lengthened lifetimes, they need to be counseled to reduce the risk of (primary prevention) and screened for (secondary prevention) other unrelated malignancies for which they would be at risk across the course of life/normal aging.³⁸

Clinically, the primary function of survivorship research is fivefold. Information about survivors is critical if we are to help patients make decisions now about treatment options that will affect their future; understand the action of and tailor therapies to maximize cure while minimizing adverse treatment-related effects; develop and disseminate evidence-based interventions that reduce cancer morbidity as well as mortality and facilitate adaptation among cancer survivors; improve quality of care and control costs; and equip the next generation of physicians, nurses, and other healthcare profes-

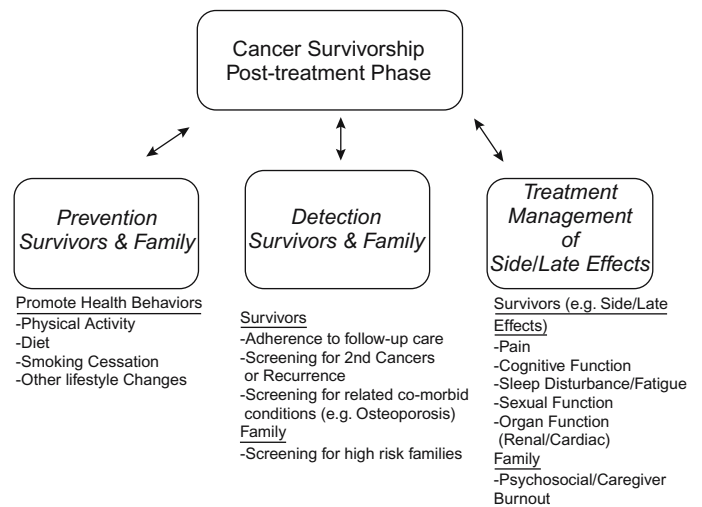


FIGURE 4.3. Aspects of cancer survivorship interventions.

sionals to provide not just the science but also the art of comprehensive cancer medicine.

The New Generation of Survivors: Who are They?

Profile of the Current Survivor Population

"The new population of survivors hanging in there can be found everywhere . . . in offices and factories, on bicycles and cruise ships, on tennis courts and beaches, and in bowling alleys. You see them in all ages, shapes, sizes, colors, usually unremarkable in their appearance, sometimes remarkable for the way they learn to live with disabilities." (Natalie Davis Spingarn,³⁹ p. 69)

In 1982, Natalie Davis Spingarn became one of a feisty vanguard of cancer survivors, and vocal patient advocates, to publish a book about their encounter with cancer. Her volume, titled *Hanging in There, Living Well on Borrowed Time*,³⁹ chronicled her experience of being diagnosed as a young woman (under age 50) and living long term with metastatic breast cancer. A journalist and investigative reporter by training, Natalie provided information often hard for fellow cancer travelers to find and encouraged them to become active participants in their care, a quite provocative message for those more comfortable operating in the paternalistic model of care of the times. In 1999 she published an update of this journey in a book titled *The New Cancer Survivors: Living with Grace, Fighting with Spirit*.⁴⁰ In this second volume she describes what she recognized as a new and emerging generation of survivors who come from all walks of life, seek an equal or at a minimum a partnership role in their health-related decision making and care, and expect to be treated as whole persons, not as a particular disease (cancer) or body site (breast patient).

The main driver behind interest in issues of cancer survivorship is necessarily the growing population of survivors. Cancer survival in the United States has risen steadily over the past three decades for all cancers combined. When Nixon declared "the war" on cancer in 1971, there were only

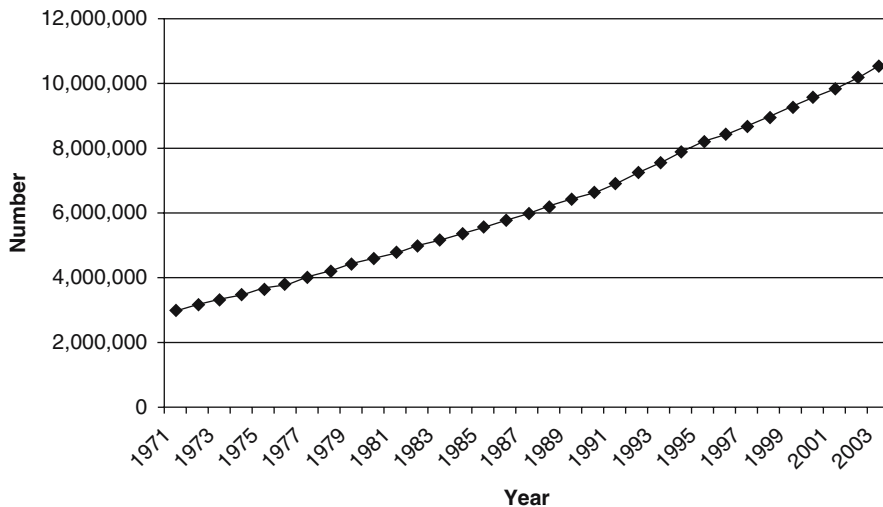


FIGURE 4.4. Estimated number of cancer survivors in the United States from 1971 to 2003. U.S. estimated prevalence counts were estimated by applying U.S. populations to Surveillance Epidemiology and End Results (SEER) 9 Limited Duration Prevalence proportions. Populations from January 2003 were based on the average of the 2002 and 2003 population estimates from the U.S. Bureau of Census. (Source: November 2005 submission.)

3 million survivors. Today, there are approximately 24.5 million cancer survivors worldwide; an estimated 10.5 million of these live in the United States alone, representing between 3% and 4% of the population (Figure 4.4).^{41a} In the absence of other competing causes of death, current figures indicate that for adults diagnosed during 1995 to 2000, 64% could expect to be alive in 5 years; this is up from 50% estimated for those diagnosed during 1974 to 1976. The relative 5-year survival rate for those diagnosed as children (less than 19 years of age) is even higher. Of children diagnosed with cancer between 1974 and 1976, while 80% survived beyond 1 year, little more than half (56%) were still alive 5 years later. Today, 79% of childhood cancer survivors will be alive at 5 years, and the 10-year survival is approaching 75%. If these trends in survival continue, we may reasonably expect to reach the 2010 *Healthy People* goal of 70% 5-year survival for all those diagnosed with cancer.

Of the 10.5 million survivors in the United States, an impressive 14% were diagnosed 20 or more years ago (Figure 4.5).^{41a} More women than men are survivors. The higher proportion of men who are within 5 years of diagnosis is consistent with the larger number of males versus females

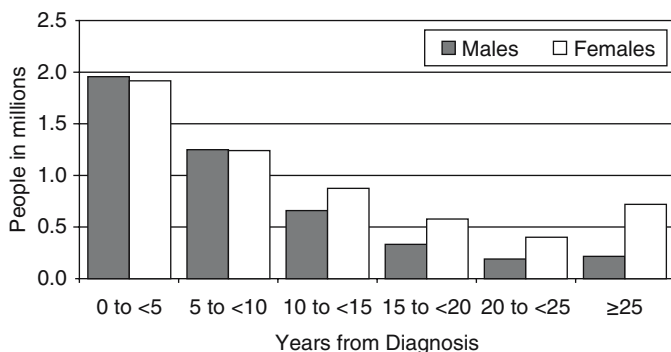


FIGURE 4.5. Estimated number of persons alive in the United States diagnosed with cancer on January 1, 2003, by time from diagnosis and gender (invasive/first primary cases only; $n = 10.5$ million survivors). U.S. prevalence counts were estimated by applying U.S. populations to SEER-9 Limited Duration Prevalence proportions. Populations from January 2003 were based on the average of the 2002 and 2003 population estimates from the U.S. Bureau of Census. (Source: 2005 submission.)

diagnosed annually with cancer. At the other end of the survivorship continuum, more women survive longer than men due to the higher proportion found to have more readily detected and treatable cancers (e.g., breast, gynecologic), the fact that fewer women ($n = 80,660$) than men ($n = 93,110$) develop lung cancer or die of it (females, 68,510 versus males, 91,930) annually,³ and the generally lower all-cause mortality rate among women versus men in this country.

Of the prevalent cancer population, the largest constituent group comprises breast cancer survivors (23%), followed by survivors of prostate cancer (19%), colorectal cancer (10%), and gynecologic cancer (9.9%) (Figure 4.6).^{41a} Consistent with the fact that cancer is a disease associated with aging [median age of cancer patients at diagnosis based on

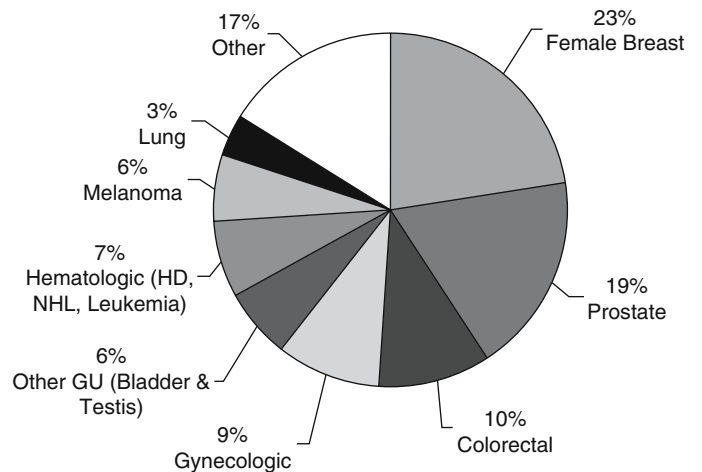


FIGURE 4.6. Estimated number of persons alive in the United States diagnosed with cancer by site. Starting *clockwise from 12:00 position*: female breast (23%), prostate (19%), colorectal (10%), gynecologic (9%), other genitourinary (GU, bladder and testis) (6%), hematologic [Hodgkin's Disease (HD), non-Hodgkin's lymphoma (NHL), leukemia] (7%), melanoma (6%), lung (3%), and other (17%). U.S. Estimated Prevalence counts were estimated by applying U.S. populations to SEER 9 for All Races, White, and Black, SEER 11 for Asian/Pacific Islander, and SEER 11 (excluding Hawaii and Detroit for Hispanic) Limited Duration Prevalence proportions. Populations from January 2003 were based on the average of the 2002 and 2003 population estimates from the U.S. Bureau of Census. (Source: 2005 submission.)

SEER (Surveillance, Epidemiology, and End Results) 12 data from 1997 to 2001 was 67 years; an estimated 56.8% of new cancers are diagnosed in patients 65 and older,⁴² the majority (61%) of our survivors are aged 65 or older, while 33% are between ages 40 and 64, 5% are aged from 20 to 39 years, and fewer than 1% are 19 or younger. It is currently estimated that one of every six persons over the age of 65 is living with a history of cancer. Although it is unknown what impact the use of chemopreventive agents such as tamoxifen will have on the larger figures for breast cancer incidence, as past and future advances in cancer detection, treatment, and care diffuse into clinical practice, the number of survivors can be expected to increase. Fewer deaths from cardiovascular disease and the aging of the population will contribute to this trend.

Projected Population of the Future

Realization that the world's population is aging is sobering.⁴³ In 2011, the first members of the baby boomer generation (those born between 1946 and 1964) will turn 65. It is estimated that by the year 2030 one in five individuals will be age 65 or older and 40% will be from minority groups. At the same time, it is recognized that older cancer patients tend to be in poorer health (34% versus 10% of the general population), often have two or more chronic medical conditions (16% versus 4%), report functional limitations (nearly 70% versus less than 30%), and experience more limitations in activities of daily living (ADL) or instrumental ADL (17% versus 3%).⁴⁴ Given these figures, it is clear that planning for the care and ongoing health of our aging population, many of whom will become cancer survivors, constitutes a critical public health challenge for the future.⁴³

The OCS includes family or caregivers as "secondary" survivors in its definition of survivors. This concept reflects the growing appreciation of the critical role they play in a loved one's or family member's illness. The American Cancer Society (ACS) in its *Facts and Figures* publication for 1996 estimated that three of every four families would have an affected family member. Recent data on caregiving in America suggest that 21% of those over the age of 18 provide unpaid care for an adult 18 and older. The second most common reason for a recipient to need care, after old age, is cancer.⁴⁵ Data obtained from cancer survivors identified by the National Health Interview Survey in 1992 indicated that approximately 24% of adult cancer survivors (1.3 million) had a child 18 years of age or younger living in the home.⁴⁶ To date, relatively little is known about the impact of living with someone who has cancer on other family members in general; even less is known about cancer's impact on the current or future health behaviors and well-being of younger and potentially highly vulnerable family members.

With advances in our understanding of genomics and proteomics and the application of novel delivery systems, many project that future antineoplastic therapies will be more targeted to cancer cells and less toxic to normal tissue, resulting in significant reductions in treatment-associated morbidity. This is not to say cancer therapy will be entirely benign, as few pharmacological treatments are ever entirely without side effects. Monitoring for the novel, potentially subtle, and late-appearing or unexpected effects of newer

approaches to cure represents a challenge to future researchers. Of equal importance will be our ability to assess the impact of delivery of these molecularly targeted treatments. Many agents will be administered orally, shifting the responsibility for delivery and monitoring away from the medical team and to the patient. Appreciating the obstacles faced by patients and families to understand and adhere to regimens will be critical if we are to understand not just drug effectiveness but also survivors' QOL and health-related outcomes.

Domains of Survivorship Research: Multidimensionality

In the early era of research on the psychosocial and physical impact of cancer, the common practice was to use global (e.g., Karnofsky) or summary scores representing overall function across a range of activities of daily living activities (e.g., FLIC, functional living index-cancer; LASA, linear analog self assessment). Perhaps unique to cancer QOL studies (as opposed to those for other chronic illnesses) is their history of emphasis on the importance of patient-based outcomes. What was quickly apparent in instrument selection and development was the need for patient (versus physician)-based measures.⁴⁷⁻⁴⁹ The few clinician-rated scales still commonly in use represent measures to assess patient status for clinical trials (e.g., ECOG, Eastern Collaborative Oncology Group, status) or were designed for use when a patient might be too sick to complete a self-assessment, e.g., the Spitzer Quality of Life Index.⁵⁰

As clinicians began looking more closely at patient-focused outcomes and more behavioral scientists joined the field of inquiry, four primary areas of QOL impact emerged: physical (symptoms), functional (capacity to engage in activities of daily living), emotional (mood/affective and cognitive status), and social (role functioning and/or support, financial burden). Examples of early scales with these four domains include the Quality of Life Index⁵¹ and the Sickness Impact Profile.⁵² These four domains remain at the core of contemporary scales.

An early challenge for the field was the need to develop and test cancer-specific tools. As already noted, initial studies of mental health outcomes for survivors relied heavily on the use of instruments borrowed from the psychiatric arena, for example, the Hopkins Symptom Checklist (SCL-90) and the Profile of Mood States (POMS). Even when studies became more sophisticated and expanded to include such domains as sexual functioning, the available measures (e.g., Derogatis Sexual Functioning Inventory) were often poorly designed to assess cancer patients' functioning or unique areas or types of dysfunction. It is of note that the recent interest in examining benefit finding among survivors led clinical researchers to reflexively go back to the psychiatric literature for tools (e.g., posttraumatic stress scale, civilian version; posttraumatic growth inventory) before realizing that they would need to develop measures better suited to capturing the cancer experience.

The most recent generation of cancer-specific measures is designed to assess domains of well-being that represent newer foci of attention. These measures include, for example, items or scales to assess fatigue, cognitive dysfunction, and

menopausal or hot flash symptoms, as well as bowel and urologic status in colorectal, select gynecologic, and prostate cancer survivors. (See the Cancer Outcomes Measurement Working group-generated publication for an excellent review of current measurement tools.⁵³) The two newest areas of attention in measurement development are long-term survivorship scales⁵⁴⁻⁵⁶ and measures of postcancer health behaviors.⁵⁷⁻⁶⁰ Curiously, although fear of recurrence is probably the single most common concern of those living with a history of cancer, efforts to create instruments designed specifically to measure this domain have languished.⁶¹⁻⁶³

There has been considerable debate as to whether current measures assess QOL or simply health-related quality of life (HRQOL).^{64,65} Many argue that individual QOL is intangible and almost impossible to meaningfully measure. Although the majority of survivorship researchers today use the terms QOL and HRQOL interchangeably, when pressed most agree that our common assessment tools are most accurate in providing (and often specifically designed to generate or elicit) information on survivors' perception of their health-related quality of life than QOL per se. One of the more recently appreciated challenges to the field of QOL assessment among cancer survivors is interpreting the impact cancer has over time in individuals' lives. Cancer researchers are (re)learning what others have reported for decades,⁶⁶ that humans are incredibly adaptable and, given time and support, can adapt to considerable limitations. The manifestation of this resilience is seen in what researchers now refer to as "response shift" in subjects' report of functioning and well-being when measured over time.⁶⁷ In this paradigm, respondents, as they accommodate to a loss or disability, are less likely to report being upset by it, even though the impairment may continue to cause the same level of, and sometimes greater, disability over time. Trying to make sense of this phenomenon while teasing out what health-promoting interventions may or may not be most helpful for survivors' recovery has become a respected field of inquiry in itself.

Trends in Survivorship Research

Past

The historical research on survivorship has been well reviewed by others.^{35,36} General themes have evolved over time. In the early era of survivorship research, most studies focused on the psychological impact of cancer or the delineation of specific sequelae of treatment (e.g., impact of stomas, lymphedema, amputation).^{68,69} As the number of survivors grew and length of survival increased, attention expanded to include examination of the social (interpersonal, family, work, school) and sexual well-being of survivors.^{6,70-72} By the mid-1980s, researchers, responding to the observation by many survivors that they continued to reexperience aspects of the events associated with their diagnosis and treatment, began to conceptualize cancer as a "traumatic event." A new wave of studies sought to determine the extent to which cancer produced symptoms of posttraumatic stress disorder (PTSD).^{73,74} In pursuing this path, investigators began to hear from survivors, particularly in studies that contained

qualitative analyses or open-ended formats, that cancer also caused them to recognize the positive aspects of their lives. The consequence of this observation is that a current trend in research is to examine the role of benefit finding in promoting and/or mediating and moderating survivorship outcomes.⁷⁵⁻⁷⁷

Since the establishment of psychosocial oncology as a field of its own in the early 1970s, clinical researchers have actively sought to take what they learned in their surveys and apply it to interventions that would reduce cancer's toll on survivors and their families. Relatively little of this research, however, was designed exclusively to meet the needs of those posttreatment.^{78,79} This picture is slowly changing.

Present

Since 2000, the NCI's Office of Cancer Survivorship has conducted annual analyses of the number and types of grants in the area of cancer survivorship funded across the National Institutes of Health. (These data are updated and posted yearly online.⁸⁰) Included in this analysis are grants that examine the health or behavior of individuals after treatment for cancer or that of their family members. Excluded from this review are studies that consider patients solely during active treatment or early posttreatment (less than 2 months follow-up) or survivors with recurrent or advanced disease. When the OCS was originally established in 1996, only 24 National Institutes of Health (NIH) grants could be identified that met these narrower criteria. In the philosophy of "build it and they will come," the NCI's commitment to this area of science, with the creation of the OCS, appears to have been successful.

Judging by the numbers, the research community is slowly being enticed to advance its expertise to tackle issues further along the cancer control continuum. In fiscal year 2003 (encompassing October 2002 through September 2003), the period for which most complete data exist, a total of 179 grants were identified as addressing survivorship issues. Of these, 154 (86%) were funded through the NCI. The remainder were supported by the National Institute for Nursing Research ($n = 14$), National Institutes of Mental Health ($n = 5$), National Institute on Aging ($n = 4$), and the National Institute of Dental and Craniofacial Research ($n = 2$). That many grants end up at institutes other than the NCI reflects the fact that many of the issues faced by survivors (e.g., depression, aging, family challenges, pain syndromes) are not always unique to cancer. In keeping with past patterns, the majority of studies supported were descriptive or analytic in nature (54%). However, 42% of the funded research projects contained an intervention component designed to improve the psychosocial well-being, physical status, and/or health behaviors of survivors and/or their family members. This latter figure is important as it denotes the transition that is occurring in the research arena away from mere identification of problems (discovery) to the development and testing of interventions designed to reduce posttreatment morbidity and mortality (development). Most of the studies continue to be unique to or include samples of breast cancer survivors ($n = 79$, 44%), who, for a variety of reasons, have historically been the focus of the majority of the psychosocial research conducted in cancer.⁸¹ Other leading cancer sites

represented in this work include hematologic, prostate, and colorectal.

A clear testament to the success of the NCI's efforts to grow in survivorship research, and the readiness of the research community to pursue questions in this area, is reflected in the response to its request for applications (RFA) for studies addressing long-term cancer survivorship (defined as studies among cancer survivors diagnosed 5 or more years ago). In 1997 the OCS presented its first such RFA (CA 97-018), which attracted 79 applications. In 2003, the RFA was reissued (CA 04-003). A total of 125 applications were received in response to this second call. Of the 125 grants received, 50 (40%) were from investigators new to the field of cancer survivorship research.

One of the reasons that the NCI reissued the Long-Term Survivors RFA was that without this impetus few investigators appeared willing to take on the additional challenges of studying individuals years posttreatment. A review of the research portfolio conducted before the RFA reissuance revealed that only 27 of 126 grants analyzed were studying survivors 5 or more years postdiagnosis; 21 of these were developed in response to the initial RFA. Critical barriers to long-term survivorship research include finding this population, obtaining access to them, including negotiating the many hurdles consequent to the recently implemented Health Insurance Portability and Accountability Act (HIPAA) regulations, developing tools that measure outcomes of relevance to the long-term survivorship experience, identifying appropriate control or comparison groups, and coordinating a team invested in addressing these issues.

Future

Staff at the American Cancer Society took advantage of the opportunity to poll investigators engaged in behavioral, psychosocial, and policy research in cancer about their current interests and expectations for future research foci when compiling a directory of these individuals in 1997 and again when they updated the directory for release in 2002.⁸² Addressing psychosocial issues and treatment and outcomes remained key interest areas over time, a finding not altogether surprising given the target survey participants. However, two important areas for future research emerged in this report: the need to address special populations, a future direction voiced by members of all five of the disciplines represented (behavioral scientist, epidemiologist, nurse, physician, psychologist), and growing attention to health education and communication. Interesting in this study was the low endorsement of interest in survivorship research. Less than 10% said they were engaged in this type of research in 1997 (7.3%), and only 1.5% in 2002. However, in 2002, 11.7% thought it was going to be an important area of research in the future.

Ongoing analysis of the NIH-wide survivorship portfolio highlights a number of areas where our knowledge is lacking. Two of these areas echo themes identified for future targeting by Nehl and colleagues⁸²: (1) the exploration of outcomes for our diverse population of survivors, specifically those from ethnoculturally diverse backgrounds, those from low-income or low educational backgrounds, rural survivors, elderly survivors, and survivors from common cancer sites under-

represented in the literature (lung, colorectal, gynecologic, hematologic)⁸³; and (2) effective communication about survivorship-related issues. To these, four more areas are added, including (3) research on the impact of cancer on the family or caregiver; (4) studies addressing the economic impact of cancer on survivors and survivorship; (5) assessment of the nature, delivery, and outcomes of follow-up care to survivors; and (6) measurement tool development, including that which would enable us to compare survivors with those without a cancer history while also controlling for other comorbid illness states.

As the field of survivorship research has matured, change has occurred not only in the focus of the research being conducted but also in how and by whom this research is being carried out. The typical published cancer survivorship study has evolved from a largely descriptive outcome report based on a small single institution sample^{84,85} to one involving multidisciplinary teams accruing large cohorts and applying complex outcome and intervention assessments.^{86,87} A concrete measure of the growing sophistication of this body of research is the expectation by standing members of study sections (peer review groups) to see power analyses, detailed rationales for measurement choices, adequate representation by appropriate diverse scientific experts, and demonstrated sensitivity to the unique needs and experience of the target survivor group in grants submitted for review, with general impatience with studies that appear to "rediscover" what is already documented. Table 4.1 provides an overview of some of these trends over time.

Looking to the future, it is expected that a healthy balance needs to be maintained between the identification of problematic long-term and late effects of cancer and our ability to address these. The roughly 60%/40% split in current NIH-funded research between studies aimed at identifying problem areas and those designed to develop and test interventions that reduce the negative effects of cancer is probably a reasonable balance. With respect to the intervention arena, two new trends are of note. It is increasingly apparent that to be successful this research must (a) attempt to explain the biopsychosocial interaction between what is being delivered and its impact on health outcomes^{88,89} and (b) control or account for the costs associated with its delivery.⁹⁰ Although psychoneuroimmunology (PNI) research in cancer is by no means new,⁹¹⁻⁹³ attention to mind-body links is expanding as researchers seek to explain what is going on inside the proverbial "black box," in particular, in the context of psychosocial interventions that might mediate or moderate the impact of these trials on cancer recurrence or survival. Further, although drug interventions are relatively low cost, most psychosocial or behavioral interventions are labor intensive and hence more expensive to deliver. Despite this, there is good evidence to suggest they can reduce medical costs.⁹⁴ In recognition of this, investigators are working hard to design interventions that can be either self-administered,^{90,95} delivered readily by available healthcare staff with minimal training,⁹⁶ and/or, the newest piece in these models, made available online.^{97,98} This last point is critical if we are to have any hope of taking into the broader community interventions that hold the promise of significantly reducing the burden of cancer on individuals and society.

TABLE 4.1. Trends in cancer survivorship research design.

	<i>Past</i>	<i>Present</i>	<i>Future</i>
Target samples	Generally small convenience samples, often single institution based and mainly white, middle class, and middle age; largely breast cancer, or mixed, some colorectal, gynecologic; also pediatric, but largely leukemia	Moderate to large samples; often multiinstitutional; some clinical trials and population- or registry-based; increasing diversity of survivor groups by age and site (especially prostate, Hodgkin's disease, other gynecologic); still limited ethnocultural, income, and geographic diversity; more focus on family/caregivers	Mix of large (e.g., cohort, population-based) and moderate size; largely multiinstitutional; greater representation of more diverse cancer sites and previously neglected populations (e.g., by ethnic/income/geographic/age groups); more use of clinical trials samples
Team	Physicians, nurses, and some mental health professionals	Multidisciplinary teams; behavioral scientists leading in many areas; nurses with strong role as well; increasing role of advocates/survivors in research design	Truly multidisciplinary teams; attention to addition of basic scientists and psychoneuroimmunology (PNI) researchers to understand mind-body implications and impact of research findings for recurrence/survival, risk, and treatments; customary role for advocates/survivors in research
Basic design	Descriptive; limited interventions; often atheoretical and exploratory in nature; almost exclusively cross-sectional designs	Increase in hypothesis- and model-driven designs; complex multicomponent interventions growing; replication studies appearing; longitudinal studies increasing	Sophisticated model building and hypothesis testing; emphasis on building on prior studies, including research to take interventions to different audiences, settings, deliverers; intervention designs incorporating biologic markers and/or economic and health services endpoints or outcomes; longitudinal/cohort research
Topic	Focus almost exclusively on documenting dysfunction: distress, disability, impairment; a few coping studies; limited risk modeling	HRQOL instrument development; shift to evaluate both benefits and deficits of illness; modeling of risk for poor outcomes; examining role of caregivers in survivor outcomes and vice versa; growing attention to treatment effects and focused attention to specific problems, e.g., sexual dysfunction, fatigue, cognitive impairment; beginning attention to health after treatment	HRQOL development for long-term survivors (including comparison to other chronic illness groups and controlling for comorbid conditions); identifying/describing late, as yet unknown effects of cancer and novel problems associated with newer treatments and risk for these; targeting and tailoring interventions to survivors; identifying who may need what delivered by whom and when in the course of care; establishing the unique human and economic burden of cancer (versus other chronic illnesses); health promotion, follow-up care studies

HRQOL, health-related quality of life.

Challenges for the Future

Looking to the future, investigators face a number of challenges in advancing cancer survivorship research.⁹⁹ These challenges can be seen as falling into three broad categories: (1) identifying the most salient topics for study, (2) creating or enhancing the resources necessary to conduct the research, and (3) developing ways to make use of what is discovered.

Discovery

One of the greatest challenges to engaging in survivorship research is keeping up with the rapid pace of change in cancer treatments and care, as is particularly well illustrated in the context of breast cancer. In the past 10 years we have seen the uptake into standard practice of the use of sentinel node biopsies (replacing axillary node dissections), neoadjuvant (presurgical administration of) chemotherapy for large tumors, dose-intense and dense regimens of adjuvant chemotherapy with their greater attendant exposure to growth factors, testing for Her2 and consideration of herceptin, autologous tissue implants (over saline or silicone implants) for breast reconstruction, and aromatase inhibitors

in the adjuvant setting, as well as a shift away from use of stem cell transplant as a treatment option. Each of these alterations in practice has implications for QOL outcomes for women treated. For example, elimination for many women of the need for axillary node dissection may result in far fewer women developing lymphedema as a consequence of their breast cancer therapy.^{100,101} Nevertheless, greater exposure to more-intense chemotherapy regimens will likely increase the number of women at risk for persistent problems with pain (related to the accompanying use of growth factors)¹⁰² and memory problems (or chemo brain).¹⁰³ Meanwhile, continued changes in the healthcare delivery system are transforming significantly the availability of and access to resources that have been shown to buffer the adverse effects of care (e.g., access to social support, information and education, and rehabilitation services). In an effort to control rising medical costs and respond to diminished insurance reimbursements, many hospitals and medical centers have sought to decrease the number of patient hospitalizations and length of stay, eliminate or downsize the types of support services as well as the number of social workers in their systems, and shift the delivery of oncology care largely to the outpatient setting.^{104,105} Third-party payers in turn have placed constraints on

patients' ability to use specialized providers and/or services. Combined, these changes in the delivery of cancer care have put enormous pressure on cancer survivors and their family members or caregivers to be more self-sufficient or in some cases to do without the support or services they might wish to have in facilitating optimal recovery.¹⁰⁶ This burden is borne disproportionately by minority and underserved members of our society.¹⁰⁷ Curiously, while research consistently shows that providing education and support is important for survivors' capacity to cope with cancer, access to this help is diminishing.

The implication of these changes for researchers is that what may have been critically important for one cohort of survivors may be less relevant to the next generation of individuals treated. For example, body image was a major focus of research in early studies of breast cancer outcomes when mastectomy was the treatment of choice.⁶⁸ Today, most women have a choice (often involving several options) in how to treat the breast and deal with the cosmetic impact of breast cancer. As a consequence, body image disruption is less salient as either an outcome or research issue. Of more concern is how breast cancer treatment may alter sexual function and/or menopausal symptoms, given that more than 50% of women diagnosed now receive some form of adjuvant chemotherapy or hormonal therapy.¹⁰⁸ Increasingly, researchers are finding themselves caught between the need to identify emerging chronic or late effects of newer therapies and chronicling and addressing the long-term effects of older ones. This dilemma can become problematic if, at review, scientific peers around the table cannot see the relevance of long-term outcomes studies (given this picture), or when forced to make a choice about limited funding dollars, opt to support studies about current therapies only.

Some of the more recently identified "hot" areas of symptom research include a focus on memory problems, fatigue, weight gain, long-term cardiac health, osteoporosis, and persistent pain syndromes (associated with exposure to taxanes and/or use of growth factors). Interest in all these concerns has occurred in direct response to survivors' accounts of specific problems with these conditions (e.g., memory problems, fatigue, weight gain, pain), or clinicians' concerns about known potential toxicities of treatment (e.g., second malignancies, cardiac dysfunction, osteoporosis). As already observed, the recent advances in modern computer and laboratory technology and the associated explosion of discovery in the molecular sciences lend hope that future therapies can be designed to have fewer adverse effects on healthy tissue. Nevertheless, listening carefully to patients' experience of these new approaches is critical if we are to identify and evaluate in future generations of survivors the impact of cancer on health.

On a larger scale, with so many individuals living longer following a diagnosis of cancer, growing attention is being given to researching the efficacy of more generic interventions in improving the future health of survivors, not merely in diminishing their current symptoms. There is a growing movement in particular to develop interventions that include elements with the potential to be generalized to other non-cancer conditions. Two good examples of this are the work being done by Antoni and colleagues in the area of stress management^{109,110} and that of Courneya and colleagues on delivery of physical activity interventions.^{111,112} With the baby boomers fast entering the years of greatest cancer risk, under-

standing the role of comorbidities on cancer outcomes and care is critical to both evaluating and reducing the burden of cancer.^{43,44,113,114} At the same time, a pressing need continues for us to understand the enormous and growing divide between survival—and necessarily the survivorship experience—of our communities of color, low income, low education, and rural status, versus the Caucasian and Asian survivor populations about whom we have the most data.^{83,115}

Development

To accomplish any of this work will take some very specific resources and infrastructure or capacity building. First is access to relevant study samples. A continuing challenge for many researchers is identifying and reaching long-term survivors, in particular those diagnosed more than 5 years earlier.¹¹⁶ Tumor registries can help,¹¹⁷ but loss to follow-up is common. Clinical trials groups, an obvious place to partner to obtain long-term follow-up data, also often lose track of their participants over time.¹¹⁸ The introduction of new federal privacy laws (Health Insurance Portability and Accountability Act, or HIPAA), by requiring individual consent for the conduct of specific studies and data sharing, has made access to survivors and their medical records even more cumbersome. This problem is not unique to the United States.¹¹⁹ Establishment of the NCI-supported Childhood Cancer Survivor Study cohort currently provides a rich resource for survivorship information generated from its ascertained sample of roughly 14,000 survivors of childhood cancer diagnosed between 1978 and 1986 and the companion sample of more than 3,800 siblings.¹²⁰ To date, no such repository exists for survivors of adult cancer.

A second critical need is a steady flow of researchers. Despite the fact that the field of psycho-oncology (or psychosocial oncology), and the more-specific area of posttreatment survivorship research, has grown steadily in the past two decades, the number of researchers devoted to this science is still very limited. Further, there continue to be only a handful of training centers across the country devoted to the education and support of the next generation of researchers invested in survivorship research. With the recent creation of the American Society of Psychosocial Oncology (APOS), now independent from the older International Psycho-Oncology Society, there is hope that this picture may change. Further, the advances in computer technology, use of self-training programs for credit, and online access to a world of expertise may help close this gap in investigator resources. In this regard, APOS and the American Society of Clinical Oncology are pioneering efforts to promote the pursuit of continuing education by members in this and related symptom management and assessment domains.^{121,122} Further, colleagues around the world are beginning to develop programs that promise to ensure a future cadre of talented clinicians and researchers.^{123,124}

A third area of necessary development is on the provider side. Some in the pediatric oncology community have been heard to lament that fewer physicians are choosing to pursue careers in this specialty, assuming (incorrectly) that with survival figures already so high, few challenges or opportunities remain to make breakthroughs in this field. Adult oncology, by contrast, continues to offer diverse challenges; one of these being to better understand the long-term and late

consequences of treatment as a way to improve cancer diagnosis, treatment, and care. Inadequate support for young physicians to engage in research remains a barrier to ensuring more oncologists will seek to expand their expertise in the survivorship arena. In a 2002 review of professional education and training in cancer survivorship commissioned by the National Cancer Policy Board (NCPB), Roger Winn found that although oncology textbooks were beginning to incorporate pieces about this aspect of care (in particular, the incidence and pathophysiology of chronic or late effects), often the material was fragmented and provided few guidelines for evaluation and care. There were, however, notable exceptions to this, including the Harris et al. volume *Diseases of the Breast*, and the monograph produced for the benefit of its members by the American Association of Family Practitioners on *Cancer Survivors*.

The picture in nursing appears to be quite different. Nurses were among the leaders in pioneering psychosocial research and QOL instrument development in cancer.^{51,54-56} In a review also commissioned in 2002 by the NCPB, Betty Ferrell and Rose Virani found that all the major nursing textbooks of oncology nursing had sections or information on cancer survivorship and addressing late and long-term effects of disease. The Oncology Nursing Society has had a Special Interest Group in this area for several years.

Engaging the entire medical community (including nurses, primary care physicians, mental health professionals, and rehabilitation specialists) is necessary to ensure that we ask the right questions in survivorship research and use the best approaches to conduct this science. All this activity will require fiscal resources. Already there has been a rapid growth in the number of federal dollars being expended on survivorship research. This amount of money remains small, nevertheless, when compared to that being invested in cancer biology, detection, and treatment. In 2003, the OCS supported \$17 million in grant-related research; NCI-wide investment in survivorship research, broadly defined to include studies among individuals across the survivorship continuum from diagnosis to end of life, was estimated at \$160 million, less than 4% of the NCI budget for that year. Further, the end of the doubling of the NIH budget with FY 2004 and expected spending limits projected for the near future threaten to make competition for this still-nascent area of research a critical source of challenge.

On the positive side, a number of additional funders committed to supporting research on survivors' outcomes have appeared on the scene; these include the Lance Armstrong Foundation, the Avon Foundation, the Susan G. Komen Foundation, and the California Breast Cancer Research Program. Recently reframed as constituting a public health issue,³⁴ cancer survivorship is also beginning to appear on the agenda of the Center for Disease Control and Prevention. In addition, as noted earlier, Congress has put forward a number of bills in the past 2 years indicating their intention that the NIH in general and NCI in particular continue to invest in this science. The creation of the Office of Cancer Survivorship at the NCI provided a critical infrastructure and platform from which to oversee, track, and direct cancer survivorship research at the Federal level. Its existence within the NCI serves as a reminder of the importance of this aspect of the cancer control continuum both across NCI and nationally. Staff from the CDC, National Association of American

Cancer Registries, ACS, NCI, and American College of Surgeons recently put forward recommendations for elements of the framework necessary to move cancer control forward in the next 20 years.¹²⁵ Similarly, members of NCI's Division of Cancer Control and Population Sciences have outlined where we need to go in the future to advance quality of cancer care across the continuum.¹²⁶

Delivery

The final challenge faced is how best to disseminate and use the information gleaned from the growing body of cancer survivorship research. To date, this process has been painstakingly slow, in particular in the adult oncology arena. Delivering on what we already know represents, both historically¹²⁷ and at the present time, the least developed area of cancer survivorship research and constitutes one of the most significant challenges for the future.¹²⁸⁻¹³⁰ This problem is well illustrated in a recent publication of the Institute of Medicine (IOM) entitled *Meeting the Psychosocial Needs of Women with Breast Cancer*.¹³¹ In this volume, the multiple authors provide a wealth of evidence indicating that we already understand the kinds of problems faced by women treated for this disease, the handful of risk factors that increase risk for poor QOL, and the types of interventions that may help improve women's outcomes. Translating this into practice remains the biggest hurdle. This need includes educating healthcare providers about the psychosocial and behavioral effects of cancer and training them to incorporate psychosocial concerns into standard treatment planning and posttreatment monitoring, as well as designing and funding healthcare delivery systems that support this activity.¹²⁸ It is of note that, even in the nation's comprehensive cancer centers, programs for survivors who have completed their cancer therapy remain limited.¹³² In addition, in many of these centers, researchers engaged in survivorship research are not routinely connected with the clinics or care centers.

These same kinds of struggles play out differently in the area of childhood cancer. In pediatrics, attention to the "total child" and his or her family is simply part of standard care.¹³³ Further, most pediatric care, whether in the cancer or non-cancer setting, is designed around promoting normal development and preventing or minimizing risk of disease. Pediatric oncologists, perhaps because of the dramatic advances made in curing childhood cancers, have been at the forefront of efforts to tailor therapies to reduce morbidity without compromising cure. For example, once trials began to show that use of central nervous system prophylaxis dramatically altered the survival for children with ALL in the late 1960s and early 1970s, clinicians quickly turned their attention to finding less-toxic ways to provide this coverage that would eliminate the need for or reduce the dose of cranial radiation to which children would be exposed.³⁷ Equivalent evidence for this approach in adult oncology is harder to identify. The movement away from more-radical excisions to greater tissue-sparing approaches to surgery, as seen in breast and colorectal cancer, are good examples of efforts to modify treatment to improve QOL without adversely affecting cure. These surgical oncology examples notwithstanding, the general trend in adult oncology remains heavily focused on delivering more, not less, treatment, even if the length of time over which these therapies are administered is shrinking.

More recently, both the pediatric and adult oncology communities have engaged in efforts to decide how best to follow themselves, or engage the larger adult healthcare delivery system to care for, the growing population of young and maturing adults previously treated as children.^{134,135} The Children's Oncology Group (COG) has taken a leadership role in shaping this effort. In spring 2004 COG publicly released the first set of comprehensive, long-term follow-up guidelines.¹³⁶ Unique to this document is its attention to the long-term and late sequelae of curative therapies. Unlike currently available guidelines for adult survivors who are posttreatment (e.g., as developed by ASCO, American Society of Clinical Oncology, and NCCN, National Comprehensive Cancer Network) that focus exclusively on cancer surveillance, the childhood cancer follow-up guidelines are constructed around identification and management of risk-based, exposure-related problems that may be screened for and potentially addressed after treatment. Largely unknown is how nononcology professionals view and care for the survivors in their patient population.¹³⁷ What evidence we have suggests that many survivors are not receiving care that might be expected for peers without a cancer history.^{38,59,138,139} In this regard, data from two NCI-led SEER-based research studies on hematologic (non-Hodgkin's lymphoma, NHL) and selected solid tumor (breast, colorectal, prostate, gynecologic) survivors' experience of posttreatment care that will be available starting in 2005 should be informative.

A final criterion for the success of what one might call the cancer survivorship research enterprise is whether it is having an impact on the outcomes of present and future survivors and/or their families and caregivers. This aspect of survivorship research is as yet the least developed of all. Benchmarks for success exist in other realms of cancer control. For example, one can track the reduction in smoking rates to assess prevention efforts, the uptake of screening modalities (e.g., mammography, colonoscopy) by the appropriate populations to monitor inroads in promoting early detection, and survival curves to determine global cancer control. However, it is not clear what the markers of success are for improved survivorship (not to be confused with survival) outcomes.¹⁴⁰ Should this be return to school for children? Return to work for younger adults? Self-reported QOL compared to the general population for cohorts of survivors? Decrease in medical care use among survivors receiving a supportive intervention? If we have learned anything from survivors it is that being disease free does not mean being free of your disease. It is not enough to cure or enable individuals to live long term with a chronic illness without attending to what they are being returned. Because so many cancer survivors are older and present with a history of other comorbid conditions and experience, determining and alleviating what may be the unique burden of cancer is an area that remains to be fully addressed.^{44,113,114,141} At a minimum, we need to be able to provide more than an estimate of the number of individuals who are living beyond a diagnosis of cancer. Finding ways to quantify how those individuals are faring in the main, and where they are on the cancer trajectory (i.e., recently diagnosed, in active treatment, posttreatment, living with or dying of progressive disease) is critical, particularly if we are to establish benchmarks against which to measure our progress. Efforts to do this are under way in Europe¹⁴² and here in the United States.^{143,144}

In summary, the evidence is clear that cancer survivorship, once merely a nascent field, is fast entering its adolescence, its pace of maturation driven by the progress made in controlling the many diseases we call cancer. Although still modest for most cancers, the body of research identifying the long-term and late effects of illness, as detailed in Chapter 101 by Aziz in this volume, is growing rapidly. At the same time, investment in the study of interventions to eliminate or reduce adverse cancer- or treatment-related outcomes is increasing. The cancer advocacy community has matured and provides an invaluable resource for ensuring continued attention to survivorship issues.¹⁴⁵⁻¹⁴⁷ However, it is becoming apparent daily that improvements in cancer survivors' outcomes will likely be affected most by what happens to our healthcare delivery system in the years to come. We already know a great deal about what harms or helps those diagnosed and treated for cancer; delivering on the promise of care that conforms to that knowledge should be our most significant overarching goal for the foreseeable future.

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