Cancer Survivors: A Booming Population

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Abstract

Background: In this first article of what is planned to be an annual series, we examine the history of cancer prevalence reporting and the role that these annual figures play in guiding the direction of cancer control research, and specifically the science of cancer survivorship. For this inaugural year, we focus on the confluence of the growing number of survivors and population aging, and the impact these combined trends will have on cancer survivorship in the future.

Methods: State or metro area-level cancer incidence and prevalence data were collected from 9 registries via the Surveillance, Epidemiology, and End Results Program. The complete prevalence method was used to estimate prevalence for 2008 and the Prevalence, Incidence Approach Model method was used to project prevalence data through 2020, assuming flat cancer incidence and survival trends but dynamic U.S. population projections.

Results: As of January 2008, the number of cancer survivors is estimated at 11.9 million. Approximately 60% of cancer survivors are age 65 or older, and by the year 2020, it is estimated that 63% of cancer survivors will be age 65 or older.

Conclusions: Improved survival and population aging converge to generate a booming population of older adult cancer survivors, many of whom have multiple complex health conditions and unique survivorship needs. This demographic shift has important implications for future health care needs and costs of the U.S. population.

Impact: The findings provide information critical for guiding cancer prevention and control research and service provision. Cancer Epidemiol Biomarkers Prev; 20(10); 1996–2005. ©2011 AACR.

Introduction

In this first article of what is planned to be an annual series, we examine the history of U.S. cancer prevalence reporting, and the role that these annual figures can play in guiding the direction of cancer control research more broadly, and the science of survivorship specifically. In each of these annual summaries, we will select a special topic of focus. For this inaugural year, the special emphasis for our analysis is on the confluence of the growing number of survivors, and the impact that the aging of our population will have on cancer survivorship in the future.

History of cancer prevalence

For the past 38 years, the nation has looked to the National Cancer Institute (NCI), or more specifically to the NCI supported Surveillance Epidemiology, and End Results (SEER) tumor registry program, to provide information regarding the success of collective efforts to reduce the national burden of cancer. Launched in 1973 as part of President Nixon’s 1971 National Cancer Act, the SEER program began collecting data on cancer cases in the states of Connecticut, Hawaii, Iowa, New Mexico and Utah, and from 2 large metropolitan regions, Detroit and San Francisco, Oakland. Today, the program includes data from all of the original sites along with those from Atlanta, Alaska, Arizona, all of California, rural Georgia, Kentucky, Louisiana, New Jersey, Seattle-Puget Sound that combined, represent approximately 28% of the U.S. population. For greater detail about the SEER program, please refer to the following brochure (1).

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population-based cancer registries, for 2 reasons. The first is that not all registries have been collecting cancer diagnosis data long enough to capture all prior cancer diagnoses and include long-term survivors. Hence, estimates using case data from these sources could only be used to provide limited duration prevalence. The second challenge is that most cancer registries are primarily mandated to collect incidence data, and so principally collect information at diagnosis. Follow-up data collection procedures to capture vital status require additional effort. Passive follow-up techniques include linkages to state and federal mortality data, local administrative sources such as voting records, federal systems like social security death claims or Centers for Medicare and Medicaid Services, and other sources. When information is unavailable from these linkages, some registries engage in active follow-up, making an effort to contact survivors, next of kin, physicians, or other cancer registry reporting sources to acquire information about whether these individuals are still alive or have since died. Few people realize that for many years, complete prevalence was actually generated from one registry only: Connecticut. The reason for this is that the Connecticut tumor registry has the longest continuous U.S. history, having been in existence since 1935 with electronic data available since 1950. Most of the other SEER registries were established in the 1970s and later; thus, information on survival available from these sites was based on shorter follow-up times and could not capture longer-term survivors (or those diagnosed before 1975).

With the establishment of NCI’s Office of Cancer Survivorship (OCS) in 1996, growing attention has been paid to the lives and care of those living years after cancer treatment. In an effort to better describe this growing population, members of OCS worked with colleagues in NCI’s SEER program to promote the development of statistical models that would permit use of the full set of SEER registry cases to estimate national cancer prevalence (2–5). The first figures using this larger data set to project complete prevalence were released in 2002 (6). Data for the most recent prevalence figures from 2008, and methods used to generate these annually, are provided in detail below.

Why focus on aging?

Age is the single most important risk factor for developing cancer (7). This effect is well illustrated in Figure 1 (8). For the majority of the most common cancers, more than half of cases occur in individuals who are 65 year or older at the time of diagnosis: for example, 68.5% of lung cancer, 66.8% of colon cancer, and 59.6% of prostate cancer cases occur in older adults. Exceptions to this pattern are breast cancer and ovarian cancer, in which the majority of cases occur in individuals under the age of 65 years.

The aging of the baby boomer generation (those born between 1946 and 1964), the first wave of whom started turning 65 on January 1, 2011, promises to expand our survivor population and to elevate the importance of understanding and addressing the needs of older cancer survivors. In 2008, an estimated 39 million U.S. citizens (13%) were 65 years or older (9). By the year 2030, this proportion is projected to increase to 19.3% (10, 11). Moreover, the segment of the population 85 and older
(the “oldest old”) is expected to more than triple in size between 2008 and 2050: from 5.7 million to 19 million people (11). These trends have sobering implications for health care delivery for 2 reasons: the imminent volume of demand, and the complexity and costs associated with treating the concurrent health burden associated with the prevalence of chronic illness and cancer in older adults.

Older adult cancer survivors may evidence psycho-social adaptation comparable with their age-matched peers and often show greater resilience than younger cancer survivors (12, 13). However, they may also experience greater illness burden, in part because of concurrence of comorbid conditions and cancer. A cancer diagnosis is likely to coexist with other chronic conditions in the older adult population, as 80% of older adults have at least 1 chronic health condition and 50% have at least 2 chronic conditions (9). The most common chronic conditions in older adults include hypertension, arthritis, cancer, and diabetes (10). In addition, approximately 27% of adults aged 60 or older are obese, and 38% report having a disability (10). This morbidity profile is reflected in medical costs: the costs associated with cancer care totaled 124.57 billion U.S. dollars in 2010 (14), and the treatment and management of chronic illness accounts for roughly 95% of health care expenditures in older adults (15).

In addition to their independent effects on health outcomes and health care costs, cancer and chronic illness may interact to adversely affect health and psychosocial outcomes in older adult cancer survivors. Coexisting cancer and chronic conditions may limit the intensity and duration of cancer treatment (16–19), be related to poorer survival (20), and put survivors at higher risk for exacerbation of comorbid conditions or declines in physical functioning posttreatment (16, 21, 22). These outcomes may render survivors in greater need of support services, and/or generate concerns about loss of independence (23). Although not yet well understood, the interaction of cancer and chronic illness is an increasingly important area that will shape cancer survivorship and service delivery in years to come, especially among the older adult population.

Finally, increased survival and older age are accompanied by greater risk for developing subsequent cancers. SEER registry data from 1975 to 2001 indicate that nearly 8% of the current cancer survivor population has a history of more than 1 cancer (24). Further, findings from this report revealed that roughly 16% of newly diagnosed cancer cases occur in individuals with a prior cancer history and the prevalence of multiple cancers increases with age. Whereas multiple cancers by age group are less than 1% for survivors aged 19 and younger, the prevalence data show an upward trend across the life course: 2.6% (ages 20–49), 4.7% (ages 50–59), 7% (ages 60–69), 10% (ages 70–79), and 12.1% for survivors aged 80 and older (16). For these compelling reasons, attention in this report of the 2008 annual prevalence figures is given to the impact of aging on survivorship trends.

Materials and Methods

To estimate U.S. complete prevalence, that is, the number of people in the United States ever diagnosed with cancer that were alive on January 1, 2008, the latest incidence and follow-up data on individuals diagnosed with malignant cancer between 1975 and 2007 were obtained from the 9 SEER registries that have the longest follow-up periods and cover approximately 10% of the U.S. population: Atlanta, Connecticut, Detroit, Hawaii, Iowa, New Mexico, San Francisco, Oakland, Seattle-Puget Sound, and Utah.

U.S. complete prevalence is estimated through a 3-step method. In this method, we first calculated 33-year limited duration cancer prevalence by counting the number of individuals diagnosed during 1975 and 2007 alive at January 1, 2008 in the SEER-9 areas. This method includes adjustment for cancer patients lost to follow-up. To include long-term survivors, people diagnosed with cancer prior to 1975 and still alive at January 1, 2008, the Complete Prevalence (COMPREV) method was used. This method fits parametric models to incidence and survival data from the SEER registry and extrapolates into the past to estimate the proportion of survivors alive who had been diagnosed prior to the first diagnosis date in the dataset (January 1, 1975). Finally, we applied these estimates to the entire U.S. population, while controlling for age, sex, and race. Population size was based on an average of the 2007 and 2008 U.S. population data. The final figures represent U.S. complete prevalence estimates, or the number of people ever diagnosed with cancer and alive on January 1, 2008 regardless of how long ago the diagnosis was made, characterized by current age, sex, time since diagnosis, and cancer site.

This 3-step approach for the estimation of U.S. cancer prevalence is the chosen method for the reporting and monitoring of cancer prevalence because it uses fewer assumptions than methods that project prevalence into the future and more closely approximates the observed data. A different method is used for cancer prevalence projections. The Prevalence, Incidence Approach MODel (PIAMOD; ref. 25) method projects prevalence by fitting models to cancer incidence, cancer survival, and mortality for other causes of death data. In a recent publication (14), this method was used to provide projections of cancer prevalence through 2020. These prevalence projections include nontumor cancers, with the exception of nonmalignant cervical cancer and benign brain cancer. Because the PIAMOD method fits models to incidence and survival data it provides prevalence estimates and projections that incorporate past observed trends but also allow for projections using various assumptions about future incidence and survival trends. In this article, we present prevalence projections from 2010 through 2020. These projections use dynamic U.S. population projections from the U.S. Census Bureau and are based on the assumption that future cancer incidence and survival trends remained the same as observed in the last years.
of data collection. For more details on the methods please refer to Mariotto and colleagues (11).

**Results**

Figure 2 shows the estimated number of cancer survivors in the United States between the years 1971 and 2008 (26). Graphically illustrated in this figure is the steady upward trend in the number of those living with a cancer history, culminating in an estimated 11.9 million cancer survivors as of January 1, 2008. Since 1971, when the “war on cancer” was launched, there has been an almost 4-fold increase in the number of survivors. This increase is a testament to the many advances in cancer detection, treatment, and supportive care in the intervening decades.

Of these 11.9 million men and women, the majority were diagnosed more than 5 years ago. Impressively, approximately 15% were diagnosed more than 20 years ago (Fig. 3; ref. 26).

The most common diagnoses among cancer survivors include female breast cancer (22%), prostate cancer (20%), and colorectal cancer (9%), followed by gynecologic (8%) and hematologic (8%) cancers. The most common tumor sites for women (all ages) included breast (41%), corpus or uterus (9%), and colorectal (9%) cancer. The most common tumor sites for men (all ages) included prostate (43%), colorectal (10%), and hematologic (10%) cancers. It is important to note that despite being the most commonly diagnosed cancer for both sexes, lung cancer represents only 3% of the prevalent population, a reminder that this disease remains a continuing challenge for cancer control science. The distribution of cancer prevalence by age, gender, and type of cancer is provided in Table 1.

Approximately 60% of cancer survivors alive in the United States in 2008 were older adults, aged 65 or older (see Fig. 4); 13% were aged 65 to 69, 25% were aged 70 to 79, and 22% were aged 80 or older. The most common cancer sites diagnosed in older adults are lung, prostate, and breast cancer (7). Those diagnosed between birth and age 49 represent only 13% of the prevalent population; individuals aged 50 to 64 account for another 27%.

Figure 5 shows the projected number of those 65 years and older with a history of cancer (including nonmalignant cancers with the exception of nonmalignant cervix cancer and benign brain cancer) from 2010 through 2020 (26). The projections presented above suggest these numbers may reach an estimated 11 million survivors aged 65.
Table 1. Complete prevalence counts by age, gender, and site at January 1, 2008 (invasive/1st primary cases only, n = 11.9 M survivors; ref. 7)

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<th>15-19</th>
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<td>44,503</td>
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and older by 2020. These numbers represent a 42% increase in the number of older adult survivors in a relatively brief historical timeframe (2010–2020). As discussed in the introduction, the years 2030 to 2050 are expected to witness the most marked increase in the number of cancer survivors aged 65 and older in U.S. history. The potential magnitude of the impact of the rapidly growing population of older adult cancer survivors on health care delivery systems, and the associated cost of their care, is sobering (8, 14).

Finally, with length of survival increasing, not only can we expect to see older adults living longer with a cancer history but also we will see younger adults aging with such a history. Figure 6 shows the number of survivors aged 65 and older in different phases of care: initial (the first year after diagnosis), the last year of life, and continuing (the care phase in between; refs. 8, 14). The largest increase in the 65 and older survivor population will be for

Table 1. Complete prevalence counts by age, gender, and site at January 1, 2008 (invasive/1st primary cases only, n = 11.9 M survivors; ref. 7) (Cont’d)

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<tr>
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* = not applicable.

Figure 4. Estimated number of persons alive in the U.S. diagnosed with cancer on January 1, 2008 by current age (invasive/1st primary cases only, n = 11.9 M survivors; ref. 23).

Figure 5. Estimated number of persons with a history of cancer from 1971 to 2008, by age group, projected through the year 2020 (3, 7).
those in the continuing phase of care, the period commonly referred to as the survivorship period.

Discussion

Overall prevalence rates among cancer survivors continue to rise. Forty years after the passage of the National Cancer Act, we have witnessed a 4-fold increase in the number of U.S. cancer survivors from 3 million to close to 12 million. Advances in the treatment and early detection of cancer, in concert with increased life expectancy and a growing aged population are contributing to the rising number of cancer survivors in the United States. The projections reported here represent the most recent data on cancer prevalence and aging and provide projections of the number of older adult cancer survivors through the year 2020. The findings suggest the coming decades will witness a significant increase in the number of those aged 65 and older living long term with a cancer history. By the year 2020, an estimated 11 million survivors will be older adults, representing a 42% increase in their numbers in just 1 decade (2010–2020). Moreover, as shown in Figure 6, the majority of these individuals will be in the survivorship phase following treatment, disease-free or managing chronic conditions, both of which require surveillance and delivery of follow-up care. These trends have important implications for research and planning for future health care needs.

Older adults are an overlooked, understudied, underserved, and vulnerable group of cancer survivors. In an internal 2009 portfolio analysis of NIH-funded grants addressing survivorship outcomes, fewer than 10% of identified studies focused exclusively on the health and well-being of individuals aged 65 and older. Although the number of grants focused on the health and well-being of older adult survivors has been rising slowly, it remains low relative to the number of studies conducted among younger survivor populations. Prospective epidemiologic studies of older adult survivor populations are urgently needed. We need to know if older adults’ posttreatment health profiles and patterns of persistent and long-term cancer-related effects differ markedly from those of younger survivors or older adults’ peers unaffected by cancer. How do the presence and progression of preexisting comorbid conditions and age-related health declines interact with the chronic and late effects of cancer? Do interventions addressing the chronic and late effects of cancer developed with younger survivors work for older adult survivors? Prospective data collection and systematic surveillance of cancer care delivery patterns in older adult cancer survivors are also needed. Is the follow-up care received by older survivors different than that for younger survivors and what are the ramifications of this on patterns of morbidity and mortality? These data should include population-based studies, case–control studies, and intervention trials, and should represent research conducted at both NCI-designated comprehensive cancer care settings and community-based settings (27). Within studies of cancer survivors, population-based data (such as that collected by cancer registries) should consider inclusion of comorbidity as a standard data element (20). More cancer clinical trials are needed that include adults age 65 and older, many of whom may have preexisting health conditions and functional limitations, and are often excluded from cancer-related research studies and therapeutic trials specifically (28). These will require trial designs that include and thoughtfully consider the effects of concurrent health conditions, rather than exclude them (29, 30). Clinical trials specifically tailored to older adults are also needed to identify which older adults are at greatest risk for declines in health and psychosocial well-being, to assess treatment tolerance, and to develop and test rehabilitation interventions to help older adults regain functionality after cancer treatment (27).

From a conceptual standpoint, future research on older adults cancer survivors should seek to (i) include psychosocial, behavioral, physiologic, and health services outcomes; (ii) span the survivorship continuum (from primary to quaternary prevention; ref. 31); (iii) differentiate age, period, and cohort effects (23); and (iv) explicitly attend to the heterogeneity and diversity of the older adult cancer survivor population. Older adults are a diverse population across physical, social, psychologic, economic, and cultural dimensions (32, 33). Further, the expectations of the Baby Boomer generation of older adults for “adequate functional status” may be drastically different from the expectations of previous generations. Given this heterogeneity, assessment of functional status, cognitive status, lifestyle behaviors, health-related quality of life, and social support is likely to provide more useful markers for cancer-related outcomes, surveillance, and follow-up care needs than chronological age alone. Beyond inclusion of the areas and topics suggested above, it is critical that psychosocial, behavioral, and biomedical knowledge be integrated in future research and translated expeditiously into practice (34, 35).
The data reported in this article have important implications for health services delivery. As reported by Mariotto and colleagues (11), the current costs associated with cancer care are estimated at 157.77 billion 2010 U.S. dollars, with the potential to reach 173 billion U.S. dollars by the year 2020. The aging of our population contributes significantly to these estimates. The interaction of chronic and late effects of cancer with extant or developing comorbid conditions may lead to more complex medical and psychosocial care needs among older cancer survivors. Because older cancer survivors are likely to be receiving care from multiple providers, they may be exposed to additional risks associated with fragmented care provision (36) and polypharmacy (37, 38). Current approaches to improving the quality of care during and after treatment involve the use of treatment summaries and care plans, shared care models for posttreatment health care delivery, cancer navigator models, and electronic health records to promote information exchange (39, 40). To effectively meet the needs of older adults, models for best practice in cancer care will need to address not only the communication and coordination of care on the provider side of the equation, but also on the consumer side. Efforts will be necessary to empower and facilitate older adults’ ability to get their needs met in a fragmented system where mastery of a daunting new array of modern electronic tools (electronic health records, personal data chips, internet use, PDA technology) may be critical to successfully navigating the multiple disciplines and specialties of medicine typically accessed by older adults. Provision of high-quality care for older adult survivors may require adoption of new metrics and strategies. These include the use of geriatric assessments of health and quality of life, the development of geriatric cancer rehabilitation programs, and the development of multidisciplinary teams with expertise in older adults’ complex and unique needs. Optimally, these teams will include geriatric specialists in social work, psychology (or neuropsychology), nursing, rehabilitation, and oncology, along with geriatricians. Health services delivery systems face stark challenges as the increasing prevalence of older cancer survivors is accompanied by impending workforce shortages in social work, oncology, and geriatrics (41, 42). Shared care and multidisciplinary models offer a means of more efficiently utilizing the skills of these providers.

**Strengths and limitations**

Among the strengths of this inquiry are its generation of U.S. population-based cancer prevalence rates using an innovative algorithm to impute and estimate U.S. prevalence counts and proportions from the most established and highest quality SEER-9 registries, representing approximately 10% of the U.S. population. The findings in this report are subject to a few limitations. First, the aging of the U.S. population makes the greatest contribution to increasing cancer prevalence. Fourth, we were unable to specify whether a survivor was cured, in active therapy, living with a chronic illness or disability, or dying from cancer. Finally, what these prevalence figures do not tell us is the health status of those who are survivors at any given point in time. This is an enduring and troublesome limitation of the current SEER resource platform.

**Summary**

The observed trend of increasing cancer prevalence rates is expected to continue. This trend is compounded by the anticipated growth in the proportion of cancer survivors who are age 65 and older, many of whom may be expected to have concomitant and complex issues associated with aging. If we are to successfully reduce the burden of cancer in the United States, a concerted effort is needed to better describe this growing population, to define and refine standards of quality care for older adults with cancer, and to develop delivery systems that reflect the multifaceted needs of this diverse and vulnerable population.

**Disclosure of Potential Conflicts of Interest**

No potential conflicts of interest were disclosed.

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