

Equitably Improving Outcomes for Cancer Survivors and Supporting Caregivers: A Blueprint for Care Delivery, Research, Education, and Policy

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Abstract: Cancer care delivery is being shaped by growing numbers of cancer survivors coupled with provider shortages, rising costs of primary treatment and follow-up care, significant survivorship health disparities, increased reliance on informal caregivers, and the transition to value-based care. These factors create a compelling need to provide coordinated, comprehensive, personalized care for cancer survivors in ways that meet survivors' and caregivers' unique needs while minimizing the impact of provider shortages and controlling costs for health care systems, survivors, and families. The authors reviewed research identifying and addressing the needs of cancer survivors and caregivers and used this synthesis to create a set of critical priorities for care delivery, research, education, and policy to equitably improve survivor outcomes and support caregivers. Efforts are needed in 3 priority areas: 1) implementing routine assessment of survivors' needs and functioning and caregivers' needs; 2) facilitating personalized, tailored, information and referrals from diagnosis onward for both survivors and caregivers, shifting services from point of care to point of need wherever possible; and 3) disseminating and supporting the implementation of new care methods and interventions. **CA: Cancer J Clin 2019;69:35-49. © 2019 American Cancer Society.**

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Rising Numbers of Cancer Survivors

More than 1.7 million Americans are expected to be diagnosed with cancer in 2018 (Fig. 1).^{1,2} This number of new cancer cases in America continues to increase each year despite declining incidence rates in men and stable rates in women³ as a result of population growth and aging. The rising cancer case burden as well as advances in early detection and treatment⁴ all contribute to an unprecedented and continuing rise in the number of Americans living with a history of cancer, a group referred to as *cancer survivors*. Although 5-year survival rates vary substantially by type of cancer (Fig. 1),^{1,2} many survivors are living years beyond their disease. Of the nearly 15.5 million cancer survivors, 67% were diagnosed 5 or more years ago, and 17% were diagnosed 20 or more years ago.⁴

Demographic shifts are expected to shape the numbers of survivors dramatically in the near future. With population aging and growth, the number of American cancer survivors is projected to rise to 20.3 million in 2026 and to 26.1 million by 2040.⁵ The aging US population also will result in increases in the number of older cancer survivors: 73% of survivors will be age 65 years or older by 2040, up from 62% in 2016.⁵ The increase in the number of older adults with cancer has implications for the delivery of oncology and posttreatment follow-up care, because older adults are likely to need management of multiple comorbid conditions concurrent with their cancer-specific care.⁵

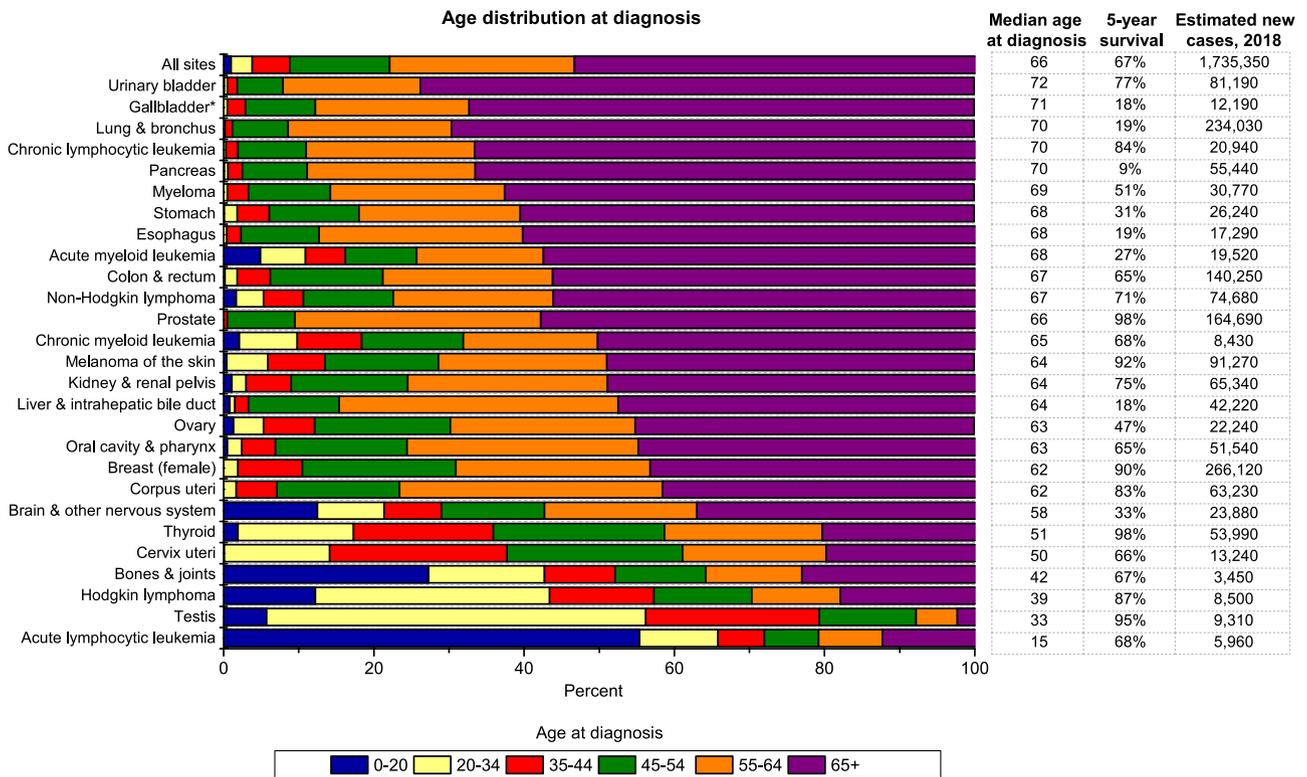


FIGURE 1. Age Distribution (%), Median Age at Diagnosis, 5-Year Relative Survival, and Estimated Number of New Cases by Cancer Type. Cancer types are ranked in descending order of median age at diagnosis. Age distribution and median age at diagnosis are based on patients who were diagnosed during 2011 through 2015 in the Surveillance, Epidemiology, and End Results (SEER) program. Five-year relative survival is based on patients who were diagnosed in the SEER program during 2008 through 2014, all of whom were followed through 2015. An asterisk indicates that a new case estimate includes other biliary sites. Data sources: Age distribution, median age at diagnosis, and 5-year relative survival: Noone AM, Howlader N, Krapcho M, et al, eds. SEER Cancer Statistics Review, 1975-2015. Bethesda, MD: National Cancer Institute; 2018.² Estimated new cancer cases in 2018: Siegel RL, Miller KD, Jemal A. Cancer statistics, 2018. *CA Cancer J Clin.* 2018;68:7-30.¹

The sociodemographic *composition* of survivors is expected to change as well. The number of racial/ethnic minority individuals in the United States is projected to rise from 125 million in 2016 to 157 million in 2030, relative to flat numbers for the non-Hispanic white population.⁶ Correspondingly, the annual number of new cancer cases diagnosed among individuals from racial/ethnic minority groups is expected to rise rapidly compared with the case burden in non-Hispanic whites.⁷ Survivors, including the socioeconomically disadvantaged, some racial/ethnic minorities, the uninsured/underinsured, immigrants, and sexual minorities, face poorer health outcomes because of informational, structural, financial, and other barriers to appropriate, timely, and effective cancer treatment; suboptimal patient-provider communication; inadequate supportive resources; poor access to comprehensive cancer centers; and low access to and awareness of health information resources.⁸ Although disparities, such as those in cancer mortality by race/ethnicity, have narrowed for older adults who presumably have access to medical care through Medicare, the mortality gap remains high for racial/ethnic minorities younger than 65 years.¹ Future demographic shifts will

heighten the need for focused strategies that effectively address the unique needs of underserved survivors, especially those younger than 65 years, who are highly vulnerable to poor outcomes.²

The Growth of Cancer Survivorship Research

The increasing number of survivors who live longer after their diagnosis has spurred growing interest in survivorship research describing and addressing their ongoing issues and health care needs and the needs of informal cancer caregivers.

Survivorship research has shown that the time from diagnosis through initial treatment is especially stressful for survivors. Pain, fatigue, and emotional distress are the most common symptoms across cancer diagnoses⁹ along with impaired physical functioning and reduced quality of life.⁹ Research has documented the impact of cancer and treatment on 4 domains of survivors' well-being, including physical, emotional, social, and spiritual.⁹ Physical well-being is affected by symptoms and side effects, such as pain, fatigue, and poor sleep quality, that affect the ability to perform normal daily activities. Emotional, or psychological, well-being is affected by symptoms of anxiety, depression,

fear of cancer recurrence, and problems with memory and concentration. Social well-being is affected by changes in relationships with family members and friends, including intimacy and sexual functioning, and by employment, insurance, and financial concerns. Spiritual well-being is affected by facing uncertainty about one's future health or drawing meaning from the cancer experience. Survivors who were diagnosed during childbearing years face additional concerns about balancing and timing their desire to preserve fertility with their decision making about cancer treatment.¹⁰

Problems in these quality-of-life domains interact to impair survivors' ability to function sufficiently to participate fully in work and life roles: 37% of adult survivors report restrictions in performing basic activities of daily living, and 55% report restrictions in performing instrumental activities of daily living (those activities that allow them to live independently).¹¹ The impact of cancer is worse for older survivors, among whom 64% report functional limitations that affect their mobility or activities of daily living.¹² Socioeconomically disadvantaged survivors are particularly vulnerable to poor quality of life, because poor access to health care hinders access to symptom management and receipt of effective treatment.^{13,14} When left unaddressed, these problems lead to reduced work productivity,^{15,16} quality of life,^{12,17} and overall survival.¹⁸ Survivors who are coping with advanced cancer¹⁹⁻²² report ongoing symptom burden and poor physical functioning that affects quality of life.^{23,24} This research has led to recommendations to facilitate referrals for early access to palliative care²⁵ and rehabilitation care^{26,27} that can improve quality of life.

Those survivors who transition out of active treatment frequently feel unprepared for what they will face.^{28,29} Peer modeling and psychoeducation have been shown to help manage symptoms for survivors who feel unprepared for reentry.³⁰ However, a minority of survivors report chronic physical and emotional symptoms and functional problems^{9,31}: over 25% of survivors report high symptom burden a year after diagnosis.³¹ Fear of cancer recurrence, the most common concern of cancer survivors,⁹ can be sufficiently severe to require clinical intervention and can negatively influence health behaviors and health care utilization.^{32,33} Other symptoms include anxiety, fatigue, lymphedema, depression, pain, impaired cognition, and loneliness.^{9,31,34} Although 25% of all cancer survivors report decreased quality of life because of physical problems, and 10% report decreased quality of life because of emotional problems,³⁵ there are significant disparities in the burden of these problems. . Survivors with lower income, less education, or more comorbid conditions; those who are unemployed; and those who are uninsured or underinsured have higher ongoing

symptom burden.³¹ Survivors who are from racial/ethnic minority groups or are socioeconomically disadvantaged and those with more comorbid conditions report worse quality of life.^{36,37}

In addition to ongoing symptoms and functional impairment after the successful completion of anticancer treatment, survivors are at increased risk for several cancer-related issues. For many cancer survivors, the initial course of treatment is successful, and the cancer never recurs.⁴ However, many survivors are at increased risk of developing new cancers compared with those who were never diagnosed with cancer,³⁸ depending on first primary cancer site, treatment type(s), and individual factors (eg, age at diagnosis), personal or family medical history, genetic predisposition (eg, Lynch syndrome), smoking status, or obesity.³⁸ Second and subsequent primary cancers are of particular concern among childhood and adolescent cancer survivors because of their longer life expectancy and the effects of treatments used for common childhood cancer types on developing organs and tissues. For example, in one large US cohort study of childhood cancer survivors who survived at least 5 years, 7.9% developed a new cancer within the first 30 years after initial cancer diagnosis.³⁹ In addition to new cancers, survivors also may experience late effects of treatment that do not appear until many years later, such as bone loss, endocrine or cardiovascular dysfunction, musculoskeletal problems, and others.⁹ For example, adult breast cancer survivors are commonly treated for several years with hormonal therapies, which are associated with hot flashes and a long-term increased risk of bone loss, osteoporosis, fractures, joint pain, blood clots, and stroke as well as endometrial cancer.⁴⁰ Prostate cancer survivors often receive long-term androgen deprivation therapy, which causes hot flashes, muscle atrophy, sarcopenia, and cognitive difficulty; increases risk of the metabolic syndrome and diabetes; and substantially increases risk of cardiovascular disease.⁴¹ Chemotherapy, including anthracyclines or chest radiation, can increase risk of cardiovascular disease in survivors of several cancers.⁴²

The cumulative impact of these chronic and late effects of cancer may represent an acceleration of normal aging or the accumulation of comorbid diseases at an earlier age than their peers without a cancer history.^{43,44} A significant number of long-term survivors (5 years or more), especially those who had more invasive and aggressive treatments, report lower overall physical well-being than their peers.⁴⁵ Over 50% of adult cancer survivors⁴⁶ and 65% of older adult survivors¹² experience persistent functional limitations many years beyond treatment. These decrements in functioning affect survivors' ability to work⁴⁷⁻⁵¹ and increase health care utilization and costs.⁵²

TABLE 1. Estimates of the Prevalence (%) of Childhood Cancer Survivors With Specific Comorbidities by Age Range^a

COMORBIDITY	PREVALENCE, %		
	AGES 20-29 YEARS	AGES 30-39 YEARS	AGES 40-49 YEARS
Impaired cognitive function	40	34	33
Compromised HRQOL-mental	20	18	16
Impaired mental health	18	17	16
Anxiety	13	13	14
Functional impairment	13	13	17
Limitations in activity	12	14	21
Poor general health	11	14	17
Compromised HRQOL-physical	10	16	23
Pain	10	12	15

Abbreviations: HRQOL, health-related quality of life.

Data used with permission from: Phillips SM, Padgett LS, Leisenring WM, et al. Survivors of childhood cancer in the United States: prevalence and burden of morbidity. *Cancer Epidemiol Biomarkers Prev.* 2015;24:653-663.⁵⁵

^aAmong survivors who had survived for at least 5 years as of January 1, 2011.

Special Survivorship Challenges for Childhood and Adolescent Cancer Survivors

Although the majority of cancer survivors are diagnosed as adults, childhood and adolescent cancer survivors, defined as those diagnosed before age 15 years (children) or between ages 15 and 19 years (adolescents), face unique challenges across the cancer trajectory. In 2015, there were an estimated 429,000 survivors of childhood or adolescent cancer in the United States, most (70%) of whom were beyond adolescence (ages 20 years or older).² Five-year survival rates approach 85% for childhood cancers²; however, the increased burden of comorbid diseases carried into adulthood is significant^{53,54} and is greater than the burden seen in adult survivors. Indeed, it is estimated that 70% have a mild or moderate chronic condition, and 33% have a severe, disabling, or life-threatening condition.⁵⁵ Most of the chronic conditions associated with childhood and adolescent malignancy stem from treatment.⁵⁶ Whereas the 15-year cumulative incidence of severe, disabling, life-threatening, or fatal chronic health problems decreased over time, it remains substantial, declining from 12.7% for those who were diagnosed in the 1970s to 8.9% for those who were diagnosed in the 1990s.⁵⁷ The decline is largely because of improvements in the treatment of Wilms tumor, Ewing sarcoma, Hodgkin and non-Hodgkin lymphoma, astrocytoma, and acute lymphoblastic leukemia, whereas the prevalence of conditions related to the treatment of acute myeloid leukemia, neuroblastoma, soft-tissue sarcoma, and osteosarcoma has not changed.⁵⁵ Table 1 provides estimates of the prevalence of specific comorbidities experienced by long-term survivors of childhood

cancer by age group.⁵⁵ The high prevalence of cognitive or functional deficits and ongoing anxiety and pain limit both educational ability⁵⁸ and employment⁵⁹ for years after treatment ends.

In June 2018, the President signed into law the Childhood Cancer Survivorship, Treatment, Access, and Research (STAR) Act, which is the most comprehensive childhood cancer legislation ever introduced. This act is designed to advance both pediatric and adolescent and young adult (AYA) cancer research and cancer treatments while also improving cancer surveillance for these survivors and enhancing resources for them. Among other things, this legislation will enhance research on the late effects of childhood and AYA cancers, including a study on insurance coverage and payment of care for childhood cancer survivors; improve collaboration among providers so that clinicians are better able to care for this population as they age; and establish a new pilot program to begin to explore innovative models of care for childhood cancer survivors.

Research on Informal Cancer Caregivers

Cancer impacts the entire family, not just the person diagnosed. Informal caregivers are a primary source of help and support for a person with cancer and are usually not paid for their work. They are often family members, partners, or close friends without formal medical training. The shift from inpatient to outpatient cancer care and shorter hospital stays have transitioned more care to home settings and increased the responsibilities and needs of caregivers.^{60,61} Caregivers typically are responsible for a myriad

of complex cancer care tasks⁶² while balancing home and employment demands, and they often feel overwhelmed with the enormity of responsibilities.^{63,64} Caregivers may feel unprepared for medical tasks required of them and lack support for proper instruction. In addition, they are at high risk for psychological distress, depression, anxiety, and social isolation.⁶²

Caregivers report persistent unmet psychosocial, medical, financial, and daily activity needs throughout cancer treatment that can linger up to 5 years after their loved one's diagnosis.⁶⁵ Caregivers' psychosocial needs are primarily centered on their ability to help the cancer survivor deal with their emotional distress and find meaning in the cancer experience. Ongoing medical needs include obtaining information about the cancer, its treatment, and side effects and obtaining the best possible care for the survivor. Issues relating to caregivers' daily life, including their ability to balance their own personal care with the demands of caregiving, are most prevalent within 2 years of diagnosis.⁶⁵ The transition out of oncology after treatment and the decreased contact with health care providers also can be difficult for caregivers who feel uncertainty about the future and fear cancer recurrence.^{66,67} This is especially difficult for caregivers of survivors of more advanced-stage or severe cancers.⁶⁸

Ensuring that caregivers are healthy, both emotionally and physically, and have information and support for their role is imperative for optimal survivorship care. Findings from a meta-analysis⁶⁹ and systematic review⁷⁰ of intervention studies with caregivers indicate that psychosocial interventions significantly improve caregivers' ability to cope, reduce care-related burden, and improve overall quality of life. In 2015, the National Cancer Institute (NCI) and the National Institute of Nursing Research held a meeting to describe national research and clinical priorities for caregiving. Recommendations centered around 4 areas: 1) improving estimation of the prevalence and burden of informal cancer caregiving; 2) advancing the development of interventions designed to improve outcomes for cancer survivors, caregivers, and survivor-caregiver dyads; 3) generating and testing strategies for integrating caregivers into formal health care settings; and 4) promoting the use of technology to support informal cancer caregivers.⁷¹

Increasing the need for caregivers to serve as extensions of the health care team, not only in cancer but also in other diseases such as dementia, are elevating caregiving as a national priority. A 2018 report from the National Alliance for Caregiving provides clear directives to caregiver advocates, health systems, and policy makers to develop programs and public policies that sustain and support caregivers as part of population health.⁷²

The Future of Survivorship: Transforming Care to Equitably Improve Survivor Outcomes and Support Caregivers

Ten years after the Institute of Medicine report, *From Cancer Patient to Cancer Survivor: Lost in Transition*,⁹ the growth of survivorship research has advanced our understanding of the chronic and late effects of cancer therapies and our ability to predict and address the ongoing needs of different types of survivors.⁷³ Given the changing landscape of cancer treatment, and especially the rise of immunotherapy and other novel targeted agents, research on the long-term effects of these therapies must continue. At the same time, the field of survivorship must rise to the challenge of transforming oncology care from diagnosis forward to minimize the long-term impact of cancer by optimizing survivors' functioning, quality of life, ability to participate in work and life roles, and overall health and better supporting caregivers. As US health care systems shift to a more value-based care model, oncology care must find ways to meet the needs of survivors and caregivers that improve overall clinical efficiency and reduce costs.

The National Cancer Policy Forum of the National Academies of Sciences, Engineering, and Medicine held a workshop on long-term survivorship care after cancer treatment in 2017 to examine progress in cancer survivorship care. The report from that workshop summarized participant suggestions to accelerate progress in cancer survivorship into 9 goals: 1) providing accessible, equitable, and affordable survivorship care; 2) reducing suffering and mortality for survivors while helping them return to life, work, and school; 3) testing risk-stratified care delivery models that take into account health and social conditions in addition to cancer-specific factors; 4) improving survivorship-related education for clinicians and survivors; 5) meeting the needs of informal cancer caregivers; 6) better including diverse populations in survivorship research studies; 7) integrating psychosocial services into cancer care; 8) eliminating services where there is no benefit; and 9) developing and implementing quality metrics to shape survivorship care.⁷⁴

To achieve these 9 goals, we present the following 3 priorities as immediate, actionable steps to facilitate needed transformations that will ensure equitable high-value care (Fig. 2). The overarching goal is to increase the capacity of health care systems and corresponding public health systems to deliver high-quality, personalized, tailored care and support for caregivers. Precision medicine,⁷⁵ or better understanding the right care for the right patient at the right time, is dramatically changing oncology care. A precision medicine approach must extend beyond understanding the genomics of the tumor to prescribe the right

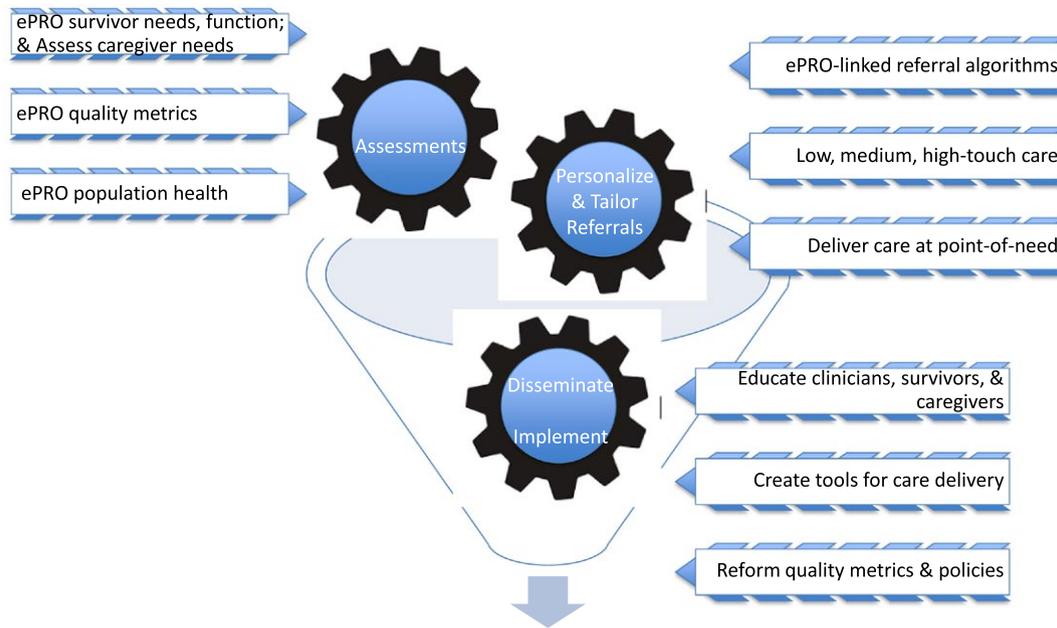


FIGURE 2. A Blueprint of Priority Strategies to Equitably Transform Care to Improve Survivor Outcomes and Support Caregivers. ePRO, electronic patient-reported outcome.

anticancer therapy. In addition to this, we must develop a multifactorial understanding of an individual's biology, behaviors, psychosocial context, and resources and use this to build a whole-person approach to predicting and caring for the chronic and late effects of these therapies as well.⁷⁶ Personalizing care based on the complexity of health needs and available resources and leveraging community and public health systems will optimize survivor outcomes while minimizing costs and addressing provider shortages. Similarly, providing tailored support for caregivers according to their needs and resources and the availability of community resources for them will efficiently address caregivers' own needs.

Priority 1: Implement Routine Assessment of Survivors' Needs and Functioning and Caregivers' Needs

The debilitating symptoms and functional limitations survivors experience are only discoverable through effective communication with the survivor and the survivor's family and informal caregiver. A process is needed to stimulate productive discussion between clinicians, survivors, and caregivers about symptoms and other matters of concern beginning at diagnosis and continuing throughout and beyond treatment. To develop such a process, the American Cancer Society (ACS) convened an expert panel to develop a prospective

surveillance model for cancer rehabilitation⁷⁷ that describes screening for survivors' needs soon after diagnosis and repeatedly throughout treatment and into posttreatment survivorship or end-of-life care. To meet the needs of survivors, this model must be extended to assess a comprehensive list of physical and psychosocial symptoms and functional impairments that would allow for referrals to a multidisciplinary team of providers and a diverse set of interventions.⁷⁸ Repeated assessments allow for timely interventions to be deployed either to prevent cancer-related problems or to treat symptoms and impairments when they are minor and before they have caused disability. Better mitigating these problems during cancer therapy will likely improve survivors' functioning and well-being, reduce the burden on their informal caregivers, and reduce the number of problems that must be dealt with in posttreatment survivorship.

Patient-reported outcome (PRO) measures are increasingly being used to assess symptoms and needs in research⁷⁹ and in clinical care.⁸⁰ Systematic monitoring of chemotherapy-related symptoms using electronic PROs (ePROs) in clinical practice has been shown to improve quality of life, reduce emergency department visits, allow survivors to remain on chemotherapy longer, and improve survival.^{81,82} These results have led the American Society of Clinical Oncology (ASCO) to list PRO-based symptom reporting as a major clinical cancer advance of 2018,⁸³ and a survey of ASCO's Quality Oncology Practice Initiative (QOPI)-registered practices found 79% of respondents reported that

the collection of PROs was a high priority for their clinic.⁸⁰ Notably, these positive results have been produced when problematic scores on ePROs trigger alerts to clinicians, who take action to manage survivors' symptoms.^{81,82} A systematic review of older trials evaluating the utility of PROs in oncology care found that, although these instruments aid in the recognition of and patient-provider communication about symptoms, the evidence for improved health outcomes was positive but weak.⁸⁴ The weak results of PRO assessment in older trials reflects the evolving state of PRO use in cancer care and underscores the need to align these measures with clinical workflow—taking action to meet survivors' needs.⁸⁵ To fully realize the potential benefits of integrating PROs into cancer care, several elements are likely required: clinician and survivor buy-in; collection and processing of PROs with minimal burden on survivors and staff; results reported in user-friendly formats that spark action in clinicians and survivors; and algorithms that assist clinicians in connecting symptoms and functional problems to specific interventions or providers. Passive data collection from sensors and wearables could reduce the burden of data collection—these technologies may be especially valuable when embedded in connected health systems. The increasing number of ePRO systems being implemented in care⁸⁰ has the potential for better clinical integration and could lead to improved care and better patient outcomes in the future.^{86,87}

A similar system of prospective surveillance is needed to assess the needs of informal caregivers over time. The ePRO systems being implemented in clinics could be extended to independently assess the needs and resources of informal caregivers to determine how best to support them. Indeed, experts have called for assessing caregivers' needs with formal measures that mirror the measures used with survivors as the first step in facilitating improvement in their well-being and supporting their essential role in the care of cancer survivors.⁸⁸ In this proposed 4-part framework, caregiver assessments are then used to educate caregivers for their caregiving roles, empower them as essential members of the care team, and assist them in their caregiving duties⁸⁸ as well as addressing their needs.

PRO data also can be used to facilitate quality care reporting and national population health surveillance. For quality reporting, PRO-based performance measures (PRO-PMs) are uniquely suited to provide feedback on quality of cancer care via patient-centric outcomes, such as symptom control, patient-provider communication, and patient perceptions of care.^{89,90} Organizations such as the National Quality Forum,⁹¹ the American Medical Association,⁹² and the Centers for Medicare and Medicaid Services⁹³ are promoting the development of PRO-PMs. Although research is needed to develop cancer-specific

PRO-PMs that are valid, useful, and equitable, early efforts suggest they are feasible and acceptable to cancer survivors and clinicians.^{85,94,95} For national surveillance of the impact of cancer on population health, central cancer registries enable estimates of national and regional cancer incidence and survival proportions. Linking cancer registry data with population-level PRO data would improve our understanding of patient-centered cancer outcomes, such as quality of life, functioning, and morbidity,⁹⁶ and would provide data to assess health disparities and improve supportive care by informing research, policy, and practice.

Priority 2: Facilitate Personalized, Tailored Care Information and Referrals From Diagnosis Forward for Survivors and Caregivers, Shifting Care From Point of Care to Point of Need Wherever Possible

Although frontline oncology clinicians are able to provide care for some of survivors' needs, addressing the broad array of problems cancer survivors face requires referral to a suite of interventions and providers from multiple specialties. To improve survivor access to these services while addressing provider shortages and decreasing costs, referrals must be personalized and tailored so that the intensity and setting of care varies according to need.⁹⁷ To facilitate the implementation of personalized referrals, PROs can be used to understand the severity of a problem and its impact on functioning, the intervention needed, and the resource constraints of the survivor and point to the appropriate referral.

Survivors who have mild levels of symptoms without functional impairments and could benefit from lower-touch, self-management-based interventions should receive these interventions. Self-management programs help survivors to address the symptoms and consequences of living with a chronic condition⁹⁸ by building skills in problem-solving, decision making, resource utilization, forming partnerships with health care providers, and creating action plans,⁹⁹ sometimes in concert with peer support. Self-management interventions can be delivered at the point of need (when health-related conversations occur and health decisions are made¹⁰⁰) outside of clinical care, for example, by using the free online self-management tool for cancer survivors, *Springboard Beyond Cancer* (survivorship.cancer.gov/, accessed October 8, 2018), developed by the NCI and the ACS. Self-management and peer support interventions can be developed for caregivers as well; for example, *Springboard Beyond Cancer* has caregiving modules in addition to survivor-focused modules. Focusing on self-management and peer support that is delivered outside the clinic also can help

address the needs of survivors in rural settings or those with limited resources and decrease the burden on caregivers who help survivors access these services.

Moving up the risk strata, survivors who need more help than self-management offers but do not require specialized medical care could get referrals to community or worksite-based interventions. The example of exercise programs is illustrative here: exercise-enhancing interventions for survivors specifically (eg, LIVESTRONG at the YMCA) or for the general population (eg, Silver Sneakers) exist in community settings or through worksite health promotion programs. Meeting survivors' needs with these interventions outside the clinic can also help address the provider shortage and reduce the burden to survivors and caregivers from traveling long distances to specialized clinics.

Finally, survivors with high levels of symptoms and functional impairments who need high-touch interventions delivered in clinical care settings should receive those interventions in a timely and feasible manner. Pilot tests of shifting as much care as possible to supported self-management in England demonstrated this change in care delivery freed up oncology visits for new patients, and met patients' needs while enhancing the quality and productivity of the health care system.¹⁰¹ This approach is projected to save England 90 million pounds over 5 years.¹⁰¹ Although health care infrastructure and delivery differ in the United States compared with the United Kingdom, these findings from England are promising and warrant research on the implementation of this approach in the United States.

For the group of survivors in need of clinical care, it is critical to facilitate timely referrals to a multidisciplinary team of providers from cancer rehabilitation, palliative care, psychosocial care, exercise, nutrition, smoking cessation services, and hospice care when survivors approach the end of life. Cancer rehabilitation, palliative care, and psychosocial care interventions help manage symptoms and improve functioning and quality of life.^{102–107} Cancer rehabilitation interventions can help survivors maintain employment,¹⁶ contributing to better financial outcomes. Palliative care also may save costs,¹⁰⁸ and research suggests that both palliative care¹⁰⁹ and psychosocial care¹¹⁰ may improve survival. Referrals to exercise professionals and dieticians to promote health behavior change in survivors have the potential to help decrease the risk of mortality from comorbid diseases, control ongoing symptoms such as fatigue and depression, and improve physical functioning.^{111–116} Finally, at the end of life, earlier access to hospice care can help survivors optimize their quality of life and symptom control and prepare caregivers for their loved one's passing.¹¹⁷

This personalized, tailored approach to care needs to extend to the posttreatment follow-up care of survivors as well. The ACS's cancer survivorship clinical care guidelines for breast,^{40,118} prostate,⁴¹ colorectal,¹¹⁹ and head and neck¹²⁰ cancers describe the comprehensive care needed after treatment, including surveillance for recurrence, screening for new cancers, assessment and management of physical and emotional long-term and late effects, health promotion, and care coordination. Many cancer survivors prefer to receive follow-up care from their oncologist.¹²¹ However, trying to accommodate seeing most follow-up patients in oncology clinics will limit timely scheduling of new patients, even if oncology shifts more care to advanced practice practitioners, increases the number of oncology fellowship slots, and delays the retirement of the current oncology workforce.¹²² Simultaneously, not all cancer survivors can be cared for solely by primary care providers, who have limited knowledge of how to manage the chronic and late effects of cancer.¹²³ Simply educating the primary care workforce about the needs of survivors is unlikely to be successful. Primary care clinicians confront a wide-ranging set of responsibilities, from the management of acute conditions, a diverse set of chronic diseases, and delivery of preventive care. Although primary care clinicians do play a role in addressing the unique needs of cancer survivors and managing their comorbid conditions, their levels of expertise and engagement in these issues vary substantially,¹²³ and the majority of primary care clinicians, even in advanced, patient-centered medical homes, are not equipped to address all of survivors' needs.¹²⁴

A personalized, tailored, risk-stratified approach for follow-up care is in use in the United Kingdom and is being adapted for Australia and other countries.^{125,126} Survivors who have a high risk of recurrence, or late effects of treatment, or multiple complex needs may be followed in oncology and by a multidisciplinary team of specialty providers, whereas those who have minimal ongoing problems and a low risk of late effects may be followed in primary care with supported self-management; and those who have moderate levels of risk and ongoing problems may be followed by providers with both primary care and oncology expertise. Outcome data from the Northern Ireland pilot tests of risk-stratified follow-up care for breast cancer demonstrated that this care improved the receipt of timely follow-up mammograms by 20% while freeing up clinic visits in surgery and oncology, decreasing waiting list time by 34%, and allowing clinicians to spend more time with survivors who had complex needs.¹²⁷

Finally, this personalized, tailored approach also can be used to address the needs of caregivers. Similar to the

proposed process for survivors, results from electronic needs assessment can help tailor the information or referrals provided to caregivers to meet their needs. Caregivers who are in need of self-management or informational materials can be linked to those resources. Those in need of community-based interventions, such as caregiving support groups or respite care, could be provided with referrals to those programs. Caregivers in need of their own treatment from medical or mental health clinicians (eg, caregivers suffering from anxiety or depression) can be provided with referrals to receive the timely care they need.

Priority 3: Disseminate and Support the Implementation of New Care Methods or Interventions

The United States has diverse and fragmented health care delivery and health care payment systems, and thus changing care practices is more complex than in countries with single-payer systems (eg, the United Kingdom). It seems clear that, with the transition to value-based care in the United States, the implementation of new care delivery methods or interventions will be facilitated by data indicating that they create higher quality, more efficient, and lower cost care for cancer survivors. Successfully changing care will involve educating clinicians, survivors, and caregivers about new care methods; normalizing the risk-stratified approach from the beginning of care; and working with them to decrease the delivery of ineffective care practices (eg, unnecessary tests or too-frequent clinic visits). Implementation also will require creating tools that integrate ePROs, treatment algorithms, and other data into electronic health records to improve clinician-patient communication about ongoing needs and care; trigger appropriate and timely referrals; deliver self-management, peer support, and other lower touch interventions where and when survivors and caregivers need them; and monitor the population health impact of these new care components. It is imperative that new care methods be implemented in a way that promotes health equity rather than exacerbates existing disparities in care delivery and outcomes. Efforts must focus on helping survivors and caregivers access these important elements of care. This may involve the creation of telemedicine services or other novel models of care that provide these interventions where survivors and caregivers live and in cost-effective ways. In addition, patient navigators may be beneficial for improving the coordination of care and reducing health disparities among the medically underserved.^{128,129}

Clinical care guidelines will need to be written to clearly communicate expectations for and guide clinicians in delivering new practices. Guidelines should be written in an easily digitized format to facilitate the integration of guideline

content into electronic health records and decision aids. These must be accompanied by regulatory or policy reforms to support (incentivize and reimburse for) new care methods or interventions. To shape evolving care, quality metrics will need to be developed by professional organizations, such as the ASCO QOPI program, the National Quality Forum, or the American College of Surgeons Commission on Cancer (CoC), which certifies hospitals for cancer treatment. For example, once clinical guidelines are developed for risk-stratified follow-up care, guidance on how to use PROs to discern the different survivors who should receive low-touch, medium-touch, or high-touch care should be incorporated into existing QOPI indicators or CoC accreditation standards on survivorship care. In addition, as new metrics are developed to measure overall quality care, existing QOPI indicators and CoC standards on the different components of care (eg, distress screening, accessing palliative care and cancer rehabilitation) could be streamlined under a single, unifying metric assessing the provision of quality care and making quality reporting easier for busy clinics.

Efforts also are needed to work with health care payers to explore models of reimbursement for currently under-reimbursed or unreimbursed care components (eg, navigation, survivorship care planning, exercise intervention, interventions that educate and engage caregivers as part of the medical care team). Partnerships with payers also are needed to test and implement new models of care, such as primary care or advanced practice practitioner-led survivorship clinics, particularly because research has demonstrated that competition with higher priority clinical initiatives that are incentivized by payers is a barrier to innovating survivorship clinical practice models.¹³⁰

Conclusions: Building on Emerging Efforts

Meeting the unique and complex needs of the growing cancer survivor population and their caregivers is a challenge that must be met by reforming our health care systems and better leveraging our community and public health systems. Care for survivors is not one-size-fits-all; rather, care must be personalized to meet survivors' needs. Shortages in oncologists, primary care providers, and nurses,^{131–134} coupled with the rising numbers of cancer survivors (particularly older adult and racial/ethnic minority survivors) and the rising costs of cancer and survivorship care,^{135,136} are taxing US health care delivery systems. With the transition from fee-for-service to value-based care, these factors create a compelling need to provide coordinated, comprehensive, high-quality care for cancer survivors and support for their caregivers in ways that meet survivors' and caregivers' unique needs while minimizing the impact of provider shortages and controlling costs to

health care systems, survivors, and families. Coordinated efforts in practice, research, education, and policy in support of the 3 priorities presented here—1) implementing the routine assessment of survivors' needs and functioning and of caregivers' needs; 2) facilitating personalized, tailored information and referrals from diagnosis forward for survivors and caregivers, shifting care from point of care to point of need wherever possible; and 3) disseminating and supporting the implementation of new care methods and interventions—have the potential to dramatically and equitably transform the health and well-being of cancer survivors and their caregivers.

The cancer care community is already mobilized for change and has demonstrated an increased commitment to improve care for all survivors. Work already has begun to enact these strategies through multistakeholder efforts and through the independent acts of many organizations. To accelerate progress in using ePROs to assess survivors' needs and functioning, in 2017, the American Congress of Rehabilitation Medicine, the NCI, and 25 stakeholder organizations from all areas of patient care worked to drive consensus about the best measures of symptoms and function that could trigger a referral to supportive services. The report from this effort lists several appropriate measures and outlines steps needed to implement a process for the assessment and referral of survivors across oncology settings (unpublished results).

The ACS and the Oncology Nursing Society continued this work by hosting a roundtable meeting of over 40 stakeholder groups in March 2018 to catalyze the development of digital tools to mitigate the adverse effects of cancer and its therapy (facilitating survivor and caregiver assessment, appropriate referrals, and survivors' and caregivers' self-management). Ongoing work from this effort will develop use cases in key areas of care that have the potential to equitably transform outcomes. The use cases will provide the basis to generate a model simulating the effects of this shift in care on survivors' outcomes, clinical efficiency, health care utilization, and costs. The group also highlighted the need for professional societies to collaboratively develop and harmonize ePRO-compatible symptom management guidelines with risk-stratified algorithms that include appropriate self-management materials for survivors and caregivers as well as clinical treatment pathways for those who need moderate-touch and high-touch interventions.

One example of ongoing work to improve the measurement of the impact of cancer on population health is the NCI's partnership with the Department of Energy to enable the acquisition of more detailed clinical data from health care documents and improve the overall quality and efficiency of data abstraction for cancer registries and cancer surveillance.¹³⁷ Once established, these efforts could be extended to include

the surveillance of cancer impact through ePROs, which also would allow for the identification and tracking of disparities.

Several efforts also have worked toward the goal of building risk-stratified cancer follow-up care in the United States. The ACS and the ASCO held a summit in January 2018 to outline a strategy of research, clinical care, and policy strategies for implementing personalized, tailored, risk-stratified follow-up care in the United States. In September 2018, the ACS held a follow-up meeting to identify and prioritize the specific research needed to create and implement risk-stratified models for survivorship care in the United States. Finally, an NCI meeting planned for late 2018 will identify quality metrics for survivorship care. These measures can be incorporated into emerging models that link payment to value and quality. If the nation is to strive for improved quality, then measures of that quality must be defined, tested, validated, and widely incorporated into emerging delivery system models.

Each of these organizations and the many national leaders committed to improving care should continue to explore the most effective ways to work together on these and other strategies to ensure that efforts are organized, sustained, and adequately funded. Greater attention and definition must be given to the concept of cancer as a chronic disease with long-term risks as well as diverse adverse effects. Our health care and public health systems must adapt to focus on this emerging conceptualization. Investing in new cancer treatments is vital; these new treatments have contributed to cancer becoming a chronic problem in which more survivors are living for years beyond their initial diagnosis but then must cope with new risks and symptoms. However, also failing to invest research funds adequately in addressing the long-term problems confronting survivors and caregivers is unethical. The portfolio of research funding must reflect the balance of the full spectrum in cancer control, from prevention, to early detection and diagnosis, to treatment, survivorship, and end of life.

Finally, this blueprint has identified numerous factors that correlate with disparate health outcomes between different populations and communities. Many of these factors relate to the social determinants of disease, such as income inequality, disproportionate access to education and health care, and discrimination. We need to acknowledge that certain racial and ethnic groups, neighborhoods, and individuals with lower incomes have different (or additional) barriers preventing them from receiving the care they need and from being as healthy as they want to be. Overcoming these barriers will require tailored approaches based upon the needs of these populations if we are to improve their cancer outcomes. Bringing the voices of cancer survivors and their caregivers into a national dialogue about these root causes of disease and disparities can be a powerful way to mobilize national action and create effective solutions. ■

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