



Introduction: The history of cancer survivorship programs in the USA: progress, challenges, and opportunities

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Improvements in treatments for many cancers have led to a major increase in the population of cancer survivors in the USA. As of 2023, there are approximately 18 million cancer survivors in the USA, which is estimated to grow to 27 million by 2050. [1] Cancer survivors, herein defined as individuals from the time of diagnosis through the end of life, often experience physical, psychosocial, and practical challenges that may occur during treatment and persist for years and adversely affect their health-related quality of life. [2–6] As the population of survivors grows and ages, the delivery of comprehensive survivorship care has become more complex, with continuity of care and care coordination becoming more important. Subsequently, optimizing cancer survivorship care, particularly for those who have completed treatment, is a priority.

In the last two decades, there have been many calls to action and new initiatives that have increased focus on improving the quality of survivorship care. A major milestone occurred in 2006, when the Institute of Medicine (now the National Academies of Medicine) released the report *From Cancer Patient to Cancer Survivor: Lost in Transition*. This report highlighted the unique needs of cancer survivors completing treatment, including screening for new cancers, monitoring for long-term physical and late emotional effects, and facilitating the coordination of care between specialists and primary care providers [7]. In 2012, the American College of Surgeons Commission on Cancer (CoC) released Standard 3.3, which required the delivery of survivorship

care plans (SCPs) to patients treated with curative intent [8]. The SCPs were described as stand-alone documents that provided a summary of cancer treatment, late and long-term effects, follow-up testing, and other information needed to achieve transition of care. This initial standard was introduced in 2015. At that time, cancer programs across the USA began tackling the challenge of developing SCPs, often with difficulty [9, 10] In October 2019, an updated CoC standard 4.8 was released. With feedback from the American Cancer Society, the American Society of Clinical Oncology (ASCO) Cancer Survivorship Committee, the National Cancer Institute, and the National Cancer Policy Forum, the updated standard did not require a threshold percentage of individuals receiving SCPs. Rather, focus was placed on the development of a robust survivorship program composed of a team of physicians, advanced practice providers, nurses, social workers, nutritionists, physical therapists, and other allied health professionals to develop and implement a survivorship program to meet the needs of survivors completing curative intent-treatment. [11]. Survivor-focused services include, but are not limited to, the provision of treatment summaries or SCPs, seminars for survivors, rehabilitation services, and nutritional and psychological services. Although SCPs are encouraged, they are no longer required.

Throughout the decades, there has been a growth in the number of US cancer centers with a specialized cancer survivorship program. The goal of this special section in the *Journal of Cancer Survivorship* is to describe the history and current status of cancer survivorship programs in eight cancer centers across most regions in the USA [12–19]. In addition to geographical reach, programs were selected to reflect the timeline in survivorship programs development over the last several decades. Some programs were early pioneers in delivering cancer survivorship care to childhood cancer survivors [15, 17], and other programs were selected because they were developed or expanded in the 2000s with

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funding from the LIVESTRONG Survivorship Centers of Excellence Program [12, 16, 20]. The remaining programs were launched in the past decade [13, 19]. Each center survivorship leadership team was asked to describe the development of their program and its focus, survivor-focused services, clinical model guiding survivorship care, initial and current implementation challenges, research components, funding sources, education, as well as evaluation metrics. They were also asked to describe success stories, challenges, and opportunities for the future of the survivorship program.

Overall, the programs offer an impressive range of cancer survivorship clinical services, as outlined in CoC standard 4.8. Clinical models of care vary widely, with many centers developing more than one care model to accommodate different care needs across their cancer center or evolved their models of care over time as needs or funding sources change. All programs describe working with integrated specialists [12–19], and some programs include generalist or internal medicine physicians [13, 14, 17, 19]. Many programs utilize a system-wide electronic health record system to facilitate bi-directional communication with providers who are not at the cancer center. Primary care integration, both within and outside the cancer center, was limited. Although most programs reported distributing the SCP to the PCPs, there was no formal implementation for care transition from oncology to primary care settings. Some centers described active engagement with their communities that was used to design a survivorship program that matched these needs [21].

Education efforts described across the cancer center programs vary in scope and focus. These programs include survivorship education programs for physicians, advance practice providers, and trainees [14, 17–19]. Research structure, size and scope varied widely. Some programs house their research in the Cancer Center's Cancer Prevention and Control Cancer Center Support Grant Infrastructure [12, 18, 19], while others house the research in the survivorship program [13–17]. Many programs hold regular research meetings to share works-in-progress and host an invited lecture series [13, 17]. Although many programs have impressive research portfolios, they are generally investigator-driven and do not rely on institutionally collected survivorship cohorts.

There are numerous challenges facing survivorship programs. One key challenge described is the ability to sustain funding. Most programs developed organically and have been driven by local champions, rather than supported by center leadership or at the institutional level, which has led to difficulty in sustainment. The programs are supported by a mixture of funding sources ranging hospital system funds for specific positions, community funding, philanthropy for specific initiatives, and federal grants. Some programs have addressed this challenge by collecting data to support the financial benefit to survivorship care. For example, Jacobs [16] showed that an advanced practice provider model of

care generated a substantial profit for the institution by increasing the number of new consults by oncologists. Flores et al. [13] collected metrics focusing on downstream revenue from imaging and clinical testing, as well as new and/or recurrent cancers diagnosed resulting in new visits. Unfortunately, there were minimal metrics collected by most of programs. Tracking utilization and formulating careful business plans with metrics that demonstrate cost effectiveness will be key to ongoing cancer center leadership's commitment to sustaining these programs. A centralized survivorship database that harnesses the evolving capabilities of electronic health records will facilitate the creation of systems to assess survivors' health-related outcomes and identify significant disparities. These data will help clinicians to target their care to address patient needs in a more cost-effective way across large networks. Further, demonstrating improved patient-reported outcomes, decreased healthcare utilization, and increased downstream revenue can also facilitate greater buy-in and financial support for survivorship programs from the home institutions.

A second challenge is the trend in the health care market towards large systems and networks. Survivorship programs are increasingly charged with delivering care across academic and non-academic settings spread over large geographic areas and populations with diverse needs. Delivery of care in this context will continue to face barriers at the system, provider, and patient levels. Without consistent and comprehensive guidance for program design, institutional support, and improved insurance reimbursement for survivorship services, the financial infrastructure to support the provision of survivorship services across large networks will be compromised. One opportunity that is offered by the community outreach and engagement programs at cancer centers is the ability to engage community-based organizations in the process of offering complementary services and reaching cancer survivors who are difficult to reach.

Training and sustaining the provider workforce in the face of the burgeoning number of cancer survivors, who are also aging with multiple comorbid issues, remains a challenge. Although the programs presented in this series are to be commended for developing strong training and education efforts for providers, including well-recognized national conferences and online course, workforce training is going to become more important as the entire healthcare field struggles with capacity. Unfortunately, to our knowledge, there are currently no accredited training programs in cancer survivorship, which would be an important step in standardizing training and setting benchmarks for the future survivorship care workforce.

Lastly, increasing the reach and availability of the evidence-based interventions that we know improve health-related quality of life among survivors (e.g., physical activity, emotional distress) is another challenge. The current

survivorship research landscape has been built upon the pioneering work emanating from these centers. This work has characterized modifiable risk factors leading to disparities in adverse outcomes, informed clinical care guidelines, and led to evidence-based approaches to mitigating adverse outcomes. However, it is imperative the future research be directed toward implementation and dissemination of effective interventions.

In summary, this special section of the *Journal of Cancer Survivorship* highlights the history of survivorship programs at eight US cancer centers. Despite the notable challenges, each center achieved major accomplishments in care delivery for a large number of survivors. This progress highlights the success and continuing evolution of survivorship care delivery to accommodate the unique needs of survivors and the systems in which they are treated. As these programs were specifically chosen for this special series, it is important to emphasize that community-based programs and those outside of the USA (in both high-income and low- and middle-income countries) will need to be examined. We believe that while many of the challenges will be similar, there will be unique issues particularly with regard to availability of sufficient resources. The population of cancer survivors is growing at an exponential pace, including individuals with advanced and metastatic cancer and older survivors; these populations are estimated to increase in tandem. It is imperative that cancer centers implement survivorship care services that address the complex set of needs of the growing and diverse population of cancer survivors, educate and train a multidisciplinary and multispecialty workforce to care for them, and actively collaborate with advocacy groups and community-based organizations to expand reach.

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Declarations

Competing interests The authors declare no competing interests.

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