OVERVIEW

The population of cancer survivors in the United States and worldwide is rapidly increasing. Many survivors will develop health conditions as a direct or indirect consequence of their cancer therapy. Thus, models to deliver high-quality care for cancer survivors are evolving. We provide examples of three different models of survivorship care from a cancer center, a community setting, and a country-wide health care system, followed by a description of the ASCO Cancer Survivorship Compendium, a tool to help providers understand the various models of survivorship care available and integrate survivorship care into their practices in a way that fits their unique needs.

As noted by Parry et al, there is a “booming” population of cancer survivors in the United States, largely as a result of advances in early cancer detection and improved cancer therapy as well as the general aging of our society. By the year 2020, it is estimated that there will be 18 million cancer survivors in the United States. This phenomenon is occurring in many other countries as well.

As the number of long-term survivors has increased, there has been a growing realization that many will develop health conditions as a direct or indirect consequence of their cancer therapy. Some of these conditions occur during therapy and persist well after the therapy has been completed and can become permanent, such as oxaliplatin-induced peripheral neuropathy. However, many outcomes, such as the development of second cancers and therapy-induced heart failure, are not evident until a decade or two after the initial cancer. Collectively, these outcomes are generally referred to as late effects.

The hallmark 2005 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition, highlighted the lack of quality care for cancer survivors in the United States, described the transition points where cancer survivors fall through the cracks of our health care system, and provided a blueprint for the standard of care that should be considered for all cancer survivors. The following were essential components of lifelong proactive and anticipatory survivorship care: prevention of recurrent and new cancers and of other late effects; surveillance for cancer spread, recurrence, and second cancers; assessment of medical and psychosocial late effects; interventions for consequences of cancer and its treatment including medical and psychosocial problems; and coordination between specialists and primary care providers to ensure that all of the survivor’s health needs are met. It was recognized that the content, intensity, and frequency of such care would vary from survivor to survivor and be based on a survivor’s risks related to the cancer, cancer therapy, genetic predispositions, lifestyle behaviors, and co-morbid health conditions. Indeed, the shared-care model was advocated as an approach to facilitate communication and coordination or care between the cancer specialists and other health care providers, particularly primary care clinicians. An integral component in this process, as advocated by the authors of the IOM report, is the Survivorship Care Plan (SCP), which is a brief synopsis of the cancer, cancer therapy, and plan of care based on the survivor’s risks. Use of this document was intended to facilitate communication between the cancer specialist, the patient, and other health care providers. Survivorship care planning has since been endorsed by the Commission on Cancer and is integrated into the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI Cores 17–19). To better understand how best to deliver survivorship care, the IOM report called for “demonstration programs to test models of coordinated, interdisciplinary survivorship care in diverse communities and across systems of care.”

In 2011, ASCO established the Cancer Survivorship Committee, which was tasked with, among other charges, advancing our understanding of different models to deliver survivorship care. In just a few short years, this committee, consisting of a multidisciplinary group of oncology providers and primary clinicians from academic and community settings, health psychologists, health services researchers, and
patient advocates, has witnessed a rapid evolution of survivorship care across North America and internationally.

In the following sections, we provide examples of three models of survivorship care from a cancer center, a community setting, and a country-wide health care system, followed by a description of the ASCO Cancer Survivorship Compendium, a tool to help providers understand the various models of survivorship care available and integrate survivorship care into their practices in a way that fits their unique needs.

SURVIVORSHIP HEALTH CARE IN THE ACADEMIC CANCER CENTER

Many academic cancer centers in the United States have developed, or are in the process of developing and evaluating, various models of survivorship care. Most programs operate according to either a consultative or longitudinal model. In the consultative model, survivors generally are referred by the oncologist or are self-referred for a one-time survivorship evaluation. Before the visit, the survivorship health care provider(s) creates an SCP. At the visit, the survivor is evaluated, the SCP is shared with him or her, and any necessary referrals for specialized services are made. Following the consultation, a copy of the SCP and the evaluation are sent to the referring oncologist and the primary care physician; the oncologist then continues the long-term follow-up care of the survivor, at least for some time. In the longitudinal model, survivors are transitioned from their oncologist(s) to a survivorship clinic (either a generic or cancer-specific clinic) generally 1 to 5 years after treatment and then followed for some period of time before transitioning the survivor back to a community provider. Figure 1 describes a risk-stratified longitudinal approach in which care is shared between the cancer center providers and the primary care physician with a transition to the community in most cases.

The Memorial Sloan Kettering Cancer Center Model

As an example of a longitudinal model, the following is a description of the past, present, and future plans at a single institution, Memorial Sloan Kettering Cancer Center (MSKCC). Similar to many academic centers where children are treated for cancer, a survivorship program for pediatric cancer survivors (the Pediatric Long-Term Follow-Up [LTFU] Program) was established in 1990. In this setting, children who are 1 to 2 years from completion of cancer therapy are transitioned to the Pediatric LTFU Program, staffed by two physicians and two pediatric oncology nurse practitioners (NPs). Patients continue to be evaluated by their treating oncologist for cancer recurrence, but the LTFU Program providers screen for and manage any sequelae of treatment. As with other similar programs, it was soon realized that although many survivors could be transitioned back to community-based primary care physicians between age 18 and 21 years, there were also high-risk survivors with multiple therapy-related comorbidities who could benefit from more specialized follow-up care at the cancer center.

Thus, in 2005 the Adult LTFU Program was established at MSKCC for high-risk adult survivors of a childhood, adolescent, or young adult cancer. This program is staffed by five primary care physicians, three NPs, and a nurse. The Pediatric and Adult LTFU programs share a nurse who prepares an SCP for all new visits. Both programs also benefit from the clinical support of a psychologist who is highly experienced in working with cancer survivors with psychosocial problems, including fears of recurrence, and with multiple serious health problems related to their cancer therapy.

Beginning in 2006, MSKCC began developing an innovative care model for survivors of adult-onset cancers in which follow-up care is solely provided by NPs (or physician assistants [PAs]). Initially, pilots were developed to evaluate the feasibility of this model with a focus on common cancers. It was found that this model was successful in having a physician refer and patients accept a transition from their oncologist(s) to a survivorship NP without compromising their care.

Using this approach, clinics have been developed within many of the MSKCC disease management teams and services, including bone marrow transplant, breast, colorectal, endocrinology, gynecology, head and neck, melanoma, thoracic, and urology/prostate. In each of these settings, a shared care approach is employed for all patients. At each visit in the NP/PA or high-risk survivorship clinics, a copy of the progress note and an updated SCP are autofaxed to the community clinician with an accompanying letter highlighting any necessary coordination of responsibilities. In 2013, there were more than 12,000 patient visits in the MSKCC survivorship clinics, of which more than 10,000 were in an NP/PA survivorship clinic.

Looking to the future needs of the institution and evolving care paradigms, MSKCC is establishing a Center for Cancer Survivorship. Five-year clinical care goals include establishment of a multidisciplinary Survivorship Management Team; implementation of an institution-wide risk-stratified

KEY POINTS

- Many cancer survivors will develop health conditions as a direct or indirect consequence of their cancer therapy.
- The 2005 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition, provided a blueprint for the standard of care that should be considered for all cancer survivors.
- The Survivorship Care Plan, a brief synopsis of the cancer, cancer therapy, and plan of care based on the survivor’s risks, is an integral component of survivorship health care.
- Models of survivorship health care will vary based on available resources and the needs of the local survivorship population. Nurse practitioners and physicians assistants are essential in cancer center and community-based survivorship programs.
- The ASCO Survivorship Care Compendium will serve as a repository of tools and resources to enable oncology providers to implement or improve survivorship care within their practices.
plan for the care of all new patients with cancer diagnosed and treated at MSKCC; development of institution-wide guidelines and guidance for screening, assessment, and management of long-term and late effects including second primary cancers; development of an integrated plan for specialized cancer survivorship services; and periodic evaluation of survivorship clinical care delivered at the institution.

**SURVIVORSHIP HEALTH CARE IN THE COMMUNITY SETTING**

In the community setting, many oncology practices have similarly implemented survivorship clinics or expanded the survivorship services they provide. The National Cancer Institute (NCI) provides funding to 30 community cancer centers in 22 states through the NCI Community Cancer Center Program (NCCCP). A key aim of this program is to enhance cancer survivorship care services available at community hospitals. Resources developed through the NCCCP network are made available to other community cancer programs through publications, presentations at national meetings, and the NCCCP website.

**Integrating a Community Solution for Cancer Survivorship Care**

Providing multidisciplinary services for all oncology patients through an integrated community survivorship model is the aim of the Fort Worth Program for Community Survivorship (ProComS). Before its establishment, survivorship services in the community were fragmented, offered only in a few hospitals and clinics for specific diagnoses and providers, and inadequate in meeting the needs of uninsured and underinsured cancer survivors. To address this issue, the University of Texas Southwestern Medical Center Moncrief Cancer In-
stitute (UTSW-MCI) obtained funding from the Cancer Prevention Research Institute of Texas to lead a community-wide partnership for local oncology providers, consolidating survivorship care and placing emphasis on the underserved.

Combining principles from the shared care survivorship model\textsuperscript{6,10} and the Folsom Report,\textsuperscript{1,11,12} UTSW-MCI addressed the challenges associated with a competitive oncology environment and organizational concerns. The Folsom Report placed emphasis on resolving population health care fragmentation through the committed involvement of the entire medical and public health community, forming a “community of solution.” These collaborations enable the delivery of comprehensive health care to be a sustainable, community-wide endeavor, successfully addressing survivorship services to a population health issue. Integrating these concepts, UTSW-MCI leadership brought together representatives from the local safety-net hospital, three area full-service hospitals, two large oncology provider groups, and three local cancer agencies to address this challenge as a community problem and proposed to provide consistent survivorship services for all oncology patients. Recognizing that UTSW-MCI does not provide direct oncology treatment, its leadership role was felt to be “competitively neutral” in working to build trust among community partners in a competitive patient environment.

As such, the ProComS clinic core services are offered onsite at UTSW-MCI, while some patient-specific services (speech/language and lymphedema therapy) are referred to a community partner. UTSW-MCI has further incorporated the Folsom Report recommendations through the initiation of the Community Advisory Board (CAB) and quarterly meetings, providing oversight and recommendations regarding patient referrals, treatment expertise, and feedback mechanisms to the primary oncology provider.

ProComS is open to all adult cancer survivors, enrolling participants regardless of health care provider, gender, diagnosis, stage, functional status, insurance level, or ability to pay. Providing ongoing supportive, psychosocial, and behavioral care for survivors, the clinic offers oncology-certified registered nurse evaluations, social worker assessments, exercise training, registered dietitian consultations, and psychologic and certified genetic counseling. In addition to these core components, ProComS offers diagnosis-driven support groups and a variety of group learning opportunities. All services are provided at no cost to the patient and are supported through various funding sources. The Folsom Report encourages accountability through measurable outcomes using reliable and valid tools for program evaluation. As such, the effect on multiple psychosocial and behavioral domains is evaluated using four questionnaires that are well validated among patients with cancer and survivors; these self-report surveys are completed at enrollment and at three additional time points. These four instruments include: the Functional Assessment of Cancer Treatment General version (FACT-G)\textsuperscript{13} to evaluate quality of life, including physical, social, emotional, and functional well-being; the Brief Symptom Inventory (BSI-18)\textsuperscript{14} to measure psychologic distress; the International Physical Activity Questionnaire (IPAQ-short version)\textsuperscript{15} to assess participation in physical activity; and the Multi-Factor Screener from the 2000 National Health Interview Survey (NHIS) Cancer Control Supplement\textsuperscript{16} to evaluate dietary intake, including processed meat, fruits and vegetables, saturated fats, and grains and beans.

In 2 years, the program has received more than 1,400 patient referrals from community partners, internal staff, and program participants. During this time, the bi-lingual multidisciplinary survivorship team has enrolled more than 400 cancer survivors, with more than 6,000 patient encounters (Fig. 2). ProComS survivors averaged 14 encounters across the various disciplines. Preliminary analysis indicates improved function for these participants with improvements in quality of life, physical activity, and dietary intake and a decrease in psychosocial distress. These intermediate measures are reviewed with the CAB along with other short-term outcomes such as patient satisfaction. Although approximately 30% of survivors referred actually participated in the program, an estimated 20% of nonparticipants reside in rural areas surrounding Dallas-Fort Worth. Distance to the program is a formidable barrier to care, despite invitation and expressed interest in the clinic and the services provided.

Leveraging its relationships with stakeholders in eight surrounding rural counties established through other programs, UTSW-MCI will expand its multidisciplinary survivorship services using a mobile delivery model (Fig. 3). Recognizing that mobile care programs have been used to successfully provide a variety of clinical services including primary care,\textsuperscript{17} perinatal care,\textsuperscript{18} preventive services, and health education in rural populations,\textsuperscript{19} UTSW-MCI intends to implement its evidence-based program using this health delivery model. Recognizing that the survivorship phase of care represents a distinct opportunity to improve health and quality of life for rural cancer survivors, the program will address lingering medical and psychosocial effects of treatment, detect recurrent or new cancers, and promote healthy lifestyle changes.

Community needs assessments have identified a shortage of organized evidence-based cancer survivorship services within the specified service area in addition to a lack of public or charitable transportation services. These barriers, when combined with health professional and facility shortages, patient inexperience in accessing care within a complex medical network, and an overarching hesitation among residents to seek help outside of a zone of familiarity, negatively affect a cancer survivor’s ability to receive appropriate post-treatment survivorship care. As such, the implementation of this mobile survivorship clinic is anticipated to have profound effect on addressing these barriers.

**SURVIVORSHIP HEALTH CARE IN THE INTERNATIONAL SETTING**

Paralleling the activity in the United States, many centers around the world are developing survivorship programs and initiatives. Here we provide an example of a program outside of the United States that is being implemented nationwide.
Implementation of Survivorship Programs in the Setting of a Nationalized Health Care System

The National Health System (NHS) in the United Kingdom, established in 1948, provides health care to all free at the point of delivery including primary, secondary, and tertiary care. During the first decade of the 21st century, there was a swell of opinion that cancer survivors were not adequately served, highlighted in the Cancer Reform Strategy published in 2007.20 Key information included the publication of the prevalence of those alive in the United Kingdom after a diagnosis of cancer21 and the description of the prevalence of unmet needs in the year following treatment.22 A multidisciplinary Think Tank event was held involving a range of stakeholders including survivors, parents, and caregivers (i.e., people who support cancer survivors) together with charities involved in cancer care. Patient focus groups were held to define the scope of the program. As a result, the National Cancer Survivorship Initiative (NCSI) launched in 2008 as a partnership between the Department of Health (England), Macmillan Cancer Support (cancer charity), NHS Improvement (national organization supporting quality improvement), and other third-sector organizations (not-for-profit organizations such as CLIC Sargent and the Teenage Cancer Trust). The primary aim of the NCSI is to reduce the effect of cancer and its treatment on the health and well-being of survivors of cancer in adults, young people, and children. The definition of cancer survivor used included anyone living following a diagnosis of cancer.23 A multidisciplinary Think Tank event was held involving a range of stakeholders including survivors, parents, and caregivers (i.e., people who support cancer survivors) together with charities involved in cancer care. Patient focus groups were held to define the scope of the program. As a result, the National Cancer Survivorship Initiative (NCSI) launched in 2008 as a partnership between the Department of Health (England), Macmillan Cancer Support (cancer charity), NHS Improvement (national organization supporting quality improvement), and other third-sector organizations (not-for-profit organizations such as CLIC Sargent and the Teenage Cancer Trust). The primary aim of the NCSI is to reduce the effect of cancer and its treatment on the health and well-being of survivors of cancer in adults, young people, and children.

Their preliminary work contributed to a Vision document24 and a summary of research findings and questions.25
A strategy of "investigate, innovate, and implement" was taken forward over the following 7 years. Five major phases in the cancer pathway were identified, and cancer prevalence was estimated for each phase to understand resource implications for each cancer. These phases included diagnosis and treatment (taken to be the first year after diagnosis), recovery (taken to be the second year after diagnosis), early monitoring (2 to 5 years following diagnosis when the risk of recurrence and first onset of persistent treatment-related consequences is highest), late monitoring (greater than 5 years postdiagnosis, when late consequences usually emerge), progressive disease (including complex treatment-related consequences, taken from the point of recurrence or identification of complex treatment consequences), and end-of-life care (defined as care during the last year of life) (Fig. 4).26

Four cancer types (breast, colorectal, prostate, and lung) were selected to test and pilot models of care, with the goal of redesigning pathways of care after primary treatment for cancer and shifting activity from routine follow-up appointments, which do not always add value, to rehabilitation and support for self-management after treatment when indi-

FIG 4. United Kingdom National Health Service breast and lung cancer pathways.
cated, with identification and management of those with complex problems. The principles behind risk stratification for each pathway are similar for adults and for children and young people (CYP). Personalized care linked to individual circumstances, needs, and preferences is key, rather than a sole dependence on the cancer type, treatment, or time from treatment. To help empower survivors, they receive a structured holistic needs assessment and care plan, treatment summary, support and education events, and a review by a primary care physician. The treatment summary provides clear written instructions on how to obtain rapid access to any necessary care via a care coordinator. These key principles support survivors to self-manage as much as possible. Implementation is ongoing with early pathway evaluation approved by the National Institute for Health and Care Excellence (NICE) with a how-to guide published to assist local teams. In 2013, the NCSI published Living With and Beyond Cancer: Taking Actions to Improve Outcomes, which set out the knowledge gained to date to support commissioners, providers, and others to take the actions necessary to improve outcomes for cancer survivors.

The CYP workstream had the same objectives as above; however, the process differed as it covered the whole survivorship pathway for all cancers diagnosed. This was because the organization of childhood cancer services differs. Only 22 centers in the United Kingdom treat all children with cancer, amounting to about 1,500 new patients per year with 30,000 centers in the United Kingdom treat all children with cancer, the organization of childhood cancer services differs. Only 22 Vor will be discussed in a multidisciplinary team meeting. This work is supported by NHS Improvement and in the third sector (e.g., charities, volunteers, and community groups). Three key questions were asked before embarking on the change program: what are we trying to achieve? what change will result in improvement? and how will we know this resource, the intent of the Committee is to provide a fast and efficient method to download or print information that would be helpful in different settings by different types of providers.

Three patient pathways were developed for children and young adults. The pathways require that each survivor receive a personalized SCP. Each patient is stratified to a different model of care depending on his risk of late effects. The pathway is flexible and includes elements of information transfer and education. At different time points, each survivor will be discussed in a multidisciplinary team meeting. Underpinning this pathway was the testing performed by the different centers (Fig. 5). “National champions” supported by the NCSI assisted in the program alongside the effective professional national network of the CCLG and the Teenagers and Young Adults with Cancer. Implementation is, in part, dependent on the health providers receiving enough recognition from commissioners to commission this service. A cost-benefit analysis was performed that suggested an effective service may not be cost-effective in the short term; however, providing effective monitoring and health prevention services should benefit survivors by reducing those lost to follow-up, thereby reducing hospital appointments and emergency admissions.

THE ASCO CANCER SURVIVORSHIP COMpendium

One of the major initiatives of the ASCO Cancer Survivorship Committee since its inception in 2010 has been to develop a toolbox for providers. Emanating from this aim is the ASCO Survivorship Compendium, recently launched on the ASCO website. As an accompaniment to the educational opportunities and clinical guidance ASCO offers on survivorship care, the Survivorship Care Compendium will serve as a repository of tools and resources to enable oncology providers to implement or improve survivorship care within their practices. Although ASCO endorses the National Coalition for Cancer Survivorship definition of a cancer survivor as starting at the point of diagnosis, the focus of the information and resources offered throughout this compendium will be on those individuals who have completed curative treatment or who have transitioned to maintenance or prophylactic therapy.

The compendium has two primary sections: Putting Survivorship Care into Practice and Online Resources. The former section includes key components of survivorship care, building a survivorship care program, implementing survivorship care in practice, and measuring the quality of survivorship care. Online resources linked to the website include clinical tools and resources, coverage and reimbursement information, educational opportunities, resources for patients and families, and research resources. ASCO’s updated SCP template is included in the Compendium as well. In developing this resource, the intent of the Committee is to provide a fast and efficient method to download or print information that would be helpful in different settings by different types of providers.

CONCLUSION

Since the 2005 IOM report on cancer survivors, much has occurred in the United States and worldwide to improve the care of cancer survivors. Although there remains much to do in terms of testing different models and components of those models to see what works in different settings, the paradigm of survivorship health care has rapidly evolved and is increasingly being adopted.
Disclosures of Potential Conflicts of Interest

Relationships are considered self-held and compensated unless otherwise noted. Relationships marked “L” indicate leadership positions. Relationships marked “I” are those held by an immediate family member; those marked “B” are held by the author and an immediate family member. Relationships marked “U” are uncompensated.


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