

# Addressing Survivorship in Cancer Care

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## Abstract

As a disease, cancer can affect an individual's well-being, from physical to psychological, social, and even spiritual wellness. The cancer survivor population must navigate a complex, constantly evolving field, with the assistance of their care team, to conquer the disease. To address the unmet needs of the cancer survivorship community, NCCN conducted an environmental scan of existing and emerging aspects of survivorship cancer care through stakeholder meetings with survivors and patient advocacy groups to discuss needs, opportunities, and challenges in providing high-quality, patient-centered cancer survivorship care. The findings of this environmental scan directly informed the corresponding NCCN Patient Advocacy Summit: Addressing Survivorship in Cancer Care, held in Washington, DC, on December 1, 2017. In addition to the many patient advocacy groups, the summit featured stakeholders from all relevant areas of survivorship care. This article encapsulates the findings of the thorough environmental scan and the discussion from the NCCN Patient Advocacy Summit, including identified gaps and needs in addressing survivorship in cancer care.

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## Executive Summary

Advances in early detection and improved treatment during the past 30 years has led to a new issue in the oncology landscape: the unmet needs of the cancer survivor community. As of January 2017, there were >16.8 million Americans with a history of cancer, a figure that is estimated to increase to >20 million by 2026.<sup>1,2</sup> For those living through and beyond a cancer diagnosis, the disease can affect an individual's physical, psychological, psychosocial, social, economic, and spiritual well-being. The cancer survivor population might experience varying chronic side effects of treatment based on cancer type, specific treatments, and individual characteristics. Moreover, there is an increasing recognition of other common and substantial consequences of cancer and its treatment, including challenges associated with resuming activities of daily living and reintegration into the workforce. Navigating the survivorship journey is a complex process, requiring tools and processes that facilitate effective communication between patients, providers, caregivers, and the extended care team. Beyond the growing body of scientific literature and evi-

dence-based tools for cancer survivorship, many questions remain regarding how to assess, treat, and prevent survivorship-related problems to promote high-quality, patient-centered cancer care.

To address the unmet needs of the cancer survivorship community, NCCN convened the NCCN Patient Advocacy Summit: Addressing Survivorship in Cancer Care in Washington, DC, on December 1, 2017. In preparation for the summit, NCCN conducted an environmental scan of existing and emerging aspects of survivorship cancer care through stakeholder meetings with survivors and patient advocacy groups to discuss needs, opportunities, and challenges in providing high-quality, patient-centered cancer survivorship care. The corresponding Patient Advocacy Summit featured stakeholders from the environmental scan and included survivorship discussions by the multistakeholder, multidisciplinary larger cancer care community (see [supplemental eAppendix 1](#), available with this article at [JNCCN.org](#), for a list of participating speakers and panelists).

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## Cancer Survivor Perspective

Diagnosed with multiple myeloma at 25 years old, keynote speaker Yelak Biru had been a cancer survivor for >22 years. Mr. Biru highlighted several issues he faced as a survivor, most of which rely on the ability of survivors and providers to adequately address and manage chronic physical and psychosocial effects. To address the growing number of cancer survivors, Mr. Biru emphasized that the oncology community must come together to address the complexities of survivorship care and help this growing community adapt to a “new normal.”<sup>3</sup>

Since the development of the survivorship movement, stakeholders and patients have used varying definitions of “cancer survivor” and “cancer survivorship.”<sup>4</sup> Definitions often vary around scope of population covered, phases in a cancer trajectory, and individual patient preference. Most clinical experts, including the NCCN Clinical Practice Guidelines in Oncology (NCCN Guidelines) for Survivorship, consider an individual a cancer survivor from the time of diagnosis through the balance of their life.<sup>5</sup> It is important to understand and convey the various meanings of cancer survivor and cancer survivorship used in advocacy, research, and policy.

To appropriately address survivorship needs, effective coordination of care must be established between healthcare providers, particularly regarding the transition between an oncologist and primary care physician (PCP). This posttreatment transition often gives patients severe anxiety, and patients and patient advocates report significant barriers to the coordination and communication between healthcare providers.<sup>3</sup> Mr. Biru noted the importance of self-advocacy because “nobody cares about me more than me.”<sup>3</sup> He encouraged patients to keep detailed records of personal data and discuss posttreatment goals with providers to help facilitate effective communication. Moreover, self-advocacy facilitates active patient engagement, which studies have shown to improve outcomes and quality of life (QoL).<sup>6</sup> Transitioning from oncologic care back to primary care can be overwhelming, but ownership of data and active participation in care planning can ease the post-care transition. However, some patients may not transition back to primary care due to the incurability of their cancer. Many of these patients will also need to use survivorship care plans (SCPs) to help them live with their cancer.<sup>3</sup>

## Viewpoint on Cancer Survivorship From Patient Advocates

The launch of the survivorship movement in the United States is tied to the 1985 publication of Dr. Fitzhugh Mullan’s article detailing his experience with cancer,<sup>7</sup> as well as the creation of the National Coalition for Cancer Survivorship just 1 year later.<sup>8</sup> At the forefront of the movement is the patient; however, cancer is a family disease, and the impact on caregivers cannot be ignored. Cancer affects patients, family members, and caregivers, and addressing the physical, emotional, and financial damage of cancer must be a focus throughout survivorship care.

A high point of distress for people with cancer is the transition into the post-acute phase of treatment, whether it is at first diagnosis or a recurrence.<sup>9</sup> Survivors often feel they are losing their safety net of regular checkups with the oncologist who fought alongside them through their disease. PCPs play a leading role in survivorship support because they will be the regularly seen, central provider posttransition.<sup>9</sup> However, the primary care community remains confused about what cancer survivorship means and may lack the resources to care for this population.<sup>10</sup> To address this gap, the oncology community can provide additional education on survivorship care to and facilitate open communication with the primary care community.<sup>5</sup>

An emerging process to help the transition from oncologist to PCP is to provide survivors with an SCP. A comprehensive SCP includes a personalized summary of previous treatment received, information regarding surveillance recommendations, posttreatment needs including information on treatment-related effects, delineation of the role between oncologist and PCP, healthy behavior recommendations, and identification of supportive care resources.<sup>11</sup> For an SCP to be useful, it must be detailed and actionable for the PCP to implement.<sup>9</sup>

Despite endorsement from the Commission on Cancer, a Fight Colorectal Cancer (Fight CRC) focus group of 35 patients who completed treatment within the past 3 years found that only 1 had an SCP.<sup>9</sup> The panel agreed that if patients, their families, or their caregivers do not know how to ask for an SCP, they likely will not receive one.<sup>9</sup> A dearth of evidence demonstrating that SCPs improve outcomes is a major impediment to their more widespread adoption. Additionally, lack of ownership of the formulation of an SCP is a primary reason they

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are not more commonly implemented.<sup>5</sup> Lastly, there is no mechanism to pay for the development and advisement of SCPs, and they require precious time and practice resources to implement.

A common misconception among the public is the association of palliative care with hospice care. Hospice care is exclusively used in end-of-life care, whereas palliative care is a complement to the management of side effects, late-term effects, and pain management, and should be used from active treatment through survivorship.<sup>12</sup> For survivors living with their disease, maintenance therapy through palliation should be a part of the treatment plan. Early identification of distress through routine screening is an important part of palliative care, and must start at diagnosis and continue into survivorship.<sup>4</sup> Shifting the public understanding of palliative care should be an immediate goal for oncology stakeholders.

Latent and long-term side effects of cancer treatment across a survivor's lifespan add another layer of complexity to adequately addressing survivorship issues. It is estimated that >350,000 cancer survivors were first diagnosed when they were aged <21 years and that >80% of children treated for cancer survive for ≥5 years after treatment.<sup>13</sup> Adult survivors of pediatric cancer and survivors who were diagnosed as young adults experience similar survivorship issues and face additional barriers to posttreatment care. Further, children and young adults have higher rates of exposure to long-term risks, both physical and

emotional, because of their unique treatment regimens.<sup>14</sup> The psychological effects of treatment is of great importance for childhood survivors, because children and young adults experience the trauma of cancer and its treatment during their developmental stages.<sup>15</sup> For young adults, dealing with cancer survivorship includes sexual and fertility considerations that may have long-term implications for family planning and sexual health. Caregivers may also play a larger role in the stewardship of SCPs for pediatric and young adult survivors.<sup>9</sup>

### Patient Advocacy Resources for Survivors

To understand the unmet needs of the survivorship community, NCCN conducted numerous stakeholder meetings with survivors and patient advocacy groups, which then informed the content of the corresponding Patient Advocacy Summit. Four patient advocate groups participated on the first panel: LIVESTRONG, Cancer Support Community, the Children's Cause for Cancer Advocacy, and Fight CRC. To highlight the range of resources that the patient advocacy community provides for survivors, 6 advocacy groups presented various survivorship programs during the summit (Table 1). Additionally, presentations of 2 best practices in the field highlighted innovative collaborations among stakeholders in the survivorship community.

**Table 1. Survivorship Resources and Collaborations**

Organization	Survivorship Program	Program Description
Cancer Hope Network	Patient Service Coordination Network	A fight with cancer doesn't end on the last day of treatment. In fact, the end of treatment is often the beginning of a new normal. From fears of a recurrence to treatment-induced health problems or a newfound desire to focus on what's most important, Cancer Hope Network's trained Support Volunteers help individuals navigate their survivorship journey.
Live by Living	Outdoor Experiences	Live By Living provides transformative outdoor experiences for cancer survivors and their caregivers. Day hikes, snowshoe outings, and cancer survivor retreats are structured to help individuals build up their strength and stamina, to find solace in the beauty of nature, and to inspire, and be inspired by, others who are traveling along the cancer journey.
Living Beyond Breast Cancer	Survivorship Beyond Breast Cancer	Living Beyond Breast Cancer offers a variety of survivorship programs in four core areas: in-person, online, by phone, and in print. All resources are free, carefully and frequently reviewed by some of the country's leading health care experts, and informed by people living with breast cancer.
LUNGevity	LUNGevity Lung Cancer Support & Survivorship Programs	LUNGevity Lung Cancer Support & Survivorship Programs connect people affected by lung cancer with other patients, survivors, caregivers, and medical experts to get the support they need at any point in their lung cancer journey. LUNGevity's Survivor Resource Center helps to bridge the practical and emotional gaps in lung cancer survivorship while offering a vast network of support for survivors and their loved ones.
NCCN Foundation	NCCN Guidelines for Patients	NCCN seeks to support the millions of patients and their families affected by a cancer diagnosis through development and distribution of NCCN Guidelines for Patients. NCCN Guidelines for Patients are based on the same clinical practice guidelines used by health care professionals around the world, with each resource designed to help people living with cancer talk with their providers about the best treatment options for their disease.
National Ovarian Cancer Coalition (NOCC)	CancerConnect Community	NOCC's CancerConnect Community is for everyone whose life has been touched by ovarian cancer. It is a place where constituents, patients, survivors, and caregivers can safely voice their ideas, thoughts, and concerns, benefit from the experience of others, and most importantly, realize that they are not alone. <sup>9</sup>

<sup>9</sup>Patient advocacy update: resources for cancer survivors. Presented at the NCCN Patient Advocacy Summit: Addressing Survivorship in Cancer Care; December 1, 2017; Washington, DC.

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### Florida Society of Clinical Oncology Patient Advocacy Initiatives

The Florida Society of Clinical Oncology (FLASCO) is a member-supported state society that provides education, acts as an advocate, and leads initiatives to support oncology care providers and patients with cancer. Among FLASCO's various initiatives is patient advocacy. Through an initial patient advocacy roundtable, FLASCO found education for patients with cancer and survivors to be an unmet need identified by both providers and patients. To meet this need, FLASCO developed disease-specific patient advocacy outreach programs for patients and caregivers: their "Living With" series.<sup>16</sup>

The "Living With" series brings together cancer survivors, caregivers, oncology experts, and corporate supporters to learn and exchange information on various types of cancer. The objectives of the program are for patients and caregivers to become educated about their specific disease, better understand their treatment options, learn about patient assistance programs, and learn about the role of the caregiver. The series features oncologists who discuss how providers share knowledge and work together for the benefit of the patient. The oncologists also discuss their involvement in the treatment plan for each patient/survivor.<sup>16</sup> Importantly, FLASCO highlights available resources for survivors and questions they can ask their providers, and teaches survivors how to become their own advocates in survivorship care.

These advocacy programs provide valuable information to patients, survivors, and caregivers, as well as an opportunity to connect with local oncologists. The program has expanded to reach more patients throughout Florida since its introduction.

### Fusing Public Health, Academic Medicine, and Patient Advocacy

Since 2014, a collaboration between the University of Colorado Cancer Center, Fight CRC, and the Colorado School of Public Health has provided an innovative opportunity for patient advocates, patients, and providers to further engage the survivorship community.<sup>17</sup> This collaboration focuses on patient education, research advocacy training, and clinical trial engagement.

Fight CRC created educational materials that provide critical information for patients. Through working with patient advocacy groups, Fight CRC

determines which topics require additional education and support for the survivorship community. This process results in the creation of actionable resources, which are sent to the University of Colorado Cancer Center, where clinical accuracy is ensured. Input from patient advocates in the development and review of their resources is the backbone of effective material development for Fight CRC. The ultimate goal is to help patients become empowered to ask their provider about issues affecting their care.<sup>17</sup> For example, Fight CRC created a campaign called Biomarked to increase awareness of the importance of biomarkers in colorectal cancer.

### Navigating the Cancer Survivorship Landscape From a Multistakeholder Perspective

Cancer survivors may experience chronic side effects that can significantly impact their current and future QoL. Compared with the general population, survivors face a higher risk of comorbid illnesses, such as cardiovascular disease, osteoporosis, multiple malignancies, and secondary cancers. These comorbidities are accompanied by the complexities associated with polypharmacy.<sup>18</sup> Moreover, the cancer survivor population may experience varying chronic side effects of treatment based on their cancer type, specific treatments, and individual characteristics, including age. To address the unique and varying needs of survivors, panelists described the importance of survivorship clinical trials, expanded research to demonstrate the value of survivorship planning, and a greater focus on the psychosocial well-being of cancer survivors and their family members.<sup>19</sup>

Within traditional therapeutic clinical trials, end points usually include disease-free or progression-free survival. Survivorship clinical trials use a more holistic approach to include patient-reported outcomes focused on QoL, symptom burden, and economic implications of treatment, among other outcomes. Emphasis is given to ensure the medical community's focus is not on cure at any cost. Providers must better understand QoL after treatment, patient values, financial outcomes, and patient tradeoffs.<sup>19</sup> Under the direction of the NCI, the Office of Cancer Survivorship (OCS) supports research to improve survival and QoL in individuals treated for cancer. In 2016, OCS awarded 216 grants to support research that examined

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long- and short-term physical, psychological, social, and economic effects of cancer.<sup>19</sup> Moreover, the Patient-Reported Outcomes Measurement Information System (PROMIS) program under the NIH is working to set the standard for patient-reported outcomes that have a significant impact on QoL. From an industry perspective, there are emerging novel outcomes in clinical research that have implications for survivorship, including minimal residual disease, treatment-free intervals, and tolerability. Panelists acknowledged the need to balance the collection of long-term data from cancer survivors with the burden of a research study on individuals, including the significant barriers to participating in clinical trials (eg, transportation, cost, time commitment).<sup>19</sup>

Survivorship care occurs within the complexities of the US healthcare system, with changing dynamics regarding delivery of care and subsequent payment. With trends indicating that there are fewer oncologists and PCPs in the workforce, both of whom are key medical providers for cancer survivors, it will be essential to train diverse providers, including nurses, nurse practitioners, physician assistants, and caregivers, on survivorship care for cancer survivors.<sup>19</sup> Furthermore, as CMS and other payers transition toward value-based reimbursement models, it will become increasingly important to demonstrate the value of cancer survivorship planning through increased research on patient-reported outcomes and inclusion in quality metrics. As part of the Oncology Care Model (OCM), demonstration sites need to document an SCP that outlines a summary of treatment and information on recommended follow-up, surveillance, risk reduction, and health promotion activities.<sup>20</sup> When looking at the efficacy of SCPs, there are limited data showing improved outcomes. However, panelists argued that current research may not explore outcomes that adequately reflect the benefits patients receive from this type of plan (eg, knowledge transfer, change in health behavior, appointment retention).<sup>19</sup> Furthermore, with the exception of the OCM, there are growing concerns about the lack of standardized billing codes specifically for survivorship care planning, follow-up treatment, and care team coordination.

There is an increasing demand for tools and measures to address the prevention and management of posttreatment psychosocial effects among cancer survivors, family members, and caregivers. The NCCN

Guidelines and their derivative products include algorithms comprising recommendations for screening for anxiety, distress, and depression, specifically designed for survivorship care. The NCCN Guidelines include recommendations for providers to help patients manage psychosocial needs while recognizing the importance of referring to other practitioners for additional psychosocial services. Panelists highlighted the improvements in screening for and measuring distress, anxiety, and depression, but identified the lack of functional measures for practical distress and outcomes, especially regarding financial toxicity and employment challenges. It is important to acknowledge that there are additional hurdles in implementing psychosocial services and care team coordination within smaller and more rural practices. Ultimately, by validating these aspects of survivorship care through evidence-based guidelines and standardization across practice settings, the cancer care delivery system can better address psychosocial needs among the survivorship population.

The cancer care community is shifting toward an understanding that “a cure is not enough.”<sup>21</sup> There is a movement to think beyond the length of survival, toward QoL after a cancer diagnosis. As the number of cancer survivors grows, various stakeholders are increasingly focused on addressing the unmet needs of the cancer survivorship population to promote optimal survivorship cancer care.

## Conclusions

Patient advocacy groups are vitally important to ensuring that patients have the resources and tools they need to access high-quality care from diagnosis to treatment and throughout survivorship. Multistakeholder groups that bring together survivors, caregivers, providers, and researchers provide an invaluable service to the oncology community. It is only through active education and research that we can provide high-quality, patient-centered survivorship care for all. Moving forward, there is a need for comprehensive coordinated care across the healthcare system posttreatment, adequate reimbursement mechanisms for posttreatment care, and research to define and quantify optimal service delivery in providing high-quality, patient-centered survivorship care.

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