

Elevating Survivorship: Results from Two National Surveys

CANCER SURVIVORSHIP

The Current Landscape

As of 2016, there were almost 16 million adults and children living with a history of cancer in the United States, a number that is anticipated to grow to more than 20 million by 2026 as the number of effective cancer treatments grows.¹ While for many organizations, including the National Coalition for Cancer Survivorship (NCCS), the National Cancer Institute, and the Association of Community Cancer Centers (ACCC), cancer survivorship begins at the time of cancer diagnosis, the concept of cancer survivorship is often equated with the period following treatment. However, that concept is evolving, as more people are living longer with metastatic and chronic cancers.² Following initial cancer treatment, patients are increasingly referred back to their community or primary care providers, who, ideally, share follow-up care with oncologists and other cancer specialists. Therefore, most healthcare providers (HCPs) beyond the oncology setting can expect to encounter a greater number of post-treatment cancer survivors in the coming years.

The gains in cancer treatment are considerable, especially in relation to durability of benefit associated with targeted and immuno-oncology (IO) therapies. Yet, cancer survivors continue to be increasingly exposed to a range of long-term and late side effects of treatment, including recurrent and new malignancies,

a myriad of physical effects, and psychosocial distress.³ These issues, combined with the growing number of survivors across different types of cancer, create an imperative to ensure a systematic planning process for survivorship care founded on evidence-based guidance.

The survivorship care plan (SCP) is a key resource in this planning process. In 2006, the Institute of Medicine (IOM) recommended a SCP as a treatment summary and follow-up care plan that should be developed by the oncology care team for patients completing primary treatment. Proceedings from a 2018 IOM workshop endorsed the SCP as a guide to support communication and coordination of treatment among the patient, the oncology care team, and the primary care team,⁴ and several SCP templates are available from professional and advocacy organizations to support SCP delivery.⁵ SCPs are also required as a quality metric or accreditation standard by several bodies, including the National Comprehensive Cancer Network (NCCN), the American Society of Clinical Oncology (ASCO) Quality Oncology Practice Initiative (QOPI), and the National Accreditation Program for Breast Centers (NAPBC). The American College of Surgeons Commission on Cancer (ACS CoC) includes a SCP for patients who have completed 'active therapy' as Standard 3.3, required for cancer program accreditation. All CoC-accredited programs were expected to meet or exceed the delivery of SCPs to 50% of eligible patients by December 2018.

Despite the importance of survivorship care planning, community cancer programs are struggling with the process to develop and implement survivorship care planning due to lack of staffing and infrastructure. Notably, it is time consuming to prepare detailed and individualized SCPs and review their contents with patients and caregivers. The rising cost of cancer care, variation in reimbursement for survivorship care planning, increasing complexity of cancer

treatment, and rapid advancement in targeted agents and immunotherapies further exacerbate these challenges.

In order to explore experiences and needs concerning cancer survivorship from both the provider and the patient perspectives, ACCC and NCCS partnered to field two online surveys to oncology providers and cancer survivors, respectively.

Figure 1. Sample

| ACCC SURVEY | NCCS SURVEY |
|---|---|
| <ul style="list-style-type: none"> • Most respondents to ACCC's membership survey (n=93) identified themselves as clinicians in medical oncology, a majority (69%) of whom were nurses or nurse practitioners (NPs). • Approximately one-third of respondents (31%) practice in non-teaching community hospitals; 40% practice in academic medical centers or teaching hospitals; and 17% of respondents are in private practice. The remaining 11% work in freestanding cancer centers or prospective payment system (PPS)-exempt cancer hospitals. • Almost half (42%) of the institutions represented by respondents treat more than 16 new patients per month with cancer immunotherapies and 28% treat more than 21 new patients per month. • Lung cancer was the most common tumor type treated in the majority of settings (95%), followed by melanoma (58%), and colorectal cancer (51%). | <ul style="list-style-type: none"> • NCCS fielded an online survey with support from nine partner cancer organizations to a convenience sample of respondents drawn from multiple channels (n=1,380). • The sample was skewed female and White but otherwise well distributed across age and region, and respondents were differentiated by type and stage of cancer, treatment exposure, side effects, and demographics. • Respondents reflected a mix of income and education, although the sample skewed toward higher socioeconomic status (SES) than the general population. • Most respondents had private insurance (59%), 24% were Medicare beneficiaries, and 9% were Medicaid recipients. • Two-thirds of respondents were married and reflected a range of cancer types and stages; one-third were breast cancer survivors. • Few respondents described their health status as "excellent;" most described their health status as "good" (44%), "fair" (33%), or "poor" (12%). • Half the patients had completed treatment or were not in active treatment; 28% were receiving treatment for an initial cancer diagnosis; and 19% for recurrence. |

The surveys aimed to identify:

- Frequent and severe side effects that cancer survivors experience;
- Resources and support that cancer survivors want to manage side effects;
- Assistance and care that cancer survivors most need in post treatment;
- Challenges that providers face in planning for survivorship care;
- Technical support necessary to improve survivorship care; and
- Gaps in educational resources for both cancer survivors and providers.

CANCER SURVIVOR PRIORITIES AND CHALLENGES Experiences Before, During, and After Treatment

Consistent with NCCS' definition of survivor, the NCCS survey included patients regardless of their treatment status and asked questions probing their experiences both during and after treatment. Survivors across the board reported experiencing a range of physical and emotional side effects during and following treatment; however, more than half of respondents reported both fatigue and anxiety as the most common and longest-lasting effects (67% and 58%, respectively). Fatigue, anxiety, nausea/vomiting or diarrhea, muscle/joint pain, and depression were the top five reported side effects, with greater severity reported by those in treatment for an initial diagnosis. Anxiety and depression were higher among cancer survivors with annual incomes under \$50,000 and those currently enrolled in Medicaid.

Even though fatigue and anxiety were top concerns for the surveyed patients, these were the very issues they felt their providers addressed the least. While 51% of respondents viewed healthcare

providers as "very helpful" in addressing nausea/vomiting and diarrhea, fewer viewed these providers as "very helpful" in addressing other physical side effects such as muscle pain (28%) or neuropathy (27%). Fewer still viewed healthcare providers as "very helpful" in addressing feeling overly tired (24%), anxiety (25%), depression (24%), and cognitive effects (14%).

Many respondents said they wished they had known more about the severity of side effects and long-term management; mental health side effects; and fertility/sexual side effects.

Perspectives on Post-Treatment Survivorship

Although approximately half of respondents felt "somewhat" prepared for the transition from active to post treatment, few felt "very" prepared for this transition and one-third reported not feeling prepared at all. While most respondents had spoken with a healthcare provider—typically an oncologist and most commonly in a physician office—about post-treatment care, 54% reported that they initiated the discussion with their provider, and far fewer (30%) said their provider initiated these conversations. A significant proportion (16%) had no discussion at all. Few survivors report discussing financial support, survivorship plans, or emotional support prior to transitioning to post-treatment care (Figure 1).

Satisfaction with post-treatment care was mixed with just over one-quarter (28%) saying excellent, (38%) saying good, 20% saying fair, and few survivors (8%) stating poor. Indeed, some respondents felt that once they had transitioned out of active treatment, their oncology team no longer considered them a priority.

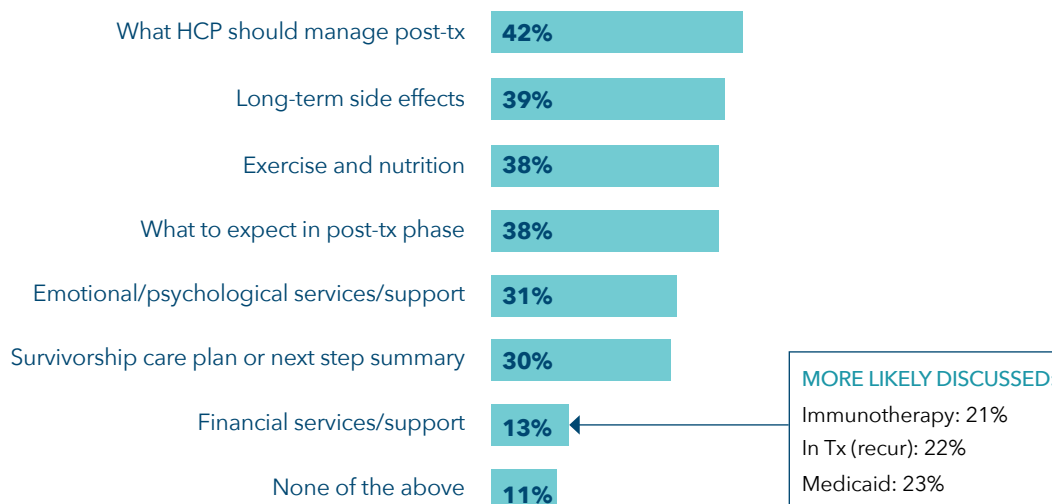
Things that Survivors Wish They had Known Before Treatment

I think there are "survivorship" issues that should really be discussed as part of treatment, not just when treatment ends.
[Completed treatment]

Survivorship was harder than treatments.
[Completed IO treatment]

I wish my healthcare team would address survivorship issues and long-term effects of my cancer diagnosis. At this point I am just told to call if there are changes in the way I feel. This leaves me feeling uneasy and uncertain about the future of my health. [In IO treatment for recurrence]

Figure 2. Topics Discussed Concerning Transition to Post-Treatment



Note: post-tx = after treatment completion in tx (recur) = in treatment for recurrence

Survivorship Needs

The NCCS survey explored multiple issues and challenges associated with survivorship, but the top five concerns identified were getting/keeping health insurance (45%), having the financial support that patients felt they needed (42%), managing ongoing side effects (42%), uncertainty about the future (41%), and having enough energy to get through the day (39%). Despite the high levels of concern expressed about these and other issues, less than one-third of respondents rated their healthcare provider as “very helpful” in responding to their main concerns, especially those relating to financial, insurance, and emotional issues.

Younger (ages 18-39) and more vulnerable survivors (low income, Medicaid, in poor health) had higher levels of concern across a range of issues and were less likely to say their providers had adequately addressed these issues. Patients in treatment for an initial diagnosis had the highest levels of concerns across a range of issues.

Many respondents expressed interest in accessing survivorship resources, especially for managing long-term symptoms, alternative medicine, insurance coverage, and exercise. Less than half (45%) of survivors relied on information from their oncologist and notably, although nurses/NPs have a role in providing post-treatment support and information, few respondents viewed them as their “go-to” resource. Instead, respondents across treatment or disease status groups relied on online sources (55%),

support groups (39%), and patient advocacy organizations (32%) for survivorship resources.

Immuno-Oncology Patients

While IO survivors (27% of respondents) shared many of the financial and psychosocial concerns that the other respondent groups voiced, they were more likely to report major concerns about visiting a physician regularly compared with non-IO respondents (41% vs. 28%) and about starting a family/having children (25% vs. 15%). However, IO respondents were more likely to report satisfaction with their post-treatment experiences than other respondents and were more likely to report feeling prepared for the transition to post-treatment (85% vs. 66%). IO respondents also reported fewer side effects than other respondent groups and higher levels of help from healthcare providers in dealing with their challenges. For instance, compared with non-IO respondents, IO respondents were more likely to say their HCPs had been “very helpful” in addressing financial and emotional concerns (32% and 32% vs. 15% and 23%, respectively) than other respondents. Most IO respondents had also undergone multiple treatments including chemotherapy (74%), surgery (73%), and targeted therapy (70%), but overall, felt they were getting appropriate care.

Although these findings potentially suggest that more effective survivorship care is being delivered to patients receiving cancer immunotherapies, this group was significantly younger than other survivor respondents and had higher income and education levels. Therefore, this group could have been better prepared than the rest of the sample to consider, manage, and discuss survivorship by virtue of age, socioeconomic background, and education.

Resources that Survivors Want

I am not critical of my healthcare providers for not helping with these services. I honestly don't expect them to—they need to concentrate on medicine. But I don't know where to go for help with these issues.
[In treatment, recurrence]

Being assigned a case worker to help with insurance benefits. Being assigned someone who can help find resources for my emotional support. I feel like I don't really know what is next. Feel a bit rushed in certain cases to get out of the office and move on. Then I try to live a normal life, but I don't know what that looks like.
[In treatment, recurrence]

Mental health counseling for anxiety about the future. Also navigating individual health insurance.
[In initial IO treatment]

I would like to meet more cancer survivors. I feel now that I am a different person and that no one understands what I've been through. Most people think that because you survived, that you are great and not in need anymore. It would be helpful to have some friends who have taken the same journey.
[Completed treatment for metastatic disease]

Caveat: The term “immunotherapy” may still not be widely understood by patients. At the time the survey was conducted 28% of respondents who indicated they had received immunotherapy (after reading a definition) had a diagnosis for which immunotherapies were not yet FDA-approved.

discussed a post-treatment care plan or next-step summary with patients transitioning from active to post-treatment care. Most respondents report they also discussed a range of other topics with patients, including what to expect in the post-treatment phase (76%), possible long-term effects of treatment (80%), and the availability of emotional or psychological support services (71%).

However, less than half of respondents said they discuss the availability of financial services and support (42%) or referrals to other providers for management of post-treatment care. Similarly, although a majority of cancer programs provide nutrition programs (74%) and mental health support groups (58%), few offer programs for managing long-term symptoms (27%), discuss integrative medicine (38%), or provide information about returning to work (43%). These findings were somewhat consistent with how respondents to the NCCS survey reported their survivorship planning discussions with healthcare providers.

FROM THE PROVIDERS' PERSPECTIVE: PRIORITIES AND CHALLENGES

Active Survivorship Care Planning

Several professional organizations have also developed resources or guidelines to support providers in survivorship care planning, including ACCC, NCCN, ASCO, and the Oncology Nursing Society (ONS). In ACCC's online survey of healthcare providers conducted from October to December 2018, a majority (86%) of respondents report their cancer program uses NCCN guidelines to support survivorship care, followed by ASCO (71%), ONS (47%), and ACCC (34%) recommendations. Over half (56%) of providers said they

Survivorship Care Plans

The ACCC survey found that although a majority (83%) of the cancer programs surveyed require the use of SCPs as part of their CoC accreditation process, only 20% of respondents

reported “always” providing SCPs to cancer patients while 54% did so “very often.” Other studies similarly suggest that SCPs are being delivered to a small population of cancer survivors.^{6,7} The ACCC survey also found that advanced practice providers (NPs or physician assistants) or navigators develop the SCP for a majority of institutions (70%), although the timing of SCP creation varied from the time of diagnosis (17%), at treatment conclusion (56%), and during treatment (11%). Similarly, recipients of the SCP varied. Almost two-thirds (60%) of institutions shared the SCP with patients; 44% shared with patients and caregivers; 65% with primary care physicians; and 13% with other treating providers.

A range of SCP templates is available from professional and advocacy organizations, including ASCO.⁵ ACCC’s survey found that 13% of cancer programs were using the ASCO SCP template; 22% reported using a commercial electronic medical record (EMR) vendor template; and 37% of cancer programs had created their own, in-house templates. Formats for delivery of the SCP also varied. Just over half (51%) provided a print SCP; 43% printed an SCP for the patient from the EMR; 22% created a digital SCP captured in the EMR; and 16% housed the SCP in the patient portal. These findings are broadly consistent with the variation reported in a 2018 IOM workshop on survivorship care.⁴

Barriers and Solutions to IO Survivorship Care Planning

Providers identified a range of barriers to survivorship care planning, especially in the context of treating patients with immunotherapies. First, for at least half of respondents, the identification of immune-related adverse effects (irAEs) and their differentiation from chemotherapy side effects posed specific challenges for IO survivorship care planning. These challenges were reflected in the irAE monitoring practices that respondents reported. Although 22% of cancer programs have a formalized follow-up procedure for patients treated with IO, 34% rely on informal follow-up, 19% on patient self-report, and 9% on reports from other physicians. Almost 16% responded that they do not monitor patients for irAEs following transition from IO treatment to post-treatment survivorship care. Unsurprisingly, one-third (36%) of respondents emphasized the importance of ongoing education for both patients and providers about the potential for irAEs and late effects of treatment.

Second, although there are general survivorship planning guidelines, the absence of specialized recommendations for IO survivorship care planning is a significant challenge for many programs (48%). For instance, the number of IO patients who transitioned to post-treatment survivorship care varied considerably across cancer programs (Figure 3).

Respondents noted that while survivorship care planning for patients with advanced disease is not yet required by NCCN and CoC standards, many IO patients with advanced disease

are living longer with stable disease. Accordingly, 21% identified targeted IO guidelines as vital to support IO survivorship care planning for patients who have not only completed treatment, but also for patients who have responded to and continue to receive IO therapy.

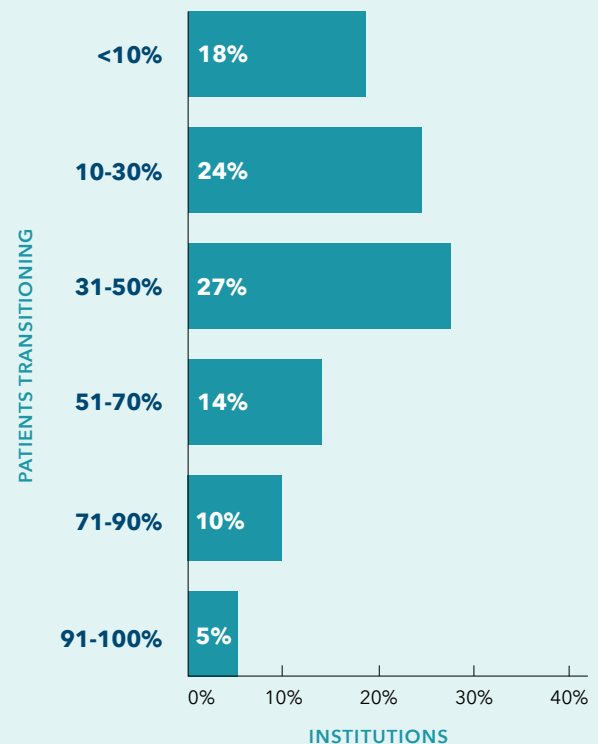
Third, respondents identified lack of staffing infrastructure (24%), a perception of low patient follow-up adherence (18%), and technical challenges (10%) as barriers to survivorship planning and, in particular, to creating SCPs.

ELEVATING SURVIVORSHIP

Current Survivorship Priorities

Both survivors and providers in these surveys reported having discussions about the transition to post-treatment survivorship. Yet, for a significant proportion of respondents these conversations appeared to mostly address logistics (e.g., responsibility for managing post-treatment care) versus the most urgent concerns for survivors. Insurance coverage, financial support, and long-term symptom management were priority concerns for cancer survivors, who expressed high levels of interest in accessing resources

Figure 3. Proportion of IO Patients Transitioning to Post-Treatment Survivorship



to manage these issues through their providers. However, both surveys suggest that while providers are helpful in addressing physical concerns, such as managing treatment-related side effects, few providers are currently providing information or access to financial or coverage resources.

Survivor respondents also identified post-treatment psychosocial support (e.g., counseling, support groups) as a key area of unmet need, since depression and anxiety are common mental health side effects of cancer treatment that can last well beyond treatment completion. Yet both surveys show that it remains challenging for providers to address these issues. Although some providers reported having discussions with patients about a range of topics associated with post-treatment survivorship, there was little indication of formal processes for survivorship planning, including long-term irAE monitoring in the context of IO treatment. Moreover, while advanced practice providers are more likely to be involved in planning/delivering survivorship care, few survivor respondents appeared to view nurses or nurse practitioners (NPs) as sources of information and support, relying, instead, on online and other resources.

Implications for Elevating Survivorship

NCCS survey results clearly illustrate the emotional and financial challenges that cancer survivors face, both during and long after their treatment. While survivors feel their physical needs are being addressed, they are not getting the help they need for some of the most frequent and severe side effects. Current consensus recommendations propose that at a minimum, planning discussions for survivorship care should be initiated at diagnosis, revisited across the survivorship trajectory, and frequently reinforced via multiple formats (i.e., verbally, via a written survivorship document, and, where possible, in the presence of caregivers). In order to engage in survivorship planning and ensure that survivor concerns are addressed, all members of the multidisciplinary team, including nurses, NPs, and primary care providers, need to be aware of the importance of survivorship planning and follow-up. Moreover, given the extent to which survivors look beyond the oncology team for support and resources, findings from this study underscore the need for education that equips all members of the multidisciplinary team to provide wide-ranging post-treatment survivorship support. These findings also highlight an opportunity for cancer programs to more fully meet patient needs by integrating and prescribing non-pharmacologic

supportive care services that draw on the expertise of a range of specialties (e.g., social work, psychology, and nutrition) and to reinforce the need for payers to reimburse these services. Finally, as IO therapies are used more extensively in the adjuvant setting, the concept of survivorship will need to evolve. ▲

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An article from the ACCC Immuno-Oncology Institute.
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