Survivorship: Tools for Transitioning Patients With Cancer

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Abstract
The number of cancer survivors will be increasing over the next decade. Caring for this burgeoning population will place demands on oncologists and primary care providers to meet the needs of the expected large numbers of new patients as the baby-boom generation ages. Many will live beyond 5 years and possibly for decades after diagnosis. Patients experience many transitions depending on the type and stage of cancer, its treatment, and the long-term or late effects they have from the disease and its treatment. The Institute of Medicine’s report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” recommends that patients be provided with a summary of their cancer treatment and follow-up care plan (ie, survivorship care plan [SCP]), including recommendations on healthy lifestyle behaviors and resources to promote self-care. This plan should be shared with the patient’s other health care providers, including the primary care provider. This will facilitate communication among providers and with the patient, which is a key component to quality care. The American College of Surgeons Commission on Cancer has also made providing SCPs to patients at completion of treatment a quality standard. Barriers to providing SCPs have been identified and include lack of time, reimbursement, and knowledge of late treatment effects and current guidelines. Survivorship guidelines are being developed by professional organizations that may be useful for providers. This article provides some practical tools that address these recommendations to help providers and patients with transitions along the cancer trajectory. (J Natl Compr Canc Netw 2014;12:1681–1687)

The number of cancer survivors needing follow-up care for their cancer history will increase over the next decade. Survival rates have improved with the advances in treatment and early detection.1,2 Compounding these numbers will be an increase in cancer diagnoses among the large aging population of baby boomers.3 Survivors’ longevity varies across the spectrum, with long-term survivors constituting a significant percentage of the population4 (Table 1). Providing care for these patients presents opportunities and challenges.

Transition has been identified as a time of difficulty during a patient’s cancer journey.5 Transition for adult cancer survivors was initially referred to as the phase after the acute diagnosis and completion of the initial intense treatment, or the time during which they adjusted to a new normal. Some patients enter a permanent phase of long-term remission, with continued survival or presumed cure.6 However, it has been recognized that patients may have multiple transitions as they are followed in their cancer care, and treatment completion has different definitions depending on the type and stage of cancer. Defining the end of treatment presents challenges: for example, patients with breast cancer may be on extended hormone therapy for 5 years, and most recently up to 10 years or more.7 For others, the initial phase of treatment may have ended, but their cancer is not cured and they will continue on extended management. Some patients may transition to death.6

Patients have differing expectations and needs depending on where they are in their care continuum, the type and stage of their cancer, and the practice setting in which they receive their care.6,5 In addition, patients move from frequent oncology visits early in the cancer care continuum to semiannual/annual visits as they live longer, and resume more frequent follow-up with their primary health care providers (PCPs) over time. These can be difficult times of transition, and ones in which...
the various roles of health care providers in the care spectrum are unclear.9

The Institute of Medicine’s report, “From Cancer Patient to Cancer Survivor: Lost in Transition,” addressed the needs of cancer survivors who felt lost in these transitions.5 Four essential components of survivorship care have been identified: (1) prevention of recurrent and new cancers with health promotion habits, including survivors using self-management; (2) surveillance for cancer spread, recurrence, or second cancers, along with monitoring for late effects, including psychological consequences; (3) interventions for these effects; and (4) coordination between the oncology providers and PCPs.5 Because many of these patients have comorbidities that develop with age, clinicians need to evaluate the potential risks for late effects of cancer treatment when caring for patients after treatment. Understanding the rates of chronic diseases among patients without cancer versus those with cancer is necessary to determine what symptoms are age-appropriate and which represent a greater burden in the survivor population. This will help with earlier identification of treatment-related problems to improve follow-up care.10

The article provides an overview of tools that are available for providers so that they can empower patients to refocus these transitions as opportunities to encourage quality self-management and health promotion. A synopsis of emerging survivorship guidelines for oncologists and PCPs is also provide, which are being developed to address the time when issues related to diagnosis and treatment have diminished and long-term management is the focus.

Table 1 Cancer Survivor Population

<table>
<thead>
<tr>
<th>Length of Survival</th>
<th>Cancer Survivors</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 y postdiagnosis</td>
<td>10%</td>
</tr>
<tr>
<td>1–5 y</td>
<td>21%</td>
</tr>
<tr>
<td>5–10 y</td>
<td>30%</td>
</tr>
<tr>
<td>≥10 y</td>
<td>39%</td>
</tr>
</tbody>
</table>


Shared Care

Ensuring best practices for the care of the survivor population is a concern with anticipated shortages of both oncologists and PCPs for these expanding volumes. Coordination and communication between providers, and including patients in this communication, is essential. The degree of shared care will be different based on risks and resources.5,11,12 Different models of survivorship care have been identified: disease-specific, general survivorship, community generalist, consultative, and shared care with and without transition to PCPs.1,11 The characteristics, pros, and cons of these various models are addressed in the ASCO Cancer Survivorship Compendium, along with other useful resources.13 In general, as survivors’ need for acute oncologic care diminishes, visits with oncologists decrease as routine follow-up with PCPs increases, and cancer becomes another comorbidity.14 PCPs manage multiple chronic conditions using guidelines for their proper management, and focus on evidence-based preventive care and screenings, with limited time for each patient visit.15 Medical oncologists and PCPs have identified barriers to/concerns about providing long-term care for cancer survivors as inadequate training, malpractice defense practice test ordering, preventive care concerns, lack of guidelines to address this population, and inadequate knowledge of long-term or late effects.12 Guidelines have been developed that can assist in the long-term care of cancer survivors.14,16–18 (Tool 1; see “Supplemental Tools” at right). Oncologists reported being confident in the management of recurrence surveillance and long-term/late effects (80% and 70%, respectively), whereas PCPs reported self-efficacy rates of 34% and 19%, respectively (both, P<.001) for these components of care.19

The NCI and the American Cancer Society (ACS) Survey of Physician Attitudes Regarding the Care of Cancer Survivors (SPARCCS) compared the beliefs, attitudes, knowledge, and practices among PCPs and medical oncologists regarding follow-up cancer care for breast and colorectal cancer survivors.20 These patients have a high percentage of long-term survivors, with guidelines from NCCN21,22 and ASCO23,24 providing nearly identical recommendations.25,26 The survey examined the overuse of imaging tests to evaluate for practices that could be a potential modifiable contributing factor.27 Both PCPs and oncologists deviated from these guidelines regarding follow-up care by recommending more testing, with more frequent intervals than recommended in clinical practice guidelines. However, PCPs were more divergent.25,26 Oncologists reported concerns with general
preventive care responsibility, insurance restrictions impeding tests and treatments, and patients requesting unnecessary testing, whereas PCPs felt inadequately trained and ordered more tests and treatments as malpractice protection.\textsuperscript{12,25}

Late effects are well-known in childhood cancer survivors, with their risks increasing with age.\textsuperscript{27} Much less information is available on adult cancer survivors’ late effects,\textsuperscript{4} but efforts are being made to address them systematically (Table 2; located at the end of this article). PCPs want clear clinical guidance, including surveillance for recurrences or second cancers, potential risks for side effects, and clear directions about their responsibilities.\textsuperscript{12,14,28,29}

The Canadian Association of Provincial Cancer Agencies produced a report that addressed supporting the primary care role in cancer follow-up. They also identified gaps in guidelines, electronic medical records (EMRs) weaknesses, resources, and communication issues. They concluded that communication among providers and patients with education will be essential to help patients through transitions and into long-term survivorship.\textsuperscript{30}

Given the variability in provider preparedness to address all aspects of survivorship care, information regarding late/long-term effects and other resources is needed. Table 2 provides examples of common effects. Information such as this could be provided to patients and/or providers and included with the survivorship care plan (SCP). Tool 1 includes useful resources for providers with a compilation of Web sites that include survivorship guidelines, family history, obesity/cancer patients for oncologists, care plan tools, calcium fact sheets for patients, and resources for PCPs that are accessible through UpToDate. Tool 2 is geared for patients, listing helpful Web sites that provide quality cancer information for patients and their families. Tool 3 provides information for patients about healthy living that addresses weight, exercise, dietary recommendations, calcium supplements, sun screen, and smoking cessation. Tool 4 provides genetic information for patients. To view these tools, see “Supplemental Tools” at right.

**Survivorship Care Plans**

The SCP has been suggested as a promising tool for improving communication, continuity, coordination, and patient knowledge.\textsuperscript{5,12} Recently revised to be more streamlined, it should include 2 parts: a treatment summary and a follow-up care plan.\textsuperscript{31} The treatment summary should at least include contact information of treating providers; a summary of the cancer with tumor type, stage, and grade, hormonal status, and/or marker information; and the treatment provided with dates, including surgeries, chemotherapy (names of drugs listed with year ending date), radiotherapy including the anatomic area treated and year ending date, and other therapies.\textsuperscript{5,31,32} The SCP should incorporate available evidence-based standards of care or clinical practice guidelines focusing on the surveillance of recurrences and late effects, management of late effects, prevention, and coordination components of survivorship care.\textsuperscript{5,33} Late effects are not only related to the type and stage of cancer and its treatment, but also vary for age, sex, comorbidities, genetics, and health habits, including diet, exercise, and smoking history.\textsuperscript{4} Along with surveillance, cancer screenings, and management of late effects, the SCP should include what symptoms to report and whom to call with concerns; healthy living recommendations; and resources for patients and families, including support groups and assistance for financial concerns.\textsuperscript{34}

With the new era of cancer genetics and the rapid developments that allow for targeted cancer surveillance and prevention strategies, family history is important for patients and providers to reevaluate over time. Family history is completed on new patients, but is not always updated by oncologists or PCPs.\textsuperscript{35} Understanding family history also encourages patients to be actively involved in the process. Approximately 10% of cancers are inherited. Thus, genetic information and recommendations on risk assessment should also be addressed in the SCP.\textsuperscript{34}

Results of a survey of Massachusetts physicians (108 medical and radiation and 400 PCPs), revealed that 56% of the cancer specialists provided treatment summaries, but only 14% provided SCPs; and 54% of PCPs received treatment summaries but only 16% received SCPs. Barriers identified for the lack of SCP use were lack of training and reimbursement and the lack of available standardized practice guidelines for follow-up care based on disease and treatment agents in all adult cancers.\textsuperscript{33} The SPARCCS sample, which consisted of 1130 oncologists and 1072 PCPs, reported that nearly half of oncologists provided treatment summaries and
34.2% of PCPs received them, and only 20.0% of oncologists provided SCPs and 13.4% of PCPs received them. These findings are also consistent with community oncology providers’ practices.

Nationally, fewer than 15% of patients receive a SCP, and fewer than 50% of the NCI cancer centers consistently deliver SCPs. This practice can be especially difficult in the community setting, because practitioners and oncologic care can be at multiple facilities. Radiation oncologists provided treatment summaries 85% of the time, with 54% of medical oncologists reporting completion. Summary information about chemotherapy can be more difficult to compile because of the long duration of adjuvant chemotherapy (6 months to 5 years), dose modifications, and uncertainty regarding when treatment ends. In addition, treatment summaries are often separate documents, with one addressing radiation received and the other summarizing systemic therapy. Overall, agreement exists that patients and PCPs need this information, but who should provide this SCP remains controversial.

The American College of Surgeons Commission on Cancer (CoC) has included dissemination of SCPs to patients at treatment completion as a new standard for accreditation to be phased into implementation by 2015. How to overcome implementation barriers, including costs, development time and resources, lack of reimbursement, and the unknown value of quality differences in outcomes, is still to be determined.

The hope is that widespread use of EMRs will facilitate standardized template formats that could directly populate fields in the treatment summary, reducing the need to track down information. EMRs may also provide easier completion through facilitating the ability of different providers to update the SCP throughout the cancer trajectory. Milestones entered by the interdisciplinary team, such as chemotherapy and radiation, can be entered into the same document. The use of EMRs was associated with greater completion and provision of treatment summaries and care plans among providers responding to the SPARCCS. This has been identified as an area for future research to determine how EMRs can best be incorporated into practice workflow. Pilot studies have been tried to automatically populate treatment summaries and provide SCPs by downloading data from registries with goals of maintaining quality and limiting practice burden. ASCO designed a Breast Cancer Registry based on the Quality Oncology Practice Initiative to provide patients SCPs at the point of care. The Colorado Central Cancer Registry also explored using data from cancer registries to populate SCPs.

### Patient Self-Management

Fear of cancer recurrence is a commonly reported problem for cancer survivors, but information is limited regarding severity level at different points in the cancer trajectory. Efforts to teach survivors self-management techniques could complement provider-based care. Survivors feel they bear more responsibility for self-care after treatment ends, and emphasize the need to know types and frequency of tests, information on what could happen, what their long-term/late needs may be, symptoms to report, and whom to call with concerns. Many have questions about genetic counseling, risks, and testing for their family. They also want information about lifestyle choices to minimize risk of recurrence, including questions about diet, exercise, and supplements.

The exercise habits of patients with cancer are poor, with less than 10% of cancer survivors remaining active during their primary treatments; 20% to 30% will be active after they recover from treatments. In addition, obesity has been identified as a risk factor for cancer and increased mortality during treatment. Patient motivation may be higher at the end of treatment, providing the ideal time to address healthy living. Multiple professional organizations have endorsed routine physical activity in cancer survivors, and ASCO has developed toolkits to address obesity for both survivors and providers (Tool 1; see “Supplemental Tools” at right). Tool 2 includes patient tools that address healthy living (see “Supplemental Tools” at right). Health promotion activities addressing diet, exercise, and smoking cessation should be shared by all health care providers throughout visits and transitions.

### Guidelines for Survivorship Care

NCCN and other professional organizations have developed survivorship and disease-specific guidelines that can be valuable tools for referring PCPs as they care for mutual patients. Tool 1 contains resources for all of these guidelines (see “Supplemental Tools” at right).
The ACS is developing guidelines specifically geared toward PCPs regarding the long-term follow-up of cancer survivors. The 10 cancer sites to be addressed are breast, colorectal, prostate, lung, gynecologic (cervix, ovarian, endometrial, and uterine), and head and neck cancers, and melanoma. The prostate cancer guideline is currently available. ASCO has released the first 3 guidelines for survivorship care, addressing chemotherapy-induced peripheral neuropathy, fatigue, and anxiety and depression. In addition, they have colorectal and breast guidelines, SCP templates (Tool 1; see “Supplemental Tools” at right), and a patient guide to cancer survivorship when treatment ends (Tool 2; see “Supplemental Tools” at right).

The Society of Gynecologic Oncology is creating guidelines for cervical, ovarian, endometrial, and uterine cancers, with templates and survivorship toolkits being developed for providers and patients (Tools 1 and 2; see “Supplemental Tools” at right).

NCCN offers specific survivorship guidelines that focus on wellness and prevention, providing healthy living recommendations including those regarding health behaviors and adult immunizations, and that address long-term/late symptoms, such as anxiety, depression, cognitive function, fatigue, sleep disorders, chronic pain, and sexual function (Tool 1; see “Supplemental Tools” at right). Additional guidelines are under development to encompass more of the issues survivors face.

The NCCN disease-specific guidelines include recommendations for cancer surveillance, with most addressing the first 5 years after diagnosis. Many of these guidelines also address disease-specific survivorship care.

Although most recurrences occur within the first 3 years, concern exists that these surveillance guidelines may miss later recurrences. Suggestions have been made for further risk stratification of specific treatment of cancer type and stage that would address recurrence patterns and/or potential late effects beyond 5 years. These could identify more clearly what laboratory tests, tumor markers, and imaging should be used for follow-up, what should be considered, and what is clearly not recommended. This may allow providers to better individualize surveillance regimens. This is another area for further research.

Conclusions

Although the value or impact of SCPs on quality outcomes has yet to be demonstrated in quantitative research studies, multiple anecdotal experiences and qualitative studies have reported the value of SCPs both being part of the medical record and to review with patients. Providers do feel SCPs provide useful information to enable PCPs to manage these patients. The hope is that the coordinated care potentially facilitated by SCP use will also control costs through preventing duplication of services with limited future resources. With limited PCPs and oncology providers, SCPs and other survivorship tools can empower survivors to become knowledgeable and active in self-management.

Patient Tools 2, 3, and 4 address most of the SCP elements identified in the Institute of Medicine fact sheet and the CoC Standard 3.3 (see “Supplemental Tools” at right). Healthy living recommendations can be copied into work documents and easily tailored and adapted for specific cancers, saving time while meeting survivors’ information needs. Many recommendations, such as those on weight, diet, exercise, and calcium supplementation, may be pertinent earlier in the cancer trajectory before the end of treatment or for patients who continue with long-term cancer therapy.

With EMRs, applications can populate sections with saved ‘macros’ or ‘insert dialogues’ for chemotherapy regimen drugs listed with only dates needing to be added to increase time efficiency. Late effects, screening, and surveillance recommendations could be rapidly populated into documents for oncologists’ frequent patient populations. The NCCN Clinical Practice Guidelines in Oncology for Survivorship include many resources for patients, including financial and work-related support (see SURV-B 1 and 2 in the most recent version of these guidelines, available online, at NCCN.org). These can be printed and provided as handouts as part of the SCP.

Most oncologists include an abbreviated treatment summary in the history of present illness. If time and tool constraints limit the use of a separate electronic treatment summary and SCP, providers should address the surveillance testing and schedule for patients, symptoms of recurrence, potential late effects, and who should be addressing each of these in the progress notes. These notes should be available to patients and providers. Tool 1 can be pro-
vided to referring PCPs to increase their self-efficacy in caring for cancer survivors (see “Supplemental Tools” at right).

The hope is that these tools will lead to smoother transitions, increasing efficiency in developing the SCP, and that they will be valuable resources for providers. Survivors, no matter where they are in their cancer trajectory, want to know what to expect, who and when to call, and that they will be cared for longitudinally.

References
