Transitioning to Cancer Survivorship: Plans of Care

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Recognition of the growing number of cancer survivors in the United States, combined with a greater awareness of the ongoing physical and psychosocial needs after cancer treatment, has created a groundswell of interest in designing quality care initiatives for cancer survivors.

The 2006 Institute of Medicine (IOM) report, From Cancer Patient to Cancer Survivor: Lost in Transition, defined the posttreatment period as a distinct phase of the cancer experience, which requires an individualized plan of care related to the treatment delivered.[1] Informing patients about the treatment they had, what they will need going forward, and who will provide it has been identified as an effective measure to ensure a successful transition from patient to survivor.[2] The second recommendation of the IOM report states that “patients completing primary treatment should be provided with a comprehensive care summary and follow-up plan that is clearly and effectively explained.” Despite many practical barriers, various organizations have responded by developing templates for implementation of survivorship care plans and nurses and other providers have adopted less formal ways of providing patients with written plans.

**What is a survivorship care plan?**
A survivorship care plan is the record of a patient’s cancer history and recommendations for follow-up care. The first part, the treatment summary, contains details of the cancer diagnosis and a listing of the various treatments administered. The details of the diagnosis should include the diagnosis date, type of cancer, location, stage, and histology, as well as the names and contact information of the providers and treatment facilities.
Treatment information should include the date range and name of the chemotherapy or biotherapy regimen, drugs, and doses (when relevant); radiation therapy, with the site treated, type of radiation, field, and dose; and any surgical procedures. Additional treatments such as bone marrow transplants and clinical trials should be recorded, as should management of outstanding complications such as chronic graft-versus-host disease following transplant. A comprehensive cancer treatment summary is important for identifying long-term health problems related to the cancer and treatment effects, particularly as the patient transitions away from oncology specialists. In the event of a recurrence or second cancer diagnosis, a record of previous anticancer therapy is essential for safe, effective treatment planning (see Figure 1, “MSKCC Summary of Cancer Treatment and Follow-Up Plan”).

The second part, the follow-up plan, contains specific recommendations for ongoing care as well as health promotional strategies. Follow-up care information includes schedules for visits with the oncology specialist and surveillance testing for cancer recurrence. These recommendations should be based on published guidelines, when available. Examples include an annual clinical breast examination and a mammogram for breast cancer survivors.[3] Colon cancer survivors should have carcinoembryonic antigen blood testing every 3–6 months for 2 years, then every 6 months for 3 years, and colonoscopy at 1 year and then as clinically indicated.[4]

Many survivors continue to experience lasting side effects of cancer and cancer treatment, such as pain, fatigue, neuropathies, and depression. The follow-up plan should identify these long-term effects and the correlating management strategies. The potential for late treatment effects, those toxicities not apparent at the end of treatment but clinically manifested at a later time, as well as recommended surveillance testing, should be noted. For example, the National Comprehensive Cancer Network (NCCN) guidelines recommend that women treated with mantle irradiation for Hodgkin’s lymphoma begin annual mammography at 40 years of age or 8 years following treatment, whichever comes first.[5,6]

An important part of the follow-up plan includes recommendations for reducing risks of future health problems. Cancer survivors are at greater risk for developing a second cancer, of either the same or another type, and screening according to national guidelines should be part of their regular
healthcare.[7–9] Preventive health behaviors such as smoking cessation, alcohol and dietary modifications, and regular weight-bearing exercise have all been shown to reduce risk in cancer survivors.[10,11] Inclusion of these recommendations into the follow-up plan takes full advantage of the “teachable moment,” the phenomenon that occurs at the completion of cancer treatment, when people are most open to making changes in health behaviors.[12]

Finally, the care plan should clearly define the responsibilities of cancer-related, non–cancer-related, and psychosocial providers. One study found that one-third of cancer survivors were not sure which physician was in charge of their cancer follow-up.[13] Clear designation of who is responsible for the various aspects of care can optimize care coordination, avoid unnecessary use of resources, and ensure that care does not “fall through the cracks.”[2] Patients should be encouraged to provide a copy of the care plan to their current primary care providers and other healthcare providers throughout life.[1]

**Barriers to providing care plans**

While most would agree that informing patients about their cancer treatment is the right thing to do, widespread adoption of care plans is met by obstacles throughout our healthcare system. Preparation of a comprehensive care plan requires access to treatment records that include pathology and operative reports, details of chemotherapy and radiation treatments, and summaries of other relevant events that occurred during cancer treatment. Because most patients are treated in community settings, care is often spread across multiple specialists and treatment facilities. One complete record does not exist.[1]

Gathering these records, particularly in the absence of an electronic system, can be challenging. Abstracting the relevant information from the records and writing the comprehensive care plan can be time-consuming and currently is not reimbursable by third-party payors.

<table>
<thead>
<tr>
<th>Table 1: Online Resources for Survivorship Care Planning</th>
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<tr>
<td><strong>American Society of Clinical Oncology (ASCO)</strong></td>
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<td>Care plan templates, guidelines for breast, colorectal cancer follow-up</td>
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<td><strong>Journey Forward</strong></td>
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<td>Tool for developing care plans based on ASCO recommendations</td>
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<td><strong>National Comprehensive Cancer Network (NCCN)</strong></td>
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<td>Disease-specific treatment follow-up guidelines</td>
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<td><strong>LIVESTRONG Care Plan</strong></td>
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<td>Patient can develop care plan and review with healthcare team</td>
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<td><strong>Prescription for Living</strong></td>
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<td><strong>Memorial Sloan-Kettering Cancer Center</strong></td>
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A significant barrier to care planning is the absence of clinical practice guidelines for follow-up care. Clinical practice guidelines are essential to decrease unnecessary and harmful care and to facilitate necessary care, but without high quality evidence or expert consensus, there is reluctance among oncology organizations to make formal recommendations.[2] Currently, the American Society of Clinical Oncology (ASCO) has developed evidenced-based follow-up guidelines for breast and colorectal cancers only.

While guidelines are best when based on evidence, they can still be useful when based on consensus.[2] The NCCN has incorporated consensus-based follow-up care into some of its disease guidelines. The Children’s Oncology Group has developed comprehensive guidelines for monitoring long-term and late effects of cancer therapy for pediatric cancer survivors based on evidence where it exists, and based on consensus where it does not. Many of the recommendations are also applicable to adults.[7]

Prospective development of a treatment summary can eliminate the struggle for collection of records when treatment ends, and is a long-term goal for many organizations and practices.[1] ASCO has created sample templates for the prospective recording of treatment, as well as a one-page summary care plan containing follow-up recommendations for breast and colorectal cancers; expansion to include other cancer types is under way.[14] There is also a generic template for use with any cancer. All of the templates are available on the ASCO web site.[15]

Other groups have developed care plan templates and made them available as resources. Table 1
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lists Internet-based resources for survivorship care plan development. Haylock et al.[16] highlight the opportunity for nurses to adopt survivorship care planning as part of their role in educating and counseling patients and providing continuity of care across health transitions. A comprehensive template as well as guidelines are included in Haylock’s article and are available via the Internet.[17] The LIVESTRONG Care Plan was developed by the Lance Armstrong Foundation in partnership with the OncoLink web site of the University of Pennsylvania, which guides patients in creating their own care plans based on specific treatment information. It is quick and simple to use, and ideally the patient will develop the care plan in conjunction with the care provider.

Journey Forward is a program created by a collaboration between the National Coalition for Cancer Survivorship, the University of California at Los Angeles Cancer Survivorship Center, WellPoint, Inc., and Genentech Inc., with the common goal of improving survivorship care. The Journey Forward plan has a simple treatment summary format and guidelines for monitoring future care based on the ASCO treatment guidelines. Passport for Care is an Internet-based care plan in development by a group from the Texas Children’s Hospital and Baylor College of Medicine. It uses the Children’s Oncology Group guidelines for the care of pediatric cancer survivors. Passport for Care is currently undergoing clinical application evaluation.

**Implementation of the survivorship care plan**
Successful commitment to providing survivorship care plans requires a great many steps. The first step is to select an available template or create a unique design that fits with workload and institutional medical record systems. The following questions will need consideration: How will the treatment data be collected and from where? Who will be responsible for collecting and entering the data? What resources will be needed? What will be the services included in the follow-up care? What guidelines will be followed for surveillance? What patient groups will be included? When is the most appropriate time to review the survivorship care plan with patients--at the end of treatment or some time later? Should there be a formal transition visit? Will the care plan be stored electronically, and will it be sent to other providers?

All of these decisions necessarily rely on multidisciplinary collaboration. In view of the identified barriers and considerable variation in practice settings and clinical resources, simplification can prove to be an effective strategy for implementation. The short templates such as those developed by ASCO provide a simple, quick approach to the care plan while covering the core elements (see Figure 2, “ASCO Breast Cancer Survivorship Care Plan”). A more comprehensive plan that includes comorbidities and specialty care requirements is more resource-intensive, but is especially important for survivors who have undergone complex treatments and for childhood cancer survivors.[14]
The following is an example of one institution’s experience with implementation of a survivorship care plan: In 2005, Memorial Sloan-Kettering Cancer Center initiated nurse practitioner–led survivorship clinics and the provision of a care plan was incorporated into the comprehensive set of services. Plans for follow-up surveillance were developed based on the consensus of each disease-specific service or were based on published guidelines, such as the colorectal cancer follow-up guidelines from NCCN, where they exist. The survivorship nurse practitioners (NPs) incorporate these guidelines into a plan for each survivor, along with cancer screening guidelines and general health recommendations by age. Evidence-based recommendations and resources for dietary modifications and physical activity are included. Individualized needs are also identified in the plan, particularly for patients with late effects and comorbidities, with clear identification of the needs attended to by the NP vs the primary care or other specialty providers. The care plan is reviewed with the patient and family at the first survivorship visit and a copy is provided to the patient. In addition, the NP sends a copy of the care plan and a letter summarizing the visit to the primary care provider and other providers identified by the patient. The care plan then becomes part of the survivor’s medical record and can be updated as needed. Current initiatives are under way to assess patient and provider satisfaction with the care plan.

The Nurse’s role in survivorship care planning

Nurses are key participants in the successful integration of survivorship as a distinct phase in the cancer care trajectory proposed by the Institute of Medicine report. Among the defining elements of oncology nursing are the provision of guidance and support to patients during cancer treatment. Oncology nurses routinely provide patients with a plan to ensure the best possible treatment outcomes with a focus on prevention and management strategies for safety, comfort, and control over the quality of their lives. As patients complete cancer treatment, nurses can extend their role by preparing patients for a transition from the safety net of their oncology care providers and for achieving a lifetime of good health.

Nurses can participate in the formal provision of care plans in a variety of ways, depending on institutional resources and support. Again, multidisciplinary collaboration on development of surveillance guidelines and screening schedules is essential. Support for the time to prepare and
review the plan with patients also is necessary for sustaining such an initiative.

Identification of the most appropriate time for reviewing the care plan with patients is another important consideration. Nurses may choose to focus on parts of the plan concerning immediate recovery needs and future appointment schedules on the last day of chemotherapy treatment, and save the broader discussion of health-care recommendations for a later visit. Physicians and nurses may share these discussions. A consistent approach across the practice setting is the most efficient method for ensuring appropriate implementation of the care plan.[14]

A further barrier to providing care plans is the absence of evaluation data about their usefulness. Despite the lack of evidence, the Institute of Medicine report concluded that, as an element of care, they “simply made sense,” that they appear to be valid, and that they “can reasonably be assumed to improve care unless and until evidence accumulates to the contrary.”[1] However, the IOM report also acknowledged that research is needed to assess the impact and costs associated with care plans, as well as their acceptance by patients and providers.

Other research recommendations include evaluation of patient desire for information, levels of satisfaction with the transition of care and receipt of information, variation in follow-up practice patterns and outcomes, disparities in quality of posttreatment care, differences in care plan formats and knowledge and satisfaction, involvement and satisfaction of specialist and primary care providers, and optimizing communications among patients and providers.[2] Development of information technology can ensure greater access to medical information for care planning and produce data that would inform policy decisions about reimbursement for survivorship care services, determine the cost-effectiveness of care plans related to improved patient outcomes, create and validate quality measures related to care planning, and facilitate creation of care plans in clinical settings.[2]

The convergence of multiple factors—an aging population, the increasing number of cancer survivors, and the predicted shortage of primary and oncology care providers in the US—raises the significance of the need for coordinated care for cancer survivors. The implementation of treatment summaries and care plans can provide a method for ensuring quality healthcare.[12] Two recent initiatives call for the implementation of care plans into the standard care of cancer patients and survivors. Legislation pending in Congress, the Comprehensive Cancer Care Improvement Act, would require a survivorship care plan and insurance reimbursement for its completion. Treatment summaries were also included in the Oncology Physician Performance Measurement Set developed by ASCO and the American Society of Therapeutic Radiation Oncology with the American Medical Association Physician Consortium for Performance Improvement.[12]

Survivorship care plans serve as a communication tool between survivors and healthcare providers. It is the basis of a dialogue about what has happened and what survivors and providers can do to ensure a healthy outcome. A culture change is necessary so that providers recognize survivorship care planning as a standard and expected component of quality cancer care and patients recognize the importance of post-treatment care and adherence to recommendations.[2] Nurses are logical partners in this effort. Their knowledge and skills can contribute to the clinical delivery of quality survivorship care and the research to validate its importance and guide practice. We are pioneers in our understanding of what survivors need and how to best provide the services. Having a plan for their care is the first step towards ensuring that they have a direction forward.


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