Survivorship Care for Adult Recipients of Hematopoietic Cell Transplantations

Jill Beavers, MS, CCRN, ACNP-BC, and Joanne Lester, PhD, CRNP, ANP-BC, AOCN®

Survivors of hematopoietic cell transplantation have undergone aggressive treatments and experience significant life-altering events. Survivorship care plans can address such issues.

An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. This definition includes family members, friends, and caregivers, underscoring that many lives are potentially impacted by the cancer experience (Hewitt, Greenfield, & Stovall, 2006). More than 12 million cancer survivors live in the United States. Of those, 900,000 have a personal history of leukemia, Hodgkin lymphoma, non-Hodgkin lymphoma (NHL), or myeloma, and many are diagnosed as adults (Jemal et al., 2009). A number of adult patients with cancer survived because of aggressive treatment, including hematopoietic cell transplantation (HCT) (Rizzo et al., 2006).

Successes from improved cancer treatments such as HCT have necessitated a paradigm shift that addresses the totality of survivorship care. The transition from active treatment to post-treatment is crucial in preventing and detecting later complications and establishing long-term health. Many of the late effects of cancer treatment are modifiable with a proactive, systematic plan of prevention and surveillance based on several factors, including treatment, genetic predisposition, comorbid health conditions, and health behaviors (Oeffinger & McCabe, 2006). Survivors of HCT may experience significant life-altering side effects because of the prolonged and extensive nature of their treatments. This article discusses the unique aspects related to short- and long-term surveillance of adult survivors who have received HCT and key points to consider when creating a survivorship care plan after HCT.

Survivorship Care

Cancer survivorship involves a spectrum of medical and nonmedical issues, including the short- and long-term consequences of treatment, psychosocial sequelae, and the risk of cancer recurrence or a second primary cancer (Stull, Snyder, & Demark-Wahnefried, 2007). Health maintenance and healthful lifestyle behaviors are essential to maximize health outcomes (Demark-Wahnefried & Jones, 2008). Additionally, coordination of care between oncology and primary healthcare providers is necessary to convey accurate information and ensure continuity of care. An integrated medical report such as a survivorship care plan provides a vehicle to document and communicate the treatment summary and surveillance plan with all members of the healthcare team and the cancer survivor.

For an adult survivor of HCT, a survivorship care plan requires collaboration among multiple disciplines as the survivor navigates from acute inpatient care to subacute outpatient care and, finally, to long-term chronic care. The treatment summary documents the clinical course of acute treatment and follow-up checkpoints to detect side effects during the subacute phase. Survivors with a history of HCT are followed closely by the transplantation team during the acute and subacute phases of transplantation but often return to a community medical oncologist or primary care provider for long-term follow-up. Prevention or detection of early complications with appropriate interventions decreases overall disability and the burden of long-term side effects.

Subacute Survivorship Care Planning

After HCT, subacute survivorship is defined as the six-month period that begins at the end of active treatment. During this period, survivorship care provides an opportunity to address acute issues with potential complications (see Table 1) including graft-versus-host disease (GVHD), viral and bacterial infections, oral or mucosal complications, liver dysfunction, muscle weakness, pulmonary disorders, avascular necrosis, endocrine deficiencies, and other organ dysfunctions (Center for International Blood and Marrow Transplant Research [CIBMTR], 2006; Rizzo et al.,

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Digital Object Identifier: 10.1188/10.CJON.136-139
Recipient(s) of allogeneic transplants are at increased risk for delayed immune reconstitution and viral infections, and immunosuppression in survivors who develop chronic GVHD (Rizzo et al., 2006; Syrjala et al., 2007). Interventions for GVHD are recommended (CIBMTR, 2006; Rizzo et al., 2006; Syrjala et al., 2007).

All survivors of HCT are susceptible to infections, but the complication may be more prevalent in survivors who develop GVHD (Rizzo et al., 2006). Immunization with pneumococcal vaccines does not provide complete protection against bacterial infections; therefore, antibacterial prophylaxis is recommended, especially if ongoing chronic GVHD or immunosuppression.

Table 1. Guidelines for Follow-Up

<table>
<thead>
<tr>
<th>ASSESSMENT</th>
<th>SIX-MONTH FOLLOW-UP</th>
<th>12-MONTH FOLLOW-UP</th>
<th>ANNUAL FOLLOW-UP</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cardiac or lung</td>
<td>Cardiovascular risk assessment, chest x-ray, and smoking cessation counseling</td>
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<td>Cardiovascular risk assessment, chest x-ray, and smoking cessation counseling</td>
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<tr>
<td></td>
<td></td>
<td>if ongoing chronic graft-versus-host disease (GVHD) or immunosuppression: pulmonary function studies</td>
<td>if ongoing chronic GVHD or immunosuppression: pulmonary function studies</td>
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<tr>
<td>Endocrine and fertility</td>
<td>–</td>
<td>Thyroid function</td>
<td>Thyroid function</td>
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<tr>
<td></td>
<td></td>
<td>• Women: follicle-stimulating hormone, luteinizing hormone, and estradiol sex hormone levels if amenorrheic</td>
<td>• Women: follicle-stimulating hormone, luteinizing hormone, and estradiol sex hormone levels if amenorrheic</td>
</tr>
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<td></td>
<td></td>
<td>• Men: testosterone if lack of libido or erectile dysfunction</td>
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<tr>
<td>Eyes</td>
<td>Routine vision examinations (for pain, dryness, or vision loss)</td>
<td>Routine vision examinations (for pain, dryness, or vision loss); if ongoing chronic GVHD or immunosuppression: Schirmer testing</td>
<td>Routine vision examinations (for pain, dryness, or vision loss); if ongoing chronic GVHD or immunosuppression: Schirmer testing</td>
</tr>
<tr>
<td>Health promotion</td>
<td>Diet and exercise counseling</td>
<td>Diet and exercise counseling; breast, skin, and testes self-examination; and second cancer vigilance and screenings such as Papanicolaou smear and mammogram for women older than 40 years or those who received radiation</td>
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</tr>
<tr>
<td>Infectious disease</td>
<td>Pneumocystis carinii pneumonia prophylaxis; if patient received an allogeneic transplant: encapsulated organism prophylaxis, cytomegalovirus testing, and possibly herpes simplex virus and antifungal prophylaxis</td>
<td>Vaccines: flu, pneumonia, hepatitis, and teta-nus; if ongoing chronic GVHD or immunosuppression: cytomegalovirus testing, P. carinii pneumonia prophylaxis, possibly herpes simplex virus and antifungal prophylaxis, and endocarditis prophylaxis per American Heart Association guidelines</td>
<td>Vaccines: flu; if ongoing chronic GVHD or immunosuppression: encapsulated organism prophylaxis, P. carinii pneumonia prophylaxis, possibly herpes simplex virus and antifungal prophylaxis, and endocarditis prophylaxis per American Heart Association guidelines</td>
</tr>
<tr>
<td>Liver</td>
<td>Complete blood count and liver function tests, and serum ferritin</td>
<td>Complete blood count, liver function tests, and serum ferritin</td>
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</tr>
<tr>
<td>Musculoskeletal</td>
<td>If patient received an allogeneic transplant: screening for steroid myopathy; osteopenia prophylaxis with bisphosphonates</td>
<td>Bone density for all men and women if on steroids more than three months; if ongoing chronic GVHD or immunosuppression: screening for steroid myopathy and osteopenia prophylaxis with bisphosphonates</td>
<td>Bone density for all men and women if on steroids more than three months and if previously abnormal; if ongoing chronic GVHD or immunosuppression: screening for steroid myopathy and osteopenia prophylaxis with bisphosphonates</td>
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<tr>
<td>Oral</td>
<td>Regular dental examinations</td>
<td>Regular dental examinations</td>
<td>Regular dental examinations</td>
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<tr>
<td>Psychosocial</td>
<td>Emotional health counseling, support groups, and sexual function assessment</td>
<td>Emotional health counseling, maintenance of robust support groups, and sexual function assessment</td>
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<tr>
<td>Renal</td>
<td>Blood pressure screening with aggressive management; blood urea nitrogen, creatinine, and urine protein</td>
<td>Blood pressure screening with aggressive management; blood urea nitrogen, creatinine, and urine protein</td>
<td>Blood pressure screening with aggressive management; blood urea nitrogen and creatinine (urine protein if previously abnormal)</td>
</tr>
</tbody>
</table>

2006; Syrjala, Martin, Deeg, & Boeckh, 2007). Recipients of allogeneic transplants may experience more significant side effects than patients receiving autologous transplants, although all HCT survivors are at risk for complications, unusual toxicities, and immune impairment (CIBMTR, 2006; Rizzo et al., 2006).

Surveillance for symptoms related to GVHD is essential in this at-risk population, especially in the case of allogeneic transplantation. Interventions for GVHD often result in extended immunosuppression with increased vulnerabilities and consequences. Prolonged treatment with high-dose glucocorticoids can cause significant morbidity and should be limited when possible (Syrjala et al., 2007). In the event of GVHD, additional screening and preventive practices during survivorship are recommended (CIBMTR, 2006; Rizzo et al., 2006; Syrjala et al., 2007).
in survivors with GVHD (Rizzo et al., 2006; Syrjala et al., 2007). Viral-induced infections are common in the subacute phase of HCT survivorship, especially infections from varicella-zoster virus or cytomegalovirus, and may cause significant morbidity. Fungal infections with late invasive aspergillosis also can occur, with devastating outcomes. Drug-induced immunosuppression complicated by high-dose steroid use can increase the frequency, morbidity, and mortality from such infections (Syrjala et al., 2007).

Complications from treatment may occur in the pulmonary, endocrine, hepatic, musculoskeletal, and integumentary systems. Chronic pulmonary complications, including late-onset pneumonitis, restrictive and obstructive pulmonary diseases, bronchiolitis obliterans, and associated pulmonary dysfunction, are risk factors for delayed mortality. Endocrine disorders related to hypothyroidism, adrenal insufficiency, pituitary disorders, and premature gonadal failure may occur. Muscle and fascia disorders with related weakness and pain may become evident and are exacerbated by prolonged steroid use. Liver toxicities related to GVHD, viral hepatitis, or iron overload from multiple transfusions, as well as other organ-related toxicities, can occur in the subacute phase (Rizzo et al., 2006; Syrjala et al., 2007).

Long-Term Care Planning
Survivorship care planning for an adult survivor of HCT involves a subacute care plan with short-term follow-up for the first six months after HCT, followed by the more traditional long-term surveillance at one year (CIBMTR, 2006; Rizzo et al., 2006; Syrjala et al., 2007). Long-term survivorship care provides a mechanism for follow-up during the chronic phase, with a surveillance plan for recurrence, late effects of treatment, psychosocial issues and resources, and continuing lifestyle recommendations. It is a period of time to begin education about long-term healthful lifestyle and behaviors, including diet, exercise, smoking, immunizations, genetic testing, and care for comorbid conditions (Horning, 2008). Following the one-year anniversary of HCT, long-term surveillance should be maintained on an annual basis (CIBMTR, 2006; Rizzo et al., 2006; Syrjala et al., 2007).

Provision of Survivorship Care
Although this article cannot address all of the acute, subacute, and long-term side effects of HCT, the earlier examples illustrate that meticulous follow-up care must be implemented in a systematic manner. Survivorship care plan provides a mechanism to summarize acute and subacute treatments, side effects, interventions, progress toward goals, and recommended surveillance. Advanced practice nurses (APNs) in the ambulatory setting are uniquely positioned to guide survivors from acute care to short-term care, the subacute phase, and eventually to the long-term chronic phase of survivorship care. The APN’s skill set includes in-depth assessment with ongoing symptom management, incorporation of evidence-based interventions, and evaluation of outcomes with a focus on health promotion, education, and healthful lifestyle.

Nurses across the healthcare continuum can have a direct impact on survivorship issues with a focus on nurse-sensitive patient outcomes. Staff nurses often are overlooked as professionals who can create survivorship care plans (Leigh, 2007). Staff nurses are integral in delivering nursing care, promoting safety, and providing psychosocial support and education. Oncology nurses often have ongoing, direct contact with survivors and families and opportunities to develop relationships that are conducive to long-term assessment and planning. Collaboration between APNs and staff RNs can create seamless nursing plans that encompass the inpatient acute and outpatient subacute and chronic phases of adult HCT survivorship within a model of wellness and health promotion.

Nurse researchers are vital in exploring survivorship issues to improve the quality of life of HCT survivors. Prospective, longitudinal, population-based studies from treatment into survivorship are needed to create evidence-based guidelines and address the complex issues surrounding HCT survivorship care. Additional survivorship issues may include access to care, financial and cultural issues, and effective interventions. Data must be collected to create a database specific to survivorship in adult HCT and measure the effectiveness of interventions.

Summary
Survivorship care is a responsibility of all members of the team caring for survivors of adult HCT. APNs and staff nurses are vital in providing survivorship care. Care planning should focus on wellness and health promotion rather than disease management. Models of short- and long-term follow-up care that focus on the subacute and chronic phases of post-HCT provide a framework in which to collect data about successful symptom management, prevention of complications, and improved patient and provider satisfaction. Education for providers and survivors alike is crucial to enable recognition of common side effects and complications. Much can be learned from pediatric colleagues who have successfully followed survivors of childhood HCT since 1983. As purposeful survivorship care becomes a reality for all cancer survivors, healthcare providers must develop a baseline framework with tailored follow-up plans for specific populations.

The authors take full responsibility for the content of the article. The authors did not receive honoraria for this work. No financial relationships relevant to the content of this article have been disclosed by the authors or editorial staff.

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References


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