Updated guidelines for planning HCT recipient care

Significant clinical advances in hematopoietic cell transplantation (HCT) have led to a steady increase in the number of long-term HCT survivors. These survivors face a broad collection of medical issues based on their individual exposures and risk factors.

Pre-HCT risk factors include radiation, alkylating agents, steroids, and prior chemotherapy, each of which can affect multiple organs/systems. Recipients may also be immuno-compromised long after HCT, especially for allogeneic recipients who can develop chronic graft vs. host disease or GVHD. Pediatric recipients need ongoing monitoring of growth and development.

Updated post-HCT guidelines published

In March 2012, an international group of HCT experts published a consensus report to provide timetables and guidance for survivorship care.1 Lead author Dr. Navneet Majhail, National Marrow Donor Program® (NMDP) Medical Director of Health Services Research, notes that the intent of the guidelines is to reduce the incidence of late morbidity and mortality in HCT recipients through early detection and treatment of transplant complications.

An example of the screening recommendations is shown in Figure 1. The guidelines include recommendations for the frequency of testing, and additional evaluations for special populations.

According to Dr. Majhail, “The guidelines can be used to develop an individualized follow-up plan for a patient so all of the providers involved in the care after transplant are focused on the individual’s exposures and risk factors. By using the guidelines, clinicians have an easy checklist of possible complications so they know how to direct exams and tests.”

A multidisciplinary approach to post-transplant care

Coordination of care in the longer-term survivorship phase can be challenging. The University of Kansas Cancer Center has adopted these newly updated post-transplant care guidelines to help us partner closely with you to ensure that HCT recipients receive the comprehensive, timely and individualized care they need.

Post-transplant guidelines mobile app

You can quickly access the latest recommendations for post-transplant care, vaccinations, GVHD screening (with photo atlas) and referral timing through the NMDP’s Transplant Guidelines app. To download the app, search for “transplant” in your marketplace or visit marrow.org/md-guidelines. Print and online versions are also available. You may also contact Dr. Joseph McGuirk to request a copy of the print guidelines.

To direct exams and tests.

Visit the National Marrow Donor Program (NMDP) website at marrow.org/md-guidelines for the latest updates.

BMT program highlights

• Region’s first BMT program accredited by the Foundation for Accreditation of Cellular Therapy, or FACT
• Designated as a Center of Excellence for all payers that utilize this distinction
• More than 1,800 successful transplants
• Designated as a CIBMTR-CTN core center
• Region’s largest BMT program
• Member of the National Marrow Donor Program since 1995
• Medicare-approved since 1977

The University of Kansas Cancer Center

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Kansas City, KS 66205

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WHAT’S INSIDE:
• New post-transplant screening and preventive practice guidelines
• Transplant from a survivor’s perspective
• Long-term survival “excellent” for 2-year survivors of allogeneic HCT
• Active clinical trials

Contact us:
913.588.5862 or Toll Free 877.588.5862
kucancercenter.org/BMT or kumed.com/BMT
Transplant from a survivor’s perspective

When Penny was admitted to the hospital in May 2004 to start chemotherapy for her acute myelogenous leukemia or AML, she was optimistic because her doctors said the treatment would likely put her disease into remission. The first round of chemotherapy achieved the desired results.

Penny’s doctors also told her that her abnormal cytogenetics put her into an intermediate risk category, and that her disease would likely return. It did, and quickly. A stem cell transplant was recommended, which Penny received just two months later.

Penny is doing well today and she agreed to share her transplant experience in order to give some insight to healthcare providers and potential transplant patients.

Key: early planning
When she learned that she had relapsed, Penny went online to learn what her expected survival might be after a transplant.

Despite the odds, Penny remembers thinking that she was determined to be in the group of patients surviving and thriving after a transplant. She also compared that number to the odds of surviving without a transplant, which were significantly worse.

Penny underwent a bone marrow transplant under the care of Dr. Joseph McGuirk and his transplant team eight years ago, using an unrelated donor located through the Be The Match Registry® operated by the NMDP.

Penny says she was fortunate that her physicians had taken steps to prepare for a possible transplant even while her AML was still in remission. After determining that Penny’s sisters were not good matches, her physicians began a search for an unrelated donor through the NMDP.

That preliminary step saved precious time when she did relapse. Penny recalls, and it gave her incredible peace of mind to know that her physicians had a head start in locating an unrelated donor.

“It seemed to take forever to find a match,” Penny recalls. “But in reality it was just two weeks.”

Penny also recalls that she approached her transplant with somewhat unrealistic expectations about the length of her recovery.

“In Penny’s case, it wasn’t until three years after her transplant that she approached her transplant with the expectation that she could return to work. In part because she developed a mild case of chronic GVHD. Her advice to patients considering transplant is to believe what their transplant team says will help them recover, but to also be somewhat flexible in their expectations. 

Critical: coordinating post-transplant care
Penny continues to have annual check-ups with her transplant team from The University of Kansas Cancer Center; the majority of her care is through her local physicians, who are partners in her care.

“You definitely need to be proactive about your care,” she says. For example, she sometimes reminds her team about how critical her whole blood counts are and small changes in them need more aggressive monitoring than in “normal” patients.

“I’m much more aware of what’s going on in my body and when to see a doctor,” she says. “You know your body better than anybody.”

When medical issues have arisen, Penny knows that she can count on the cancer center transplant team to answer calls from her team of physicians related to issues unique to transplant recipients.

Equally important: post-transplant self-care and support
Penny also identified two things that helped her through her long recovery: her faith, and her social network.

“A network of family and friends is very important for recipients,” she says. Transplant recoveries are rarely without setbacks. It’s critical to prepare for those times. “Recipients need to know that there are loved ones to help, and you shouldn’t be shy about asking for their support.” Penny says that connecting with her family and friends was a key factor in maintaining her emotional and physical well-being.

Eight years post-transplant, Penny says she is grateful for so many things: good health is at the top of her list, followed by the great care from all the doctors and nurses she connects with, and her family and friends.

But Penny says she feels a different, and deeper, kind of gratitude to the woman who donated stem cells to her. “She gave me a second chance at life, and for that I will be forever grateful.”

Long-term survival “excellent” for 2-year survivors of allogeneic HCT
A large-scale study of transplant outcomes confirms that the long-term life expectancy of HCT survivors who have reached the two-year post-transplant mark is good, with 80 percent to 92 percent of 2-year recipients surviving at 10 years after HCT.

The study, led by Dr. John Wingard of the University of Florida, Gainesville, examined the transplant outcomes of 10,632 patients worldwide reported to the CIBMTR or Center for International Blood and Marrow Transplant Research, who survived two years post-transplant and with a median follow-up of nine years.

All patients underwent myeloablative allogeneic HCT, and were only included in the study if they were free of their underlying disease at two years post-transplant. All patients were transplanted before 2004 and had acute myelogenous leukemia or AML, acute lymphoblastic leukemia or ALL, lymphomas, myelodysplastic syndromes or MDS, or severe aplastic anemia or SAA. Donors were HLA-identical siblings (n=7,643), unrelated (n=2,380), and other related, including haploidentical (n=609). Other patient characteristics and transplant outcomes are shown in Table 1.

Long-term survival after HCT

<table>
<thead>
<tr>
<th>Disease</th>
<th>N</th>
<th>Median age, years (range)</th>
<th>Median follow-up, years (range)</th>
<th>5-Year survival, %</th>
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<tbody>
<tr>
<td>AML</td>
<td>4,017</td>
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<tr>
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<td>16 (&lt;1-64)</td>
<td>9 (2.26)</td>
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<tr>
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<td>34 (&lt;1-66)</td>
<td>8 (2.20)</td>
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<tr>
<td>Lympoma</td>
<td>619</td>
<td>34 (2-61)</td>
<td>9 (2.27)</td>
<td>84</td>
</tr>
<tr>
<td>SAA</td>
<td>2,171</td>
<td>18 (1-66)</td>
<td>9 (2.31)</td>
<td>92</td>
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Table 1. Patient characteristics and outcomes of 10,632 patients transplanted for AML, ALL, MDS and SAA.

Mortality due to secondary cancers in late survivors was 2 percent to 10 percent, according to Dr. Wingard, and among HCT recipients with malignancy, late relapse was the leading cause of death (27 percent to 42 percent of all deaths). Despite the risks and changes that occur, many survivors are able to maintain a high quality of life.

The study authors concluded that “the prognosis for long-term survival is excellent for 2-year survivors of allogeneic HCT.” However, they also noted that life expectancy remains lower than expected in comparison with the general population and that prolonged follow-up to prevent, identify and treat late complications are needed in this patient population. (See story on page 5 for recommended screening and preventive measures for long-term HCT survivors.)


In addition to standard care and treatments, the University of Kansas Cancer Center offers clinical trials to help find better ways of preventing, diagnosing and treating various types of cancer.

Featured
• Novel preparative regimens for patients with active AML undergoing allogeneic stem cell transplant: Cord4u-A Multi-center, single-arm Phase II. Study of Myeloablative Allogenic Stem Cell Transplantation for non-remission AML using Clofarabine and Busulfan x 4 (CloBu4) regimen.
• Tyrosine kinase inhibition with chemotherapy and/or allogeneic stem cell transplant for Ph+ ALL: SWOG 0805–A Phase II of combination of Hyper-CVAD and Dasatinib with or without allogeneic stem cell transplant in patients with Ph+ ALL.
• Comparing two approaches to alternative donor allogeneic transplants: CHT 1101-4 Multi-Center, Phase III, Randomized Trial of Reduced Intensity (RIC) Conditioning and Transplantation of Double Unrelated Umbilical Cord Blood (dUCB) versus HLA-Haploidentical Related Bone Marrow (Haplo) for Patients with Hematologic Malignancies.
• Chronic graft-versus-host disease prevention trial: Fresenius iVAT-SCT-01-A randomized, prospective, double blind, placebo controlled Phase III study of iVAT-GF prophylaxis as a supplement to standard care prophylaxis to prevent moderate to severe chronic GVHD in adult AML, ALL and MDS after allogeneic stem cell transplantation from unrelated donors.

Visit kucancercenter.org/clinicaltrials to learn about these additional BMT and hematological malignancy clinical trials.

Refer a patient
Contact us at 913.588.1227 or toll free at 800.332.6048.

SAVE THE DATE
We invite you to attend our upcoming educational program:
Advances in Blood and Marrow Transplantation
• Date: April 27, 2013
• Time: 9 a.m.-5 p.m.
• Location: Robert E. Hemenway
Kansas Life Sciences Innovation Center
1001 Beller
Kansas City, KS

Contact
Clint Divine at cdvine@kumc.edu for more information.
When Penny was admitted to the hospital in May 2004 to start treatment for AML, she was told that her only hope was a bone marrow transplant. The odds were against her surviving two years after the transplant. But Penny was determined to live through the NMDP. She attended transplant classes and met other transplant patients, which helped her prepare for the transplant. She also connected with her transplant team, which helped her feel more comfortable and prepared for the transplant.

Penny underwent a bone marrow transplant under the care of Dr. Joseph McGuirk and his transplant team eight years ago, using an unrelated donor located through the Be The Match Registry® operated by the NMDP. She says she was fortunate that her physicians had taken steps to prepare for a possible transplant even while her AML was still in remission. After determining that Penny’s sisters were not good matches, her physicians began a search for an unrelated donor through the NMDP.

Penny right, with donor Susan
Disease: AML
Transplant physician: Dr. McGuirk

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That preliminary step saved precious time when she did relapse, Penny recalls, and it gave her incredible peace of mind to know that her physicians had a head start in locating an unrelated donor. “It seemed to take forever to find a match,” Penny recalls. “But in reality it was just two weeks.”

Penny also recalls that she approached her transplant with somewhat unrealistic expectations about the length of her recovery. In her recovery, she lost 30 pounds, but still lost 10 percent of her body weight. She finally returned to work in part because she developed a mild case of chronic GVHD.

Her advice to patients considering transplant is to believe the advice of their doctors. “You know your body better than anybody.”

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“Your definitely need to be proactive about your care,” she says. For example, she sometimes reminds her team about how critical her whole blood counts are and small changes in them need more aggressive monitoring than in “normal” patients.

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Eight years post-transplant, Penny says she is grateful for so many things: good health is at the top of her list, followed by the great care from all the doctors and nurses she connects with, and her family and friends. But Penny says she feels a different, and deeper, kind of gratitude for the care from all the doctors and nurses she connects with, and her family and friends.

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