Life After BMT

Updates from the Blood or Marrow Transplant Long-Term Follow-Up Study

BMTSS Progress

UAB SCHOOL OF MEDICINE

Institute for Cancer Outcomes and Survivorship

BMTSS is the Blood or Marrow Transplant Survivor Study. Researchers at the University of Alabama at Birmingham, the University of Minnesota, and City of Hope continue to work together on this important study. If you are receiving this newsletter, it means you have participated in BMTSS. The expanded study was started in 2013 and is currently about halfway through. Thanks to you, we have collected over 3000 questionnaires from survivors and about 900 questionnaires from brothers and sisters of survivors. We are very excited to have finished our first in-person pilot study on physical function at the University of Alabama at Birmingham. Although we do not require any action in response to this newsletter, we encourage you to update your contact information with BMTSS staff if you have moved. That way, we can continue to send you this newsletter and keep you informed about the results of this study, and about future studies that you may be interested in. Thank you so much participating in BMTSS and helping with this important research!

For More Information:

Email:
BMTStudy@peds.uab.edu

Call:
855-903-2136 (BMTSS)

Mail:
Blood or Marrow Transplant
Long-Term Follow-Up Study
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Lowder 500
Birmingham, AL 35233

Ask the Researchers

After the last newsletter, we received a lot of great questions that we wanted to address and share. Please send in your questions to the BMT LTFU Study Staff at bmtstudy@peds.uab.edu. Although the study is still collecting data, we'll do a preliminary analysis on 1 to 2 topics or questions that we receive, and we will publish the results in the next newsletter. In this newsletter, we are pleased to publish the answer to the following question, received in response to our last newsletter.

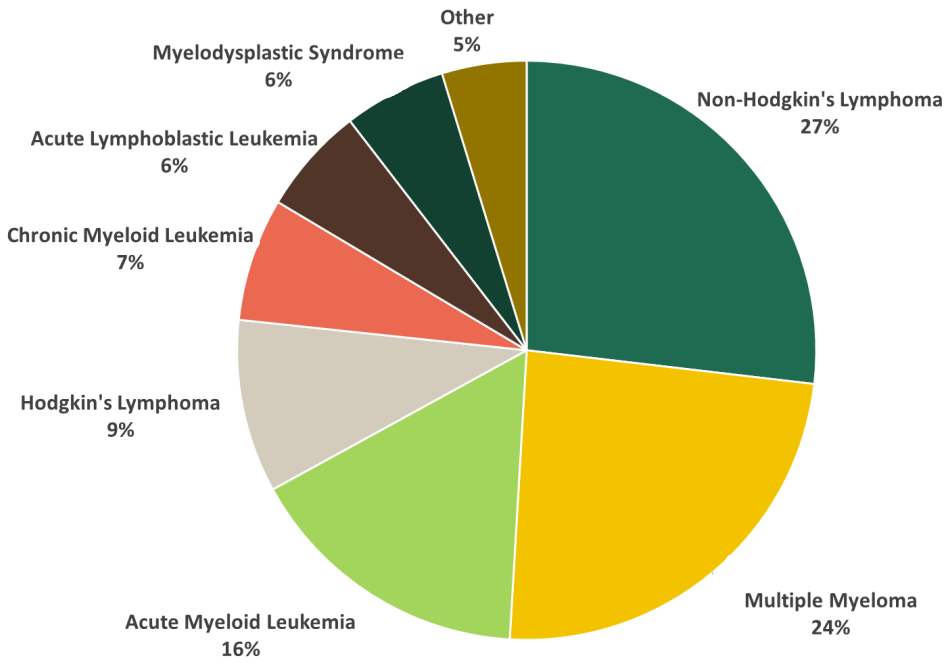
Are esophageal strictures due to Graft-versus-Host Disease?

Esophageal strictures are a tightening or narrowing of the esophagus (the tube that carries material from your mouth to your stomach). This tightening can make it difficult to swallow foods or liquids. Esophageal strictures can be caused by damage from acid reflux, radiation therapy to the neck, or some medical devices, such as plastic tubes placed in the throat to carry food and medicine to the stomach. Esophageal strictures are associated with graft-versus-host disease, a condition in which the cells from the blood or marrow donor can injure the recipient's tissues or organs. In the BMT Long-Term Follow-Up Study, we found that about 4.5%, or 4 to 5 out of every 100 patients who received blood or marrow cells from a donor, had esophageal strictures. We found that only about 2%, or 2 out of every 100 patients who received their own cells, had esophageal strictures. This is about the same rate of esophageal strictures seen in people who did not have a BMT. Patients who had graft-versus-host disease were more likely to have esophageal strictures, compared to those who did not have graft-versus-host disease. A change in diet, medication, or stretching of the esophagus may help to reduce some of the symptoms of esophageal strictures.

What are the Most Common Diagnoses in the BMTSS?

Common diagnoses of patients in the BMTSS include Non-Hodgkin and Hodgkin lymphoma, multiple myeloma and other plasma cell dyscrasias, leukemia (including acute myeloid leukemia, chronic myeloid leukemia, and acute lymphoblastic leukemia), myelodysplastic syndromes, and severe aplastic anemia. These cancers and blood diseases result in a lack of healthy blood cells; therefore, blood or marrow transplants may be used to treat these patients. The following sections give some insight into the five most common diagnoses in the BMTSS.

BMTSS Patient Population Diagnosis



Non-Hodgkin Lymphoma (NHL)

#1

Non-Hodgkin lymphoma (NHL) is a cancer of the lymphocytes (a type of white blood cell) that most commonly starts in the lymph nodes, spleen, bone marrow, or other tissues that are part of the body's immune system. NHL is more common in males and in those over the age of 60. Treatment options depend on the particular type and stage of NHL, and may include chemotherapy, immunotherapy, targeted therapy, radiation therapy, and BMT.

Multiple Myeloma

#2

Multiple myeloma is a blood cancer that affects plasma cells (a type of white blood cell). The cancerous cells overpower the healthy blood cells in the bone marrow. This may cause weakness of the bones, pain, fatigue, lowered resistance to infections, kidney problems, nerve damage, and other complications. Most people diagnosed with multiple myeloma are over the age of 65 years. Chemotherapy, radiation, medications to prevent bone loss, and BMT are common treatments. Many patients receive additional myeloma treatments after BMT.

Acute Myeloid Leukemia (AML)

#3

Acute myeloid leukemia (AML) is a cancer that occurs when myeloid cells (a type of white blood cells) in the bone marrow become abnormal and crowd out healthy cells. These abnormal white blood cells prevent the body from fighting off infection and from making healthy blood cells. People with AML may have bruising, bleeding, fatigue, and infections. AML is most common in males and in those over the age of 45. Common treatments for AML include chemotherapy, immunotherapy, radiation therapy, and BMT.

Hodgkin Lymphoma

#4

Hodgkin lymphoma is a cancer that develops in the lymphatic system (part of the immune system) and lowers the body's ability to fight infection. Typically, Hodgkin lymphoma develops in the lymph nodes (glands) in the neck, under the arms, and in the area between the lungs. Hodgkin lymphoma is more common in younger people (in their teens and 20's) and in people over the age of 55. The most common treatment options include chemotherapy, radiation therapy, and immunotherapy. Some people with Hodgkin lymphoma need a BMT, especially if the lymphoma doesn't respond to standard treatment, or if the lymphoma comes back (relapses) after treatment.

Chronic Myeloid Leukemia (CML)

#5

Chronic myeloid leukemia (CML) is a cancer that begins in blood-forming cells of the bone marrow. CML is caused by a genetic change in immature white blood cells that turns healthy cells into leukemia cells. In CML, there is usually a gradual build-up of abnormal white blood cells in the bone marrow. Without treatment, CML may become a faster growing (acute) form of leukemia. CML is slightly more common in men than in women, and the risk of CML increases with age. Common treatment options include targeted therapy. Interferon (immunotherapy), chemotherapy, radiation therapy, and BMT are sometimes used to treat CML.

Recent Publications

Bhatia S, Armenian SH, Landier W: How I monitor long-term and late effects after blood or marrow transplantation. Blood 130:1302-1314, 2017

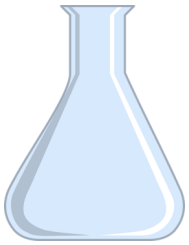
Published in September 2017, “How I monitor long-term and late effects after blood or marrow transplantation” provides a look at what doctors think about when caring for a patient who has received a blood or marrow transplant (BMT). The article discusses several case studies and focuses on what steps patients and their healthcare providers can take to prevent future complications.

For example, one BMT survivor was treated for Hodgkin lymphoma in his 30s. Five years after his transplant, the patient started seeing his primary care doctor instead of his cancer doctor. About ten years after the transplant he was diagnosed with type 2 diabetes and prehypertension (a warning sign of having high blood pressure in the future). Unfortunately, he did not receive treatment for high blood pressure at that time. Two years later, he developed heart failure and was referred to a heart specialist. This survivor had received anthracyclines (a type of chemotherapy that can increase the risk for heart problems) during his treatment. A proactive approach that included both screening for heart problems, and early treatment of medical conditions that can increase the risk for heart problems (such as high blood pressure and diabetes), may have helped to avoid this complication, or to catch it earlier, when it would be more easily treated.

It is important that patients learn about potential risks that can happen after BMT. When people know about these risks, they can talk to their doctors and take steps to stay as healthy as possible. In this example, a healthier lifestyle, such as eating more fruits and vegetables and getting regular exercise, may also have helped lower the risk for developing heart problems. Making small behavior changes like this can help prevent future health problems.

After several years, most BMT survivors begin seeing primary care providers rather than their cancer doctors or BMT specialists. Sometimes, primary care providers are not aware of the long-term effects of BMT and other cancer treatment. The authors of this paper suggest there is a need for more communication between cancer doctors and primary care providers. Research being done in the BMT Long-term Follow-up Study can help doctors better understand which survivors are at risk for potential complications and can be used to establish guidelines for future BMT survivors and doctors to follow.

Interested in Participating in More Clinical Research?



We’ve included websites specific to City of Hope, University of Minnesota, and University of Alabama at Birmingham if you are interested in participating in more clinical research.

City of Hope: http://clinicaltrials.coh.org/

University of Minnesota: https://studyfinder.umn.edu/

University of Alabama at Birmingham: https://www.uab.edu/reporter/clinicaltrials