Guiding Patient Decision-Making Regarding Bone Marrow Donation

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ABSTRACT

Primary care providers (PCPs) must have accurate information regarding bone marrow donation to effectively educate patients. Since unrelated bone marrow donors are important sources for individuals requiring bone marrow transplant, providers must understand the donation process in order to facilitate it. How bone marrow donations are used, how to join the registry, the process of donation, and the risks and benefits of donation are described. With the increasing need for bone marrow donation, PCPs who are well-educated on this subject can guide their patients in making the potentially life-saving decision to donate.

Keywords: bone marrow donation, bone marrow education

A healthy 23-year-old man presents to your office for his annual exam and asks about becoming a bone marrow donor. His inquiry was triggered by a bone marrow registry drive that is being held at his office next week. He asks the following questions: what are bone marrow donations used for, who can become a donor, how does someone join the registry, what steps are involved in the actual donation, and what are the risks and benefits? Would you, as his health care provider, be able to answer these questions?

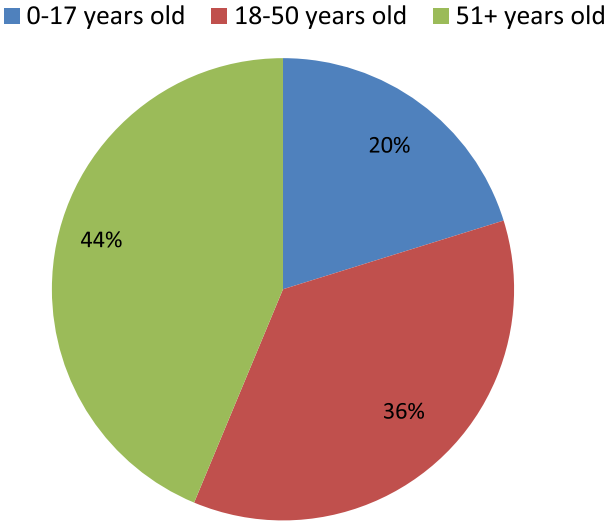
Individuals, such as the patient described above, may present to their primary care providers (PCPs) with similar questions concerning bone marrow donations. PCPs are an important source of health information for patients, but unfortunately, many providers are often misinformed about bone marrow donation. Many health care professionals do not want to donate because of misperceptions regarding the process, including the pain of the procedure, recovery time, and the requirement for surgery.[1] In order to fully inform patients, it is important for PCPs to provide accurate information and guidance regarding the bone marrow donation process. The purpose of this article is to provide PCPs with that information to allow them to more effectively educate patients regarding this important issue.

INDICATIONS FOR BONE MARROW DONATION

In 2012, more than 5,800 bone marrow transplants (BMTs) were performed in the United States.[2] More significantly, approximately 10,000 individuals were on the waiting list for a BMT. An estimated 60% of the individuals on the list die while waiting for a potentially life-saving transplant because they do not have a matched donor.[3] The need for bone marrow transplantation crosses age, gender, and ethnic boundaries. In 2012, children 0-17 years old represented 20% of donors, people 18 to 50 represented 36%, and adults over 50 represented 44% (Figure 1).[4]

Autologous BMTs are those in which the stem cells are from the individual receiving the transplant, while allogeneic BMTs are when an individual receives stems cells from a donor. Bone marrow donations are usually provided by a human leukocyte antigen (HLA)-matched sibling or parent.[5] Having the immediacy of a family member to donate stem cells for an allogeneic transplant is attractive when possible, but there are many situations when this is not feasible. About 70% of patients do not have a relative who is a matching donor.[2] In these instances, a patient must rely on matching an unrelated donor. The importance of familial unrelated bone marrow donors is paramount as clinical outcomes for patients who have

Figure 1. Recipients by age.



Data from the Health Resources and Services Administration.[4]

had either related or unrelated HLA-matched donations have favorable outcomes.[6]

Bone marrow donations are used for stem cell transplantation in individuals with hematologic, immune system, or metabolic abnormalities.[5,7] This transplantation can be a lifesaving treatment for these individuals.[8] A large proportion of stem cell transplants are for hematologic and lymphoid malignancies, including chronic myelogenous leukemia (CML), acute myelogenous leukemia (AML), acute lymphocytic leukemia (ALL), myelodisplastic disorders (MDS), non-Hodgkin lymphoma (NHL), and other lymphomas.[7,9] In fact, AML and ALL accounted for 49% of the BMTs in 2010.[10] For example in AML, conventional treatment involves induction with the goal of complete remission through chemotherapy, then consolidation with chemotherapy and stem cell transplantation for removal of residual leukemia cells.[11] Beyond hematologic and lymphoid malignancies, BMTs are also used to treat neuroblastoma.[5] Clinical research is continuing to evaluate the use of transplantation in other malignancies.[5,9]

Malignancies are not the only clinical disease area where stem cell transplantation provides benefit or potential for benefit. Aplastic anemia, thalassemia, and sickle cell disease are nonmalignant diseases that are treated with stem cell transplantation.[7,9] While clinically controversial, studies have shown that transplantation of adult bone marrow-derived cells for heart repair in patients with ischemic heart disease can improve left ventricular function, decrease infarct size, and improve cellular remodeling, which contributes to reduced risk of death, recurrent myocardial infarction, and stent thrombosis in these patients.[12]

BONE MARROW RECIPIENTS

Bone marrow recipients vary by racial background and ethnicity (Table 1), with the majority of recipients being white. However, only 28% of the potential bone marrow and stem cell donors are from racial communities other than white.[4] Despite an overall increase in the number of people registering to become donors, people from diverse ethnic and racial backgrounds have a lower likelihood of finding a match because of lack of diversity of those willing to donate.[5] For example, African American patients find matches less than 30% of the time.[13]

Some phenotypes are more common among certain racial groups, so the importance of bone marrow donation across all races and ethnicities is essential. In a study evaluating intentions of African Americans to donate bone marrow, fears regarding the procedure, side effects, and racial discrimination correlated with the intention not to donate, while the perception of helping others correlated with the intention to donate.[13] Educated providers must

Table 1. National Marrow Donor Program by Race: 2010

Race	Recipients (N = 5,235)	Donors on Registry
Caucasian	4,408 (84%)	6.5 million (74%)
Hispanic	404 (8%)	860,000 (9%)
African American	228 (4%)	Nearly 650,000 (7%)
Asian	166 (3%)	More than 610,000 (6%)
American Indian/ Alaska Natives	23 (< 0.5%)	100,000 (1%)
Native Hawaiian/ Pacific Islander	6 (< 0.5%)	13,000 (0.1%)
Multiracial	Unavailable	300,000 (3%)

Data from the Health Resources and Services Administration.[4]