

Knowledge, Attitudes, and Behaviors Regarding the Bone Marrow Registry among College and Medical Students in Rhode Island

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INTRODUCTION

A critical shortage exists for donors of bone marrow or peripheral stem cells. Each day, between 6,000 and 7,000 individuals nationally with leukemia, lymphoma and other blood disorders search for a potential match. As few as 30% are able to find a match within their own family; the remaining 70% depend on national or international registries to find potential donors to treat these deadly diseases.^{1,2} The “Be the Match” registry (formerly the National Marrow Donor Program), a national donor registry, is comprised of individuals ages 18-60 who join via a brief health questionnaire and a painless cheek swab used for **human leukocyte antigen (HLA)** typing, the technique employed to compare patients to potential donors. Joining the registry indicates willingness to donate marrow or peripheral stem cells in the future to anyone in need if they are discovered as a potential “match”.^{1,3}

Recipients of transplanted cells from younger donors tend to have better outcomes and increased survival.⁴ Younger age at registration translates to more potential years on the registry. College and graduate students have become a key focus for marrow donor registration drives as students fit demographics of those most likely to donate—young, healthy, well educated,² more open to new information, and part of a community. The racial and ethnic diversity of college campuses provide large pools of diverse registrants. Willingness to join the registry and follow through with donation may be linked to participation in prior blood donation drives, common on college campuses.³ Data also suggests that students are more influenced by student-led campaigns.^{5,6}

Patients are more likely to find matches within their racial or ethnic group.^{4,5} As there are higher numbers of Caucasians on the national donor registry, Caucasian patients have a 50-70% chance of finding a matched, unrelated

donor from the registry.^{6,7} Among African Americans and some other racial and ethnic minorities with lower representation on the national donor registry, however, patients find suitable matches in as few as 25-30% of cases.^{2,6-10} A national effort exists to increase registration of racial and ethnic minority individuals.^{7,8} Survival after transplantation correlates with the strongest and most precise HLA matches resulting in increased survival. Expanding the registry pool results in more patients finding suitable HLA matches for transplants.

The registry is bolstered by those who do not simply join, but actually follow through with donation if selected. Willingness to sign a letter of intent, however, does not correlate well with actual agreement to organ donation. Data indicates that less than 50% of college students indicating willingness to sign a letter of intent, actually did so.⁹ Further information is needed to target college-age individuals to improve low levels of registration and donation to improve survival for those with deadly disorders. Our study goal was to assess knowledge, attitudes and behaviors to identify barriers influencing willingness

to donate among college and graduate level students. Prior data indicates that misconceptions and misinformation are widespread concerning the realities of this process. We compared responses among those who indicated “willingness” to join the registry with responses among those who indicated “unwillingness” to join.

METHODS

Survey Design

We created and administered an investigator-designed survey utilizing internet survey software that permitted the survey to be completed once per IP address. Items included 15 Yes/No formatted questions, ten five-point Likert scale of Agree/Disagree formatted questions, and basic demographic questions. The survey took three and five minutes to complete. Potential subjects were recruited via email list serves for the following groups: Brown University medical students, University of Rhode Island pharmacy students, Brown undergraduates in the **Program of Liberal Medical Education (PLME)**, Brown undergraduate students on the “premedicine” email listserve, and a sample of student leaders

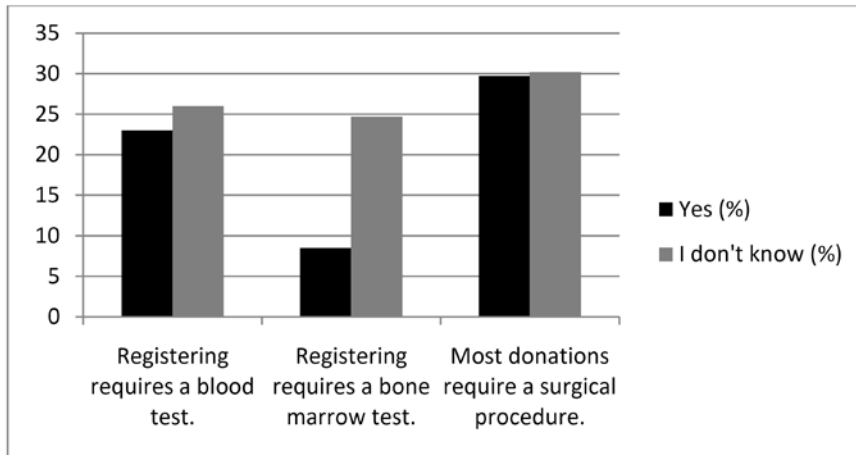
Table 1: Response totals for yes/no questions testing misconceptions about the marrow donor registry.

Question	Yes (%)	No (%)	I don't know (%)	P value
I am currently a member of a marrow registry.	198 (32.7)	397 (65.6)	10 (1.7)	n/a
I am not currently a member but I would register if a drive were held at my college	138 (26.8)	158 (30.7)	218 (42.4)	n/a
Registering at a marrow donor drive requires a blood test	139 (23)	308 (51)	157 (26)	< 0.0001
Registering at a marrow donor drive requires a bone marrow test	51 (8.5)	403 (66.8)	149 (24.7)	< 0.0001
About 80% of patients with diseases treatable with marrow or peripheral stem cell transplantation can find a matched donor among their family members	157 (25.9)	206 (34)	243 (40.1)	< 0.0001
I am more likely to be a match for a transplant candidate from my ethnic or racial group.	345 (57.3)	55 (9.1)	202 (33.6)	0.0001
Most donations require the donor to undergo a surgical procedure under anesthesia in which bone marrow is extracted from the donor's pelvic bones.	180 (29.7)	243 (40.1)	183 (30.2)	< 0.0001

Key: P value = significance of differences in responses among those who demonstrated “willingness” to join the registry vs. those who expressed that they were “unwilling” to join.

* Respondents who demonstrated “willingness” to join the registry were consistently more likely to correctly identify tested myths about the marrow registry as false. Those who expressed unwillingness to join tended to believe, or were unsure about these myths.

Graph 1: Misperceptions about the Marrow Registry
 (% of total responses who answered “Yes” or “I don’t know” respectively)



from diverse student groups. Data was analyzed via chi square and stepwise logistic regressions to assess statistical significance of different responses among “willing” versus “unwilling” respondents, with “willingness” to join the registry defined as a current member of the registry (yes to question one on survey) or one who would join if a registration drive were to be held (yes to question two on survey).

RESULTS

Responses were received from 606 individuals (31% male, 69% female). Participants indicated varied fields of study, including 29.5% medical students, 23.8% pharmacy students, 25.0% majoring in hard sciences, 17.1% majoring in humanities, and 4.5% identifying as graduate students. A total of 51.5% of respondents indicated willingness to join the registry.

Several pervasive registry “myths” were evaluated. These “myths” were inaccurate statements about the registration or donation process that individuals cited as barriers to joining the registry. There were significant differences among respondents who demonstrated “willingness” to join the registry and those who expressed that they were “unwilling” to join. Respondents “willing” to join the registry were consistently more likely to correctly identify tested myths about the marrow registry as false. Those “unwilling” to join tended to believe, or were unsure about these myths. Among total respondents, 23%

believed incorrectly that registering for the marrow registry required a blood test, while an additional 26% did not know. 60% either did not know or mistakenly believed that donating stem cells required a surgical procedure under anesthesia. Almost 30% falsely believed that most donations required a “bone marrow test” while an additional 30% were unsure. Only about one-third of total respondents knew that 80% was not an accurate representation of the ability of patients to find a matched donor from a family member (Table 1, Graph 1).

Among possible donor deterrents tested via the Likert five point scale questions, stepwise regression determined three statistically significant independent

deterrents in terms of difference between “willing” and “unwilling” respondents: fear of pain, fear of complications, and perceived financial costs (all $p < .05$). Those who strongly agreed that pain was a deterrent were approximately 20 times less likely to express willingness to join the registry as those who strongly disagreed with this statement. Whereas 30% of “willing” individuals did express concern for pain as a deterrent to donating, 70% of “unwilling” respondents reported fear of pain. Fear of complications elicited a similar pattern of decreased odds of willingness to join the registry with increased fear: whereas 65% of “willing” respondents either disagreed or strongly disagreed with a fear of complications associated with donating, only 28% of “unwilling” participants expressed similar disagreement. 66% of “willing” respondents disagreed that financial costs associated with registering and donating were too high, compared with 39% of “unwilling” respondents. Also of note, less than half of total respondents disagreed with the statement that “important or rich people” receive priority in getting donations, and only about 40% believed that the time commitment associated with donation would not be excessive. (See Table 2, Graph 2).

Comment

Our goal was to identify factors including misconceptions and biases which affect college age students’ willingness to

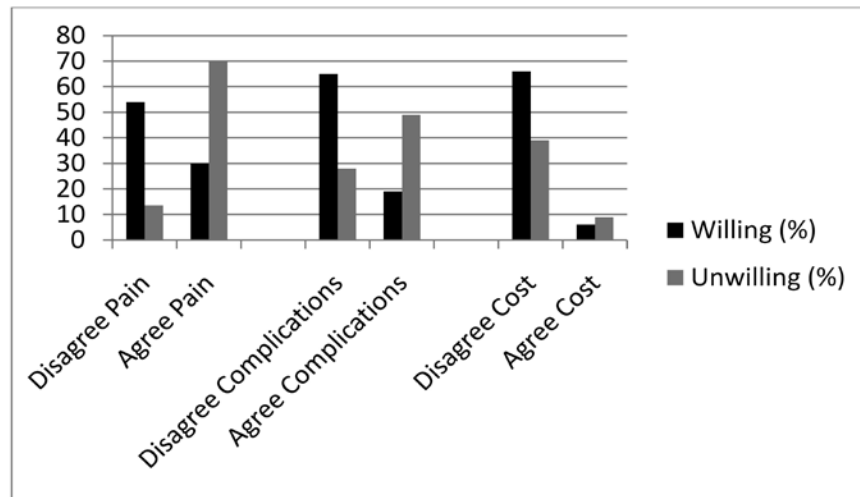
Table 2: Response totals for 5-point Likert scale Agree/Disagree questions.

Question	Strongly Disagree (%)	Somewhat Disagree (%)	Neither agree nor disagree (%)	Somewhat Agree (%)	Strongly Agree (%)	P value
Important or rich people get marrow transplants before others.	129 (23.1)	114 (20.4)	141 (25.2)	152 (27.2)	23 (4.1)	0.0438
Financial costs of registering and tissue typing are too high for me.	202 (36.2)	98 (17.6)	215 (38.5)	33 (5.9)	10 (1.8)	< 0.0001
I am afraid of serious complications associated with the marrow registration procedure.	149 (26.8)	118 (21.2)	105 (18.9)	147 (26.4)	38 (6.8)	< 0.0001
I am worried that the time commitment will be excessive if I am asked to donate	101 (18)	134 (23.9)	96 (17.1)	183 (32.7)	46 (8.2)	< 0.0001
Pain associated with donating bone marrow or peripheral stem cells would be a barrier for me to donate.	88 (15.8)	107 (19.2)	88 (15.8)	179 (32.1)	96 (17.2)	< 0.0001

Key: P value = significance of differences in responses among those who demonstrated “willingness” to join the registry vs. those who expressed that they were “unwilling” to join.

* Respondents who demonstrated “willingness” to join the registry were consistently less likely to believe various misconceptions about the registry.

Graph 2: Three barriers to donating, “willing” vs. “unwilling” respondents



Key: “disagree” = those who answered “strongly disagree” or “disagree” “agree” = those who answered “strongly agree” or “agree”

Pain: “Pain associated with donating bone marrow or peripheral stem cells would be a barrier for me to donate.” **Complications:** “I am afraid of serious complications associated with the marrow registration procedure.” **Cost:** “Financial costs of registering and tissue typing are too high for me.”

join the registry. The population surveyed included medical students, pharmacy students, undergraduate students pursuing medicine, and student leaders and activists. We expected this cohort of medicine-focused students and student leaders to be more informed and thus more likely to join the registry than the general population. Prior studies support our hypothesis that this study population was less likely to hold inaccurate perceptions than the general population.^{2, 10-12} Yet, even among our participants pervasive myths and inaccurate information appear to dissuade many from considering joining the registry.

Registration among college students, an altruistic group, may increase by publicizing the reality that thousands die on the waiting list yearly because no suitable donor exists. Misperceptions about pain, complications, and perceived financial costs deter many from joining. These misperceptions would be expected to be more prevalent among the general college population than among the specific groups we surveyed. Our results indicate that informational materials for registration drives should address specific reality-based information, highlighting, for example, “registering requires only a painless cheek swab and *no* blood test.” To account for the potentially misleading designation of “marrow” donor drive, advertisements should highlight that the

vast majority of donations are via **peripheral blood stem cell (PBSC)** donation, a non-surgical outpatient procedure. Educational efforts should be made to dispel inaccurate representations of marrow donation as a very painful procedure, a description not perceived as accurate by most actual donors. Donors generally have no medical and non-medical costs associated with registering and donating; thus, the “perceived costs” barrier to donation can be easily refuted. Expressed doubt about “rich people” receiving top priority for donations and excessive time commitment necessary to donate can also be addressed directly in donor drive materials. Greater use of contemporary media as an information tool may enhance participation by the young.

Limitations

Our study cohort was non-random. Survey distribution to select groups inhibits the external generalizability of results. However, this study population is likely to be more knowledgeable and more likely to join than the general college and college-age population. Selection bias may exist with email survey research. Individuals who are familiar with the bone marrow registry may be more likely to fill out the survey and have different opinions about the registry and donation than the general population. Prior studies of general populations have demonstrated

that more individuals classify themselves as “willing” to sign an organ donation letter, a related issue, than are actually willing to donate.⁹ Thus, the 51.5% willingness rate expressed on our survey may be higher than the rate of actual registration. Finally, our investigator-designed questionnaire, has not been validated; however, our survey instrument was based on prior surveys used to assess other populations.

CONCLUSIONS

Myths about marrow donor registration and donation are pervasive and must be dispelled to increase registration and donation. Our data indicate that widespread barriers exist related to inaccurate perception of both the registration and donation processes. Our results indicate that these widely held beliefs deter individuals from expressing willingness to donate by registration. College and graduate students are an underutilized, accessible and important group to target. Educational efforts, by circumventing these perceived impediments, can augment the marrow registry and have the potential to improve patient outcomes and save lives.

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Disclosure of Financial Disclosure

This survey-based study was deemed IRB exempt by Brown University's IRB chapter, as it primarily addresses "quality improvement and needs assessment" of a current health issue. Study participants were contacted via email and provided with a link to the survey. The email informed all potential participants that survey responses were confidential and that by clicking on the survey link and filling out the survey, one consents to participate.

The authors and or spouses/significant others have no financial interests to disclose.

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