

****Continuing Education Contact Hour Opportunity Pending**

Getting to the Heart of Being the Match: A Qualitative Analysis of Bone Marrow Donor Recruitment and Retention among College Students

Elizabeth C. Kaster, Charles R. Rogers, Kwon Chan Jeon, and Brittany Rosen

Abstract

Introduction: For those with certain blood or bone cancers, bone marrow donation can mean the difference between life and death. The National Marrow Donor Program® (NMDP) operates the largest bone marrow registry of potential donors; however, at times when potential matches are identified, many donors opt not to donate. The purpose of this study was to describe perspectives from college-aged students on recruitment to a bone marrow donation registry and retention to the registry/follow-through with the donation process. **Methods:** Researchers employed a one-time qualitative study using 7 focus groups comprised of 10 – 11 college students each (n = 76). **Results:** Results yielded three overarching themes: donor recruitment, donor retention, and factors contributing to the overall donation process. More specifically, this study identified key factors affecting bone marrow donation in an essential population: facilitators, barriers, knowledge, and ‘goodness’. Additionally, marketing and communication were found to be major determinants of potential donors staying with the NMDP. **Conclusion:** Better explanations and awareness/

promotion campaigns are necessary for recruiting potential donors to the NMDP and to increase the likelihood that the donor will follow through with the donation should a potential match be identified. Recommendations from this study may improve recruitment and retention rates among the NMDP campaigns targeting college students.

Introduction

“Penny’s death could have been prevented,” her husband said during an interview with WABC-TV. “It was terrible in the end, knowing that help was out there. This didn’t have to happen. Someone didn’t do their part and follow through.”

Brian was referring to his wife having had four bone marrow matches, but each time, the anonymous donors declined to go through with their donations (Carollo, 2010, para. 2-3). The tragic story of Penny and Brian Lindenberg raises the question: Why do people not follow through with donation, after signing up at a registry?

In the U.S., over 20,000 individuals (aged 0 – 74) each year have been diagnosed with severe or life threatening diseases (e.g., lymphoma, leukemia, or genetic metabolic disorders). These illnesses can be treated by a bone marrow or an umbilical cord blood transplant from matched donors—these transplants being the only potential cure and best treatment option. However, only 30% among people needing a transplant can find matched donors among family members. The other 70% must find suitable donors who are able to transplant from registries (U.S. Department of Health and Human Services, n.d.). Be the Match® operated by the National Marrow Donor Program® (NMDP), the largest major registry with potential marrow donors and cord blood units in the world, has provided patients who seek a bone marrow and/or a cord blood unit transplant with potential donors from a pool of more than 22.5 million and over 601,000 cord blood units from the national and international registries (Be The Match®, 2014b).

Despite the fact that Be The Match® has a number of potential donors, retaining donors poses a significant problem. After the actual bone marrow donation process has begun, only 18.5% of registered donors in Be The Match® actually donates bone marrow or blood stem cells to people needing a transplant (Yao et al., 2013). For uncertain reasons, potential donors may either remove themselves from the registry or decide not to donate. This problem demands attention because, for those in need of bone marrow, retention of potential donors means treatment and survival.

Other studies have focused on blood donation in general, using quantitative designs and listing motivators for that particular type of donation (Bednall & Bove, 2011; Boe & Ponder, 1981; Glynn et al., 2002; James, Schreiber, Hillver, & Shaz, 2013; Oswalt, 1977; Piliavin, 1990). However, these studies do not research the extent to which whole blood donation

*Elizabeth C. Kaster, M.S; Doctoral Teaching Assistant, Texas A&M University, Department of Health and Kinesiology, 4243 TAMU, College Station, TX 77843-4243; Phone: (979) 458-2217; Fax: (979) 862-2672; Email: ekaster@hlkn.tamu.edu; ESG Chapter Affiliation: national member-at-large

Charles R. Rogers, PhD, CHES; Post-Doctoral Associate, University of Minnesota Medical School, Program in Health Disparities Research, Department of Family Medicine & Community Health, 717 Delaware St SE, Suite 166, Minneapolis, MN 55414; Phone: (612) 626-3894; Fax: (612) 626.6782; Email: crrogers@umn.edu

Kwon Chan Jeon, MS; Doctoral Teaching Assistant, Texas A&M University, Department of Health and Kinesiology, 4243 TAMU, College Station, TX 77843-4243; Phone: (979) 862-7656; Fax: (979) 862-2672; Email: kc_jeon@hlkn.tamu.edu

Brittany Rosen, PhD, CHES; Assistant Professor, University of Cincinnati, School of Human Services, PO Box 210068, Cincinnati, OH 45221; Phone: (513) 556-3872; Fax: (513) 556-3898; Email: brittany.rosen@uc.edu

* Corresponding Author

affects other types of donation, nor whether these donors transition to other types of donation such as bone marrow. For studies that do reference bone marrow donation, the focus is either necessarily on minority donors (Laver et al., 2001) or on a general population sample (Studs, Ruberg, McGuffin, & Roetzer, 2010; Switzer et al., 1999).

The purpose of this study, however, was specifically to describe perspectives from college-aged students on recruitment to a bone marrow donation registry and retention to the registry/follow-through with the donation process if a match is found. Focusing on a young age group, like college students (aged 18 to 44), is important because marrow from this young group leads to more successful transplants for patients (Be The Match®, 2014; Kollman et al., 2001; Laithy, 2012; Stolzing, Jones, McGonagle, & Scutt, 2008).

Methods

Researchers employed a qualitative study using one-time focus groups comprised of college students within a health education honor society at a large university in Texas. These students were chosen due to their health education and promotion major and willingness to participate. College students (aged 18 - 44) were appropriate as the population of interest for marrow donation because prior research indicates adults in this age range have better marrow donation success rates (Be The Match®, 2014; Kollman et al., 2001; Laithy, 2012; Stolzing, Jones, McGonagle, & Scutt, 2008). Furthermore, because our sample cohort was actively involved as recruiters in bone marrow drives on campus, the researchers also believed this group would have a better understanding of their student peers.

Prior to the study, researchers obtained seven open-ended questions from the local NMDP clinic (housed within a regional hospital) and extrapolated these questions into a focus group protocol (see Table 1). These questions explored recruitment to the NMDP and retention of registered donors. Specifically, questions came from previous experience with donor retention within the NMDP and focused on these participants' perceptions of bone marrow recruitment and retention as well as their perceptions of other college-aged students' thoughts on bone marrow recruitment and retention.

The health education honor society completed training in NMDP recruitment procedures through the regional hospital, and completed two successive drives on the university campus (one each semester in the academic year). Following completion of these two drives, researchers implemented this study. Approval was obtained through the university's Institutional Review Board prior to data collection.

Participants were recruited through the health education honor society. In May of 2012, seven one-time focus groups with 10-11 participants designated to each (for a total of 76 undergraduate participants) were conducted on the university's campus. No other demographic data were collected as giving a voice to this particular group of students was the priority of the qualitative study more so than generalizability. However, researchers observed that majority in this particular organization were female. Each group was assigned a moderator who asked questions and facilitated discussions. Before the focus groups began, the moderator obtained informed consent from all participants. Participation was voluntary and any participants who wished to leave at any time were allowed to do so. No identifying information was included during the focus groups and participants were encouraged to refrain from

Table 1

Focus Group Protocol Used in This Study

1. What made you want to join the registry, or what would make you want to join the registry?
 2. What are some reasons you might join the registry, but say no when you are called to be a donor?
 3. How likely would you be to join the registry if you knew when joining that you would 100% be a matched donor and why? What if you only had a 1% chance of being matched?
 4. If you joined the registry at a campus drive, but later changed your mind, what would be the most comfortable way for you to let the registry know you wanted to be taken off the list?
 5. If you needed to communicate a change in health status of a sensitive nature, perhaps having contracted a communicable disease, what would be the way you would feel most comfortable going about letting them know?
 6. What would be the best way to ensure that donors' addresses and phone numbers are current with the registry at all times?
 7. What approaches or strategies might the bone marrow registry try to increase the likelihood that a person on the registry would donate if a match or a transplant recipient were identified? So, we are thinking of strategies. What can we do to increase the likelihood that they will stay on if there is a match?
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using identifying information so that results would remain anonymous. Focus group sessions ranged from 20-45 minutes. All focus groups were audio recorded to ensure all data were captured.

Focus group data were transcribed and checked for typographical errors by research assistants. A thematic analysis was employed for each transcript with salient themes being coded and checked for validity using the peer-debriefing and constant comparison methods. Theory emerged from identified themes to help give explanation to results (grounded theory). Frequency counts were used to quantify the themes.

Results

The study's research questions were two-fold: 1) college-student perspectives on recruitment to a bone marrow donation registry and 2) college-student perspectives on retention to the registry/follow-through with the donation process. Accordingly, our thematic analysis yielded three overarching themes: thoughts students had on recruitment strategies, thoughts students had on retention strategies, and thoughts students had pertaining to the overall donation process. The researchers termed these overarching themes recruitment, retention, and donation, respectively.

Recruitment

The overarching theme of recruitment refers to those comments focused on how to recruit people to the NMDP, including aspects of the recruiters as the recruitees and specific recruitment strategies.

Recruiter as the recruitee. With the nature of this study, the NMDP also recruited many of the recruiters themselves. When asked about joining the NMDP, some 'recruited recruits' felt they were *obligated as students in health promotion* and because they were *healthy*. As one participant said: "I think that it is important that you are advocating something, that you are also a part of it. So, that's why I was definitely like, 'I need to join' because otherwise I shouldn't be telling other people to join."

Another aspect of recruitment dealt with the participants' past *donation experiences*, both good and bad. Specifically, findings revealed that *bad experiences* influenced potential recruits' decision to join the NMDP. Although their bad experiences may have been with other common forms of donation (e.g., blood, plasma), this may affect participants' decisions to join the NMDP as these donation procedures are quite similar. The following response corroborated these ideas: "Speaking of that—it's interesting, I know I don't like giving blood, although I give it now, because one time I had a vampire that didn't know what they were doing and they messed up my arm for months. I mean, I had a bruise for two weeks and I couldn't work out or anything. When you have a bad experience or know somebody who's had a bad experience with even a simple procedure, like a bone marrow transplant or donation, [it] can scare people out of it."

Recruiting strategies. Regarding recruiting strategies, the theme of *explanation* emerged from the data where the participants felt *persuading* potential donors was pertinent for the success of the project. The students mentioned how there were some "people at the drive that [they] finally convinced to

sign up, that were hesitant the whole time." Statements that the students made in an attempt to persuade individuals included telling them "the chances are really small [of being selected]" or indirectly making them feel guilty by saying "there are serious consequences for this person [if you do not donate]." It was interesting to the researchers the ethical implications of potentially coercing potential donors to register, as well as the effect this may have on these donors' retention rates in the future. Findings revealed that the participants felt they were *obligated* to donate. Alike, social responsibility/obligation and altruism have been the most common reasons for donating blood in other studies (Glynn et al., 2002; Oswalt, 1977; Piliavin, 1990).

Other recruitment strategies identified by the participants included *clarification/thorough explanation* and *explanation/promotion* of the bone marrow donation process. The following participant responses validate these imperative ideas: "Not knowing what the procedure is like, not even necessarily knowing anything about it. Most people know they have bone marrow and that's about the extent of it. They don't even really know where that bone marrow is or where the procedure is or how it works. So, I think simple education is a significant factor."

"You could stress the importance of the decision to sign up to be on the registry when they first do it because some people do not realize, if you get called, it's like getting a heart transplant: it's a really big deal and you should be able to go through with your decision. I think letting people know that it is a big decision; some people may not realize that if you do get matched it's a big deal and you should be able to commit."

Retention

The retention theme referred to the discussion of retaining people on the NMDP long term and facilitating individuals who were potential NMDP matches to follow through with donation. These two sub-themes were entitled retention strategies and communication methods.

Retention strategies. Retention strategies were further divided into two categories: *mitigating logistical issues with potential donors* and *marketing*. Logistical issues referred to maintaining up-to-date contact and health information from potential donors as well as managing donors who were no longer interested in being a member of the NMDP. Respondents believed it was the NMDP's responsibility to make sure donors' contact information was updated, with *online* being the suggested route. An opportunity for *no personal interaction* (e.g., website) was preferred in instances of not wishing to donate, leaving the registry, or communicating a sensitive change in health status. Marketing strategies included *social networking* and opportunities for *testimonials* from past donors for emotional attachment, *better promotion and advertising* to increase awareness, and addressing any donor concerns through meetings and continuous follow-up.

Communication method. Communication methods emerged as a major theme for retention across several questions. These methods, in order of preference, included email, website, phone, and postal mail. Mainly, this theme focused on ways to maintain open communication among recruitees, whether communicating a change in health status, desire to leave the registry, or updating contact information.

Again, as found in the *retention strategies* theme, respondents tended to prefer whichever communication method provided little to no interaction with a live person.

Donation

The final theme that emerged contained factors that would affect both recruitment of potential donors and retention of these potential donors. This theme was important as it identified factors that contribute to bone marrow donation among college-aged students, namely *facilitators*, *barriers*, *knowledge*, and *goodness*.

Facilitators. The theme of facilitators was present in each of the responses to the questions asked during the focus groups. Specifically, *potential convenience* responses emerged from the data when the responses from the focus groups alluded to *ease and convenience* as important factors during registration. When the participants were asked how likely they would be to join the Registry if they knew 100% at sign-up they were a matched donor, they felt that the process would again be *assuring and convenient*, thus, increasing uptake. However, the participants also felt that the process itself would need to be *easier and faster*. One participant stated that “it would have to be made easier for me to be able to be a donor” where another student added that “if it was so black and white, [one]...either will or...pretty much won’t [donate].”

Connecting or hearing from and about bone marrow recipients appeared to be a critical networking-focused facilitator. The following participant response supports this idea: “If I was given personal information about the person I was helping, like a picture, or their name, or their age, I would be more willing to donate. It is more personable and you really know who it is going to.”

Barriers. Barriers reported by the students included *inconvenience/lack of time*, *apathy*, and *monetary cost*. An alarming number of the students voiced their concern with *inconvenience and a lack of time*. One student expressed the frustration faced: “I tried to get a lot of my friends to join, just telling them what we were doing, and a lot of them were like, ‘If I got a phone call, there is no way I could get away from my life and go take time to do this. What if I had to go somewhere?’ They’re like, ‘I couldn’t just drop everything and go do this.’”

In terms of *apathy*, students were discouraged from donating because they simply saw it as a waste of time. As one participant stated: “If they don’t think they are going to be chosen, then they are like, ‘Why bother spending any time signing up if I am not going to be chosen.’”

This student’s indifference can be closely linked to the final barrier of *monetary cost* that emerged from the data. Since travel, medical, and registry registration costs are covered and reimbursed in most cases, permitting donors to never pay to donate marrow, this theme confirms the need for better recruitment training.

Knowledge. Knowledge was another factor that influenced recruitment and retention. Specifically, *low knowledge levels concerning the disease and donation process* were reported. Also contributing to lack of recruitment and retention of participants was *unawareness or lack of knowledge* of the donation process. As one respondent expressed: “I

know when I was out trying to get people signed up, I felt like maybe some of the people signing up didn’t really understand what they were getting themselves into.”

Additionally, the data revealed that a lack of knowledge and unawareness of the donation process contributed to *fear* of the process itself: “Even though this is a procedure that less people need to do as compared to donating blood, you can make the procedure well known so people know what they are getting into and aren’t so afraid to do it. There are still a lot of people who think they are actually going in and doing surgery;...we should tell them the percentage of what that is now.” Literature has corroborated this finding that fear is a major bone marrow donation barrier (Bednall & Bove, 2011; Boe & Ponder, 1981; Oswalt, 1977).

Goodness. As a final point, students simply felt that being a good steward who donated was the right thing to do. This *goodness* theme was apparent as participants felt that *saving lives* and *helping people* was very critical in encouraging individuals to join the NMDP.

Discussion

By employing qualitative research methods, this study identified four key factors contributing to bone marrow donation recruitment and retention among these college students. These 4 factors included: *facilitators*, *barriers*, *knowledge*, and *goodness*.

When examining facilitators to recruitment and retention, most participants expressed the need for convenience and ease when registering. Supporting the findings in this college student-focused study, convenience and ease were the greatest facilitators in donating blood among African American adults. Since African American adults are half as likely to donate blood than their White counterparts, James and colleagues (2013) investigated factors that serve as barriers and motivators to blood donation among 4,000 African American and White voters between 18 and 69 years old. Consistent with other studies, the researchers learned that convenience was the major motivator (facilitator). Connecting with bone marrow recipients has also been reported as a facilitator for decisions to register for the NMDP. For instance, Studts and colleagues (2010) found family cancer history had a significant impact as people whose lives have been affected by cancer appeared more willing to register owing to a greater empathy for others diagnosed with cancer.

An inconvenient donation process and lack of time were also reported as barriers influencing bone marrow donation and retention to the NMDP’s registry. As we expected, this finding was consistent with literature reporting people are concerned about time spent away from work and fear of the pain, needles, and side effects associated with donation (James et al., 2013; Switzer et al., 1999). Additionally, apathetic feelings toward bone marrow donation due in part to lack of interest and delayed NMDP follow-up was reported as a barrier affecting the decision to continue when contacted as a potential match and for further blood typing (Studts et al., 2010). In detail, appealing to people’s emotions were found to be more effective at recruiting participants to a bone marrow registry than appealing to their rational side (Studts et al., 2010).

Additional barriers reported by the participants in

our study included lack of personalized communication and marketing strategies. Since Johansen and colleagues (2008) found regular communication with potential donors increased retention of racial and ethnic minority donors—a population that is under-represented and underutilized in the NMDP registry—for hematopoietic stem cell transplantation, personalizing communication efforts may serve a key solution to increasing bone marrow donor retention among college students. Our study participants also proposed that the NMDP utilize more effective marketing strategies such as testimonials, mentor-donor experience sharing, and social networking.

According to Laver and colleagues (2001), implementing educational programs that target knowledge significantly increases the potential bone marrow donor pool among hard-to-reach groups (e.g., minorities, college students). When creating these educational programs, with the intent of increasing donor registration, it is important to consider that statistical messages seem more effective than narrative messages, for a long-term cognitive effect (Studts et al., 2010). Our study participants expressed concern regarding possible poor explanations about bone marrow donation, and stressed the need for clarification. While a narrative message may arouse an emotionally stronger response, research suggest it will likely decrease after several days (Studts et al., 2010). Therefore, a narrative message appears more appropriate for accomplishing donation registration compliance whereas a statistical message appears more suited for increasing future donor retention (Kopfman, Smith, Yun, & Hodges, 1998; Studts et al., 2010).

Another study found the following psychosocial variables are important donor retention predictors: past behavior (e.g., being a blood donor), reasons for joining the NMDP, other people's reactions, and current attitudes (Switzer et al., 1999). The attitudes variable is particularly interesting as it corroborates the obligatory attitude found amongst our group participants. Our participants also mentioned potential coercion that could occur at drives that may affect potential donor's attitudes negatively because signing up felt forced. This is an important issue to be stressed during trainings for recruiters. Another way in which to encourage positive attitudes toward donation and alleviate any distrust on the potential donor's behalf may be to incorporate primary health providers at the donor drives, as suggested by Edwards, Ellingwood, Hebbon, Foli, and Freeman (2014).

There are several limitations to consider when interpreting this study's results. First, not all trained moderators chose to follow-up with probing questions based on certain answers to the protocol, thus potentially affecting the richness of information participants in different focus groups gave or would be willing to give. Also, because participants were asked to discuss their own NMDP experiences and recruiting drives experiences, there may be some indistinct memories from participants drawing on their experiences from these drives or remembering the training.

Conclusion

Bone marrow transplants are lifesaving procedures for patients with a matching donor. Unfortunately, only an estimated one-third of patients needing a transplant utilize the NMDP (Johansen et al., 2008). This study provides information about factors (e.g., inconvenience, apathy, personalized

communication) that affect recruitment and retention for bone marrow donor programs among college students. Future recruiting and retention programs targeting college students have the ability to become more successful at obtaining and retaining potential bone marrow donors, thus increasing the chance for more patients to find a matching donor. Through increased matches and willing donors, the ability to save lives through transplants will increase.

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