

Case Study: Radiation Therapy Program Works to Educate about Disparity of Marrow Donations

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Abstract

Introduction: The major tool in the treatment of many blood related disorders is bone marrow transplantation. Finding a matching donor can be a daunting task and is significantly more difficult if you are an ethnic minority because of the lack of potential donors. An estimated 7,500 Americans are searching the national registry at any given time, while only 2% of the population is registered as a potential donor. The statistics are even more challenging for minorities. **Methodology:** This case study investigates the outcomes of an educational community project that connected students across college campuses throughout one state. The purpose of the project was to mobilize radiation therapy students as part of a marrow donor outreach designed to educate college students and recruit registrants within south Texas. **Results:** A total of 8,098 new marrow donors were recruited since the fall of 2012. **Conclusion:** As radiation therapists, we touch the lives of many patients each day who are currently undergoing treatment for cancer. As cancer experts, we hold the knowledge to impact exponentially more through education and outreach. It is our responsibility as the health care professionals to disperse this knowledge to others and work in all aspects of cancer research including, prevention, screening, detection.

The Kathy Soliz Texas State Radiation Therapy Outreach program was established as a way to continue the legacy of a young Latina, Kathy Soliz, who lost her 11-year battle with Leukemia at the age of 24. Kathy never found a match because of the lack of Hispanic donors currently on the registry; however we hope her loss will remind others of the importance of joining the fight against leukemia and other blood disorders, and educate them that a simple cheek swab can hold the cure for another individuals' devastating disease. The Texas State Radiation Therapy Program works in honor of Kathy Soliz, and in collaboration with universities and organizations, such as the National Marrow Donor Program (Be the Match), to hold multiple day marrow donor drives each year. This case study describes the efforts, and encourages others to pursue similar outreaches.

Introduction

Leukemia and lymphoma are diagnosed in over 10,000 people in the United States every year, and for many, the only hope for a cure is a marrow or stem cell transplant.¹ Finding a matching donor can be a daunting task and is significantly more difficult if you are an ethnic minority because of the lack of potential donors.^{2,3} An estimated 7,500 Americans are searching the national registry at any given time, while only 2% of the population is registered as a potential donor.^{2,3} The statistics are even more challenging for minorities.⁴ The process of marrow transplantation has been well-established and saving lives for over thirty years, however each patient must find a match in order to be eligible for a transplant.⁵ While the number of marrow donors has increased thanks to the recruitment efforts of donation registries such as the National Marrow Donor Program (NMDP) in the United States, there is an ever increasing need for potential donors representing a wider range of ethnicities.^{2,3,4,6} Currently, 67% of registered marrow donors are Caucasian.⁶ The purpose of this case study is to describe the impact of the Texas State Radiation Therapy Marrow Outreach Program on the recruitment of college aged Hispanic donors.

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This outreach program began after the death of Kathy Soliz in order to educate college students about the importance of the marrow registry and educate them on how they can become potential donors. The Hispanic population was chosen as the focus of the outreach because according to the United States Census Bureau, Hispanics are the largest minority in Texas making up over 38% of the population.⁷ Hispanics however constitute only 47% of donor registrants who are willing and able to donate.^{2,7} This case study describes the efforts of a radiation therapy program in Texas which organized and conducted marrow drives at Hispanic Serving Institutions (HSI) in order to determine if specifically designing marrow drives for the Hispanic population increases the number of Hispanics willing to become marrow donors. The research question guiding this study was, "What type of impact will educational outreach have upon marrow donor recruitment among Hispanic college students?"

Literature Review

Several researchers have investigated the disparity amongst donor registrants to get a better understanding of why there is such a low representation amongst minorities on the registry.^{8,9,10,11} Fear of pain, and side effects of donating bone marrow appear to be the major factor in lack of participation.^{8,9,10,11} The perception of pain as a result of donating bone marrow however is unfounded. There are no studies indicating that being a marrow donor is painful or impactful to quality of life, which could scare individuals away from volunteering. The "Be the Match" website even has testimonials of past donors describing the process and their surprise at lack of pain in order to help debunk this theory.¹² In fact, serious adverse events are uncommon with the main risk being related to anesthesia.⁵ One study conducted by Ontilio et al, surveyed individuals to assess barriers for potential donors.⁸ Questions were included addressing knowledge of a registry, willingness to be a donor, and reasons why they might refuse to be a donor.⁸ While this study ended up showing no difference in willingness to donate across the different races, the fear of pain was the most common reason given for unwillingness to donate, and it was significantly higher amongst minorities.⁸ Another study conducted by Vasconcellos, et al in 2011 approached college students and medical students in Rhode Island to assess their knowledge of the process and determine different barriers keeping them from becoming donors.⁹ This study also found that there are barriers that exist related to inaccurate perceptions of both the registration and donation process, including a fear of pain.⁹

What both of these studies succeeded in showing is that myths about registration and donation are pervasive and need to be dispelled in order to increase the number of potential donors in the registry. "Be the Match" took steps to encourage people to sign up for the registry by dispelling these very myths that the donation process is complicated or painful.¹² In July of 2012 they even launched a national campaign for African American Bone Marrow Awareness Month.⁴ With college students being the ideal population for marrow donation because of their age and health, education specifically geared to these students may increase participation. Because of this, "Be the Match" has begun partnering with universities to determine how to better recruit college students and educate them on the marrow donation program. Faculty members at Texas State University became aware of "Be the Match" efforts and began discussing a partnership that would enable radiation therapy students to become ambassadors of the "Be the Match" program in the hopes that college students are better recruited and educated by other college students.¹³ This marrow outreach program has transcended metropolitan and university boundaries with a focus on changing the statistical challenges faced by cancer patients in Texas, particularly those of Latino heritage. As an integral service component of the radiation therapy curriculum, the program mobilizes students equipped with sufficient knowledge as ambassadors of cancer and treatment education within communities.¹³ The essential goal of the outreach program was to save lives by educating minority populations, wiping away myths and misunderstandings about the marrow processes, and substantially improving the odds that Hispanics have in finding matching donors.

Methodology

The nature of research and scientific method in its simplest form involves the testing of ideas in the public arena. Research methodology involves putting educated guesses or assumptions - a hypothesis to a test and examining how an outcome relates to it, positively or negatively. For this non-experimental case study, it was hypothesized that an educational intervention upon Hispanic college students would yield a positive impact on marrow donor recruitment. The research question guiding the study was, "What type of impact will educational outreach have upon marrow donor recruitment among Hispanic college students?" A simple measure for data analysis was the tracking of marrow donor registrations reported by the National Marrow Program by each targeted institution after the intervention.

For this research the dependent (outcome) variable was the impact upon the marrow donor registry; the independent (manipulated or treated) variable was the Hispanic college student; and the intervention was informal, spontaneous, face-to-face education. The targeted population was Hispanic college students. The targeted facilities were college campuses with at least 95% Hispanic enrollment. The aim was to have a positive impact on the National Marrow Donor Registry's number of Hispanic registrants. The Texas State Radiation Therapy program is a two year baccalaureate degree program in San Marcos, Texas. Sixteen students are accepted each year with a maximum of 32 students at any one time enrolled in the program. Texas State is a Hispanic Serving Institution (HSI) meaning that Hispanic enrollment constitutes a minimum 25% of total enrollment. The researchers, faculty members, and students had worked with "Be the Match" representatives to conduct marrow drives on the Texas State University campus for about 3 years before the outreach. As a marrow outreach, the group engaged with three other campuses. Two campuses reported a high enrollment of minority students, or were classified as HSI's in line with our outreach mission, and one campus, UT Austin was by invitation. The campuses visited were, The University of Texas Pan Am in Edinburg Texas, The University of Texas in Austin, Texas, and The University of Texas at Brownsville. The students also participated in a marrow drive in Austin Texas at Town Lake. This function was to recruit registrants but also to collect donations for future marrow drives. This function was called Kayak for a Cure. Texas State radiation therapy students underwent training provided by "Be the Match" that explained the importance of collecting marrow donors, dispelled myths that prospective donors often have, and trained them in collecting cheek swabs and properly filling out applications. The faculty and students then traveled to the chosen universities, and participated in a training session with the campus partners the night of arrival, then conducted a three day marrow drive. Students and faculty from Texas State University were paired with students and faculty from the hosting universities, teaching them proper collection techniques and information with the intent that in the future, the host campus will conduct marrow drives independently. "Be the Match" representatives paired radiation therapy students, with hosting university students placing them in strategic stations spread out across the campus in order to reach as many people as possible. Several "Be the Match" representatives traveled from various regions in Texas to team together for the south Texas event in order to have one representative at each of 8 to 10 tables.

Throughout the day an experienced designated student or a "Be the Match" representative checked for completion and accuracy of completed donor applications and buccal samples in preparation for shipment to the lab registration entry. Duplicate and or incomplete applications were discarded, and final tallies were then released to the faculty members and are describe below. Each day ended with a group briefing led by "Be the Match" representatives that announced the day's totals. Each briefing was highly spirited and encouraging. As this was not an experiment, simply an outreach effort, no IRB was necessary. The students did not directly indicate that they were part of a radiation therapy program because they were acting as "Be the Match" ambassadors, however if they were asked where they were from they were free to answer. Totals from the outreach were provided by "Be the Match" at the end of each day as is common practice when holding a donation drive and so this was not confidential information. The students who became donors and so are represented in the results provided consent upon filling out the donor application as "Be the Match" to be included in the drive count.

Results

A total of 8,098 new marrow donors have been recruited since the fall of 2012 (See Table 1). In its first collaborative outreach, the program successfully recruited 1,055 new student marrow donor registrants, almost all Latinos (97%) and 36 (3%) Non-Hispanic/White at the University of Texas-Pan American. The Kayak for a Cure event resulted with 71 registrations, with 34% minority. In spring of 2013, the total registered at Texas State was 1414, with 61% minority; UT Austin yielded 2091 registrations with 66% minority. On the UT Brownsville campus the total of registrations was 1310 with 98% minority. In spring of 2014 the marrow drive at Texas State yielded a new record for any marrow drive held at any U. S. campus with 2157 registration and 1272 classified as minority, 59% of registrants. At each outreach, "Be the Match" sets a projected goal, or a number of registrants they would like to obtain during that effort. Statistics from each outreach including the location, semester conducted, projected goal set for outreach, number of students registered, number of specifically minority students registered, and the percentage of the total number registered that were minority students is available in Table 1.

Table 1: Texas State Radiation Therapy Marrow Outreach

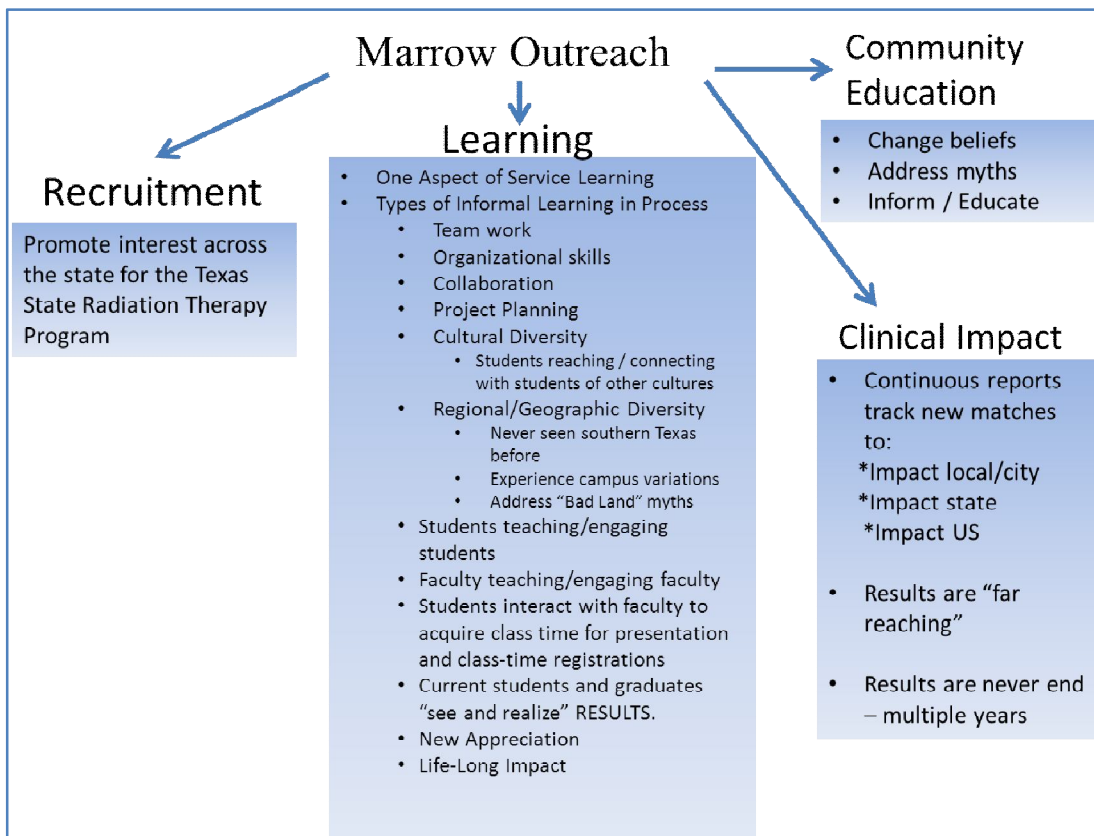
Texas State Radiation Therapy Marrow Outreach Location	Semester	Projected Goal Set by "Be the Match"	Total Registered	Minorities	Percentage of registrants who were minorities
UT Pan American	Fall 2012	800	1,055	1,019	97%
Kayak for a Cure	Fall 2012	50	71	24	34%
Texas State University	Spring 2013	1200	1414	864	61%
UT Austin	Spring 2013	1,500	2,091	1376	66%
UT Brownsville	Fall 2013	1000	1310	1283	98%
Texas State University	Spring 2014	2,000	2157	1272	59%
Totals		6550	8,098	5,838	

Discussion

At each of the campuses, the percentage of new donors classified as a minority exceeded the percentage of new donors from the Non-Hispanic/White category. The percentage of minority registrants ranged from 59% to 98% of the total number registered on each campus. On each occasion, the projected goal set by the regional "Be the Match" representative was exceeded by at least 157 registrants. Students working with the outreach program educated and solicited each student as they passed, and so no racial profiling or selective recruitment took place. Because of this, these numbers are indicative of the population of the specific university population, but also indicate that individuals of any ethnicity are open to the idea of becoming a donor and are willing to participate when given the proper education about what becoming a donor entails, the procedures if chosen, and most importantly the lack of pain involved in the donation process. In specifically recruiting for donors at institutions of higher learning that are HSI's or have a diverse student population, the "Be the Match" registry greatly benefits as a more diverse pool of potential new donors leads to more possible future matches and lives saved. For the radiation therapy students, they gained a wealth of education on marrow donation and how it is utilized to save patients' lives of diseases that they will work closely with throughout their career. They gained empathy towards individuals struggling with these diseases and gained a greater perspective on the lack of education the general population has on how little self-sacrifice it takes to potentially save another life. They also learned that as future health care professionals, and individuals who have extensive knowledge of cancer and how it is treated, it is our responsibility to educate others. Taking a closer look at the types of impact of this educational community project as the group worked towards educating about disparity of marrow donations identifies multiple outcomes at various levels. Figure 1 breaks down outcomes observed for various aspects of each organization or entity. In terms of education, a group of 32 students engaged in face-to-face communication at strategic stations throughout the hosting campus calls attention and spurs interest among both the student body as well as faculty and administration. Radiation therapy students formulate strong foundational knowledge of cancer at levels higher than most students. Allowing them to become instrumental in community education and awareness efforts with this background makes them Cancer Awareness Ambassadors. As such these students are equipped to represent and promote as one may be a good ambassador for a profession, an organization, or a sport, the radiation therapy student can be an ambassador of cancer education and awareness to communities of interest. Another element of learning observed for our students while engaging in public and community education, involved aspects of collaboration between organizations, planning, design, and project implementation. An important aspect of informal learning stemmed from merely traveling to different geographical regions and entering and working among a cultural group mix significantly different from home base. Most importantly, something that facilitated an even deeper appreciation by our students came from repeated student to student discussions as those already afflicted came by, just to tell their story of a loved one.

This creates a life-long appreciation that was expressed by our students during the end-of-day briefings. The outreach holds as its mission, a goal of strong community education to dispel myths by informing and educating. And lastly, reports of matches found for registrants during an outreach provide a positive clinical outcome. In 2014 three matches were identified from an outreach held in 2012. Further, UT Pan American has since conducted two marrow drives independently. These types of results may be described as “far reaching” having a positive effect both on a patient, and a profound effect showing benefit and positive change that makes a difference to the student group. It is unclear what the impact was that the students were from a cancer related field of study. The radiation therapy students acted as extension of the “Be the Match” foundation and did not specifically broadcast that they were radiation therapy students unless specifically asked. However being radiation therapy students, and working closely with cancer patients on a daily basis may have made the students more passionate about the recruiting efforts than the typical college student which could have increased donations. Because they did not indicate that they were different than any other “Be the Match” volunteer, it can be deferred that this level of recruitment could be obtained at any marrow drive and that it is the education that leads to donor registration. This means that specifically targeting and educating the desired population should enhance donor participation amongst any group and should be researched further.

Figure 1: Types of Outcomes for Educational Community Project



The greatest limitation to this study was the geographic location that could be covered by the students. As Texas State University is located in central Texas, it took great effort and funding to transport all students to the outreach campuses and house them for the event. Because of this all campuses were located in Texas as well with the majority of the minority students being of Hispanic ethnicity. The fundamental principle to understand is that because tissue types are inherited, patients are most likely to match someone of their own race and ethnicity. With this in mind, as mixed marriages increase within modern, global societies, the need for donors of mixed heritage will rise.

This is an additional factor as the critical need rises proportionally with the growth of multiple race families and the anticipated outcome of the need for mixed marrow donors. This underscores the importance of the need for further study and dedication.

Conclusion

As radiation therapists, we touch the lives of many patients each day who are currently undergoing treatment for cancer. However, as cancer experts, we hold the knowledge to impact exponentially more through education and outreach. It is our responsibility as the health care professionals to disperse this knowledge to others and work in all aspects of cancer research including, prevention, screening, detection, and different areas of treatment such as marrow transplantation. It is easy to contribute and become a marrow donor. Simply go onto the "Be the Match" registry and personally join. Encourage friends, family members, and co-workers to do the same. Or take it a step further as this case study describes and organize a marrow drive through your work, church, school, or neighborhood. Each donor is a potential match to help save the life of an individual struggling with a life limiting disease. Kathy Soliz lost her battle with leukemia, but hopefully in discussing her loss, and how easily her life could have been saved, many lives will in the future be spared.

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