Social Disparity in the Curing of Blood Disease

Claire Bendig

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Dr. Read

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Introduction

In the 21st century, cancer is projected to be the single greatest killer in the world. While nearly 10 million deaths due to cancer occurred globally in 2018, approximately 70% of those deaths occurred in low-income countries, reflecting a huge social justice problem. Blood cancers and diseases such as Leukemia, Lymphoma, Sickle Cell Disease and Severe Combined Immunodeficiency (SCID) can all be cured with a bone marrow transplant. The challenge is that many patients do not have a single match on the national bone marrow registry and are unable to receive a cure for survival. 77% of Caucasian patients are able to find a match, whereas only 23% of African American / Black patients are able to find a cure. That is a 54% disparity, all because of a barrier of communication. Beyond that, donors need to be between the ages of 18-44 in order to be qualified to register. Although Be The Match community representatives are hired to educate the public, there is a sales element of this position. Representatives need to hit a certain number of new donors each quarter. These recruiters would target 'easy' communities through private colleges and media influencers to encourage donor recruitment. What was happening was tons of cacuasian donors were registering and not enough diverse donors were being targeting for donor education. This lack of equality created a social justice and racial inequality problem. Depending on one's race, a patient will be told their chance of survival. This social justice problem poses the question: who has the power to decide which race needs more support and are their resources in place to accurately communicate the problem?

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 (Be The Match®, 2013). For uncertain reasons, potential donors either remove themselves from the registry or decide not to donate (Be The Match®, 2013). This problem demands attention because, for those in need of bone marrow, retention of potential donors means treatment and survival. Technical communicators in the medical field can make an impact by changing documentation and educational resources for bone marrow donors through the lens of social justice. Social justice is the type of justice which is concerned with the fair and just distribution of wealth, equal opportunities for the individual, and privileges within one's society. Walton, Moore, and Jones 4R's (Reveal, Reject, Replace, Reflect) guide the process of being honest with the current forms of technical communication in the bone marrow donor space and it can be changed for the better. The field of technical communication has grown and expanded internationally, and as a result, "is complicated by forces of postmodern globalization" and confronted by "complex processes of power, hegemony, ideology," and other tensions, "which raise social justice concerns in which technical communicators have vital roles to play" (Agboka, 28). Godwin Y. Agboka is a technical writer who studied localization and the ways technical writing can be adapted to better benefit the user. Be The Match's approach to diverse recruitment can be bettered if the process was created with a diverse array of users in mind.

Reveal

Be The Match provides the majority of stem-cell and bone marrow for patients in the United States. The registry works to educate the public about the need for diverse donors because diversity plays a huge role in a patient's ability to match with a donor. "When it comes to matching human leukocyte antigen (HLA) types, a patient's ethnic background is important in predicting the likelihood of finding a match. This is because HLA markers used in matching are inherited. Some ethnic groups have more complex tissue types than others. So a person's best chance of finding a donor may be with someone of the same ethnic background" (Be The Match website). Patients of minority backgrounds have a substantially harder time finding a match. If a patient comes from a mixed heritage, the chances of finding a cure become even lower. The problem lies in the process of educating the public. The technical communication documents that are created to spread the word about the national marrow registry need substantial work to create equal opportunity in providing cures for all patients with blood disease.

Looking at diverse HLA bone marrow availability through a social justice framework defines solutions for creating equitable cures for blood disease. Walton, Moore, and Jones 4R's (Reveal, Reject, Replace, Reflect) guide the process of being honest with the current forms of technical communication in the bone marrow donor space and how it can be changed for the better. One key term in this framework is the idea of universal human values. A global standard may appeal to "universal human values", but it can marginalize groups of people. Even worse, "it can be used for various forms of psychological violence in business interactions, because the craving for uniformity may be mistaken for lack of cultural diversity. Finally, it can become the normative standard for racializing or othering cultures" (Agboka, p. 173).

There was a recent study by Agboka that took a look at sexuopharmaceutical user documentation in Ghana. Technical communicators were quick to write the documentation with a universal user in mind. The product was shipped around the world and the instructions did not translate well leading to misinterpretations with dangerous consequences. A global standard may appeal to "universal human values", but it can marginalize groups of people. Even worse, "it can be used for various forms of psychological violence in business interactions, because the craving for uniformity may be mistaken for lack of cultural diversity. Finally, it can become the normative standard for racializing or othering cultures" (Agboka, p. 173).

When applied to the social disparity in the curing of blood disease, it is imperative that community educators do not design documentation with the idea of a universal user and a localized thought process. Localization is the process of adapting content to a specific market and in the context of technical communication, content is often written with a universal user in mind. This is referring to the mainstream user based off of user statistics (age, gender, race, ect). It is often is not inclusive to diverse populations that may not speak the language or have other barriers of access to the material. Accessibility of content needs to be at the forefront of Be The Match communicators' minds. The goal of the national bone marrow registry is to access a diverse group of donors to provide cure opportunities for all. In order to do so, there needs to be diverse and flexible forms of communication.

There are many barriers of access to information in the bone marrow realm. Currently, most of Be The Match donor recruitment efforts are presentations during corporate lunch and learns, small liberal arts classrooms, and niche community events. If the focus is diverse recruitment, communication needs to extend beyond the walls of corporations and small

universities. Donors need to be between the ages of 18-44 and beyond that, they need to be committed when joining the national marrow registry. Currently, 54% of donors do not go on to donate when they receive a call that there has been a potential patient-donor match. In order to retain commitment, trust needs to be built between the donor and the marrow community representative. A potential donor is much more likely to join the registry if they feel a personal draw to the mission. Even if there is no personal relation to blood disease, having a representative that the potential donor can identify with is imperative. Without a level of self-identification, members of the public are not going to feel trust and commitment in the donation process. Godwin Y. Agboka, a technical communicator, wrote about participatory localization in a social justice approach to navigating cultural sites for *Technical Communication Quarterly*, 22:1, 28-49, "ethnographic, participant-observer approach … in which users and designers coconstruct knowledge." Participatory localization emphasizes participation of the users in adapting the product to reflect their values and customs and to fit the linguistic, social, and economic needs of their culture. The user, being the potential bone marrow donors, needs to be able to identify the need for joining the registry. Without connecting one's own personal culture, the cause seems meaningless. A failure to speak to users in ways that are relevant and significant within their particular sociocultural context is a failure of communication. Public health materials can and should draw from other (i.e. non-Western/non-hegemonic) sources. Culturally appropriate communication is the only way Be The Match will successfully gain the trust of diverse donors.

LucStrong, a Sickle Cell foundation based in Los Angeles, focuses on the African American and Latino community. The organization serves any child under 18 who requires a

bone marrow transplant as a result of Sickle Cell Disease. SCD affects approximately 100,000 Americans. SCD occurs among about 1 out of every 365 Black or African-American births. SCD occurs among about 1 out of every 16,300 Hispanic-American births. About 1 in 13 Black or African-American babies is born with sickle cell trait (SCT). It is imperative to provide education resources to specific communities to provide transplant options. LucStrong's communication is focused on participatory localization, focusing on a community bringing resources together to help one another. By revealing the need in one's own community, there tends to be quicker action to provide support.

Replace

On Be The Match's website, the only content that is shared about the importance of adding diversity to the registry is the following:

> *A patient's likelihood of finding a matching bone marrow donor or cord blood unit on the Be The Match Registry® ranges from 19% to 80% depending on ethnic background.*
>
> *When it comes to matching human leukocyte antigen (HLA) types, a patient's ethnic background is important in predicting the likelihood of finding a match. This is because HLA markers used in matching are inherited. Some ethnic groups have more complex tissue types than others. So a person's best chance of finding a donor may be with someone of the same ethnic background. (www.BeTheMatch.org)*

This content is lacking the necessary context to motivate the public to become marrow donors. There is no personal community connection. There are many different opportunities on this web page to provide more information for the user. In order to get rid of the first obvious barriers is to design a button that will translate the next in various languages.

All users should have the opportunity to download documents in their native languages to better share and spread the word of adding new donors within their specific community. For example, a two year old named Jazmyne in 2018 had zero matches on the registry. She is half cuban and mexican. In order to encourage donor registration in Los Angeles the materials needed to be translated in Spanish. Since Be The Match lacked resources, the community engagement team worked with Telemundo, a news channel, to promote Jazmyne's story ([here](#)).

Technical writers at Be The Match can make simple changes to the donation web pages. Some UX Design principles to consider including translated documents is to reserve enough space in the user interface for longer text because each language is going to vary. By providing translated documents such as flyers and reusable social media posts, the technical communicator is providing the users with the power to advocate for their own community. Internal representation is going to lead to the most amount of trust and in the end more committed users.

No. of characters in English source	Average expansion
Up to 10	200–300%
11–20	180–200%
21–30	160–180%
31–50	140–160%
51–70	151–170%
Over 70	130%

[1]

Language	Translation	Ratio
Korean	조회	0.8
English	views	1
Chinese	次檢視	1.2
Portuguese	visualizações	2.6
French	consultations	2.6
German	-mal angesehen	2.8
Italian	visualizzazioni	3

[2]

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[1] The suggested expansion margin to reserve in the interface for translations. Source: W3C

Another opportunity to strengthen the level of trust and understanding with the current 'Why Ethnicity Matters' webpage is by creating diverse representation with real life donor and patient stories. The current page has two paragraphs spewing statistics, but doesn't connect the words to a real life altering problem. A simple fix is to provide a video at the top of the page. This video could be one of the many reunions documented between donor and patient. Majority of donations come from a complete stranger. The gravity of the situation is that humanity is coming together to help one another forgoing personal gain.

Beyond the design of the document, technical communicators need to understand the bigger context of the community that is trying to be accessed. There is a huge divide in African American and Black recruitment because there is a lack of trust. Mistrust stems from historical events including the Tuskegee syphilis study and is reinforced by health system issues and discriminatory events that continue to this day. Mistrust is an important barrier to understand when looking at the communication used to register diverse donors. In the medical study "More Than Tuskegee: Understanding Mistrust about Research Participation" in the manuscript *J Health Care Poor Underserved,* it is found that African Americans continue to participate less frequently in medically funded research. "Lower participation rates among African Americans have been reported across various study types (*e.g.*, controlled clinical treatment trials, intervention trials, as well as studies on various disease conditions, including AIDS, Alzheimer's disease, prostate cancer and other malignancies, stroke, and cardiovascular disease16)." From a

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historical perspective, the Tuskegee syphilis study is widely recognized as a reason for mistrust because of the extent and duration of deception and mistreatment and the study's impact on human subject review and approval. However, the history of medical and research abuse of African Americans goes well beyond Tuskegee. As recently as the 1990s, unethical medical research involving African Americans has been conducted by highly esteemed academic institutions. For example, researchers at a prestigious U.S. university recruited African American boys into a study that hypothesized a genetic etiology of aggressive behavior. Through the use of monetary incentives, they were able to convince parents to enroll their sons in a study that included withdrawal from all medications (including asthma medications), ingesting a mono-amine (low protein) diet, an overnight stay (without parents), withholding of water, hourly blood draws, and the administration of fenfluramine, a drug known to increase serotonin levels and suspected to be associated with aggressive behaviors. In addition to these methods, "several other significant human subject violations were cited, including restricting the recruitment to Black children. It is fair to ask whether mistreatment of African Americans that has occurred more recently than the Tuskegee syphilis study is exacerbating mistrust today." [3] There is a blatant lack of medical trust in the African American community for good reason. Technical communicators need to understand the context behind the ask in order to be ethical about the situation. In order to rebuild trust, the presenters and videos should come from within the community. Be The Match representatives should go to presentations and have a member of the community speak about the internal problem. Videos need to include diverse patients and donors with different backgrounds so that the public can see themselves as current donors. Self

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[3] "Understanding Mistrust about Research Participation"

identification is going to take away some of the initial fear of the unknown and provide comfort. Equal representation encourages a comfort level that will allow communities to overcome barriers of access.

Reject

Another technical communication problem that can be seen through a social justice lens is the process of joining the Be The Match registry. Currently there are two ways to join. If Be The Match representatives are out in the community, donors can register by signing up at the table through their smartphones. Registration tables are not equipped with laptops or tablets. Donors are expected to have mobile devices with roaming data. Currently when registering, there are only two language options: English and Spanish despite the need for every culture to be present on the registry. The main screen speaks colloquially saying, "you could be someone's cure. You could *literally* save a life." What does this do for the user? It doest provide the reason why the user might be the perfect donor.

There are four pop-up question options: Am I eligible to join the registry? What's donation like? Does it hurt? Are there risks? Although these are important questions, it does not provide context to HLA marking and racial matching. Donors need more context about why racial matching matters. Once donors fill in the initial phone, they are prompted to check their phone for an email to verify their account. They have to sit through the verification process in order to finish registering. The entire process takes approximately 15 minutes and doesn't provide ease of use for potential donors that do not have the resources for quick roaming phone data, those who don't speak English and Spanish, or are short on time and unable to register right

away. The other way to join the registry is to sign up online and have a cotton swab mailed to the donor's residence for a saliva swab. The biggest barrier of access here is that the ideal donor is between the ages of 18-22. These individuals are likely to be living at colleges or universities and may not have access to receiving mail. The donation process is time sensitive and this can slow down the entire process. The kit return rate for online registration is only 33%, meaning the majority of registration kits are sent out and never returned to complete the donor registration process.

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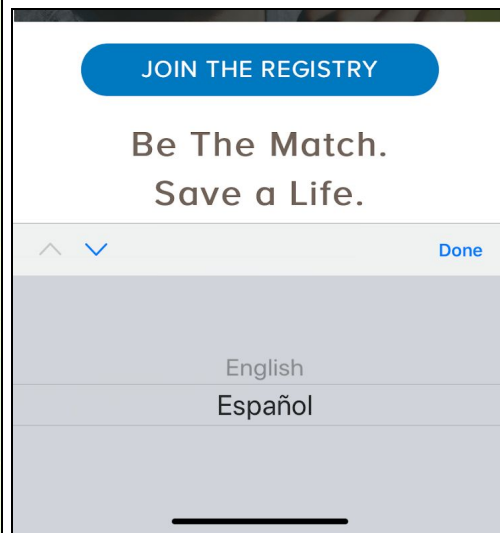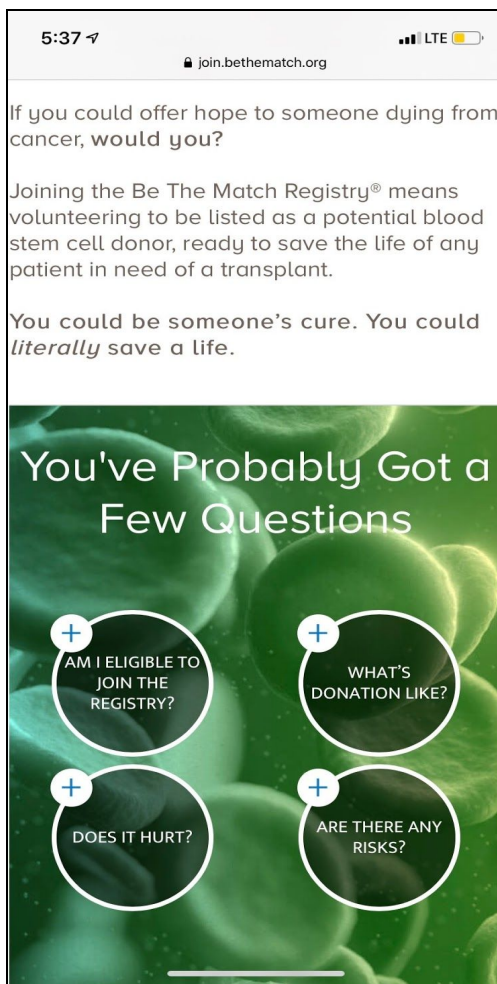
[4] Screenshots of registration process on a smartphone.

Reflect

The main objective of Be The Match is to provide bone marrow transplant options for patients in need. The issue is that there is not enough diverse availability in the registry. The best way to change the system is to look at the communication problem through a social lens. All documentation needs to be translated and easily accessible for diverse communities. The idea of a universal user only creates a barrier of access to both the registration process and information about the national bone marrow registry in general. There needs to be equal representation to create trust between the community engagement representative and the user. Without trust, doctors and patients cannot expect committed donors. If the community representative does not align with a community, a member from the internal community should be the one to educate. Building resources for any member of society to use is going to make the problem much more accessible. There are thousands of patients who will not survive without a bone marrow transplant. Majority of patients do not have a match on the registry and must rely on a stranger in the public to step up and provide a cure. Communication is the only way to bridge the problem with the general public, and in the end save lives.

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