Minorities Facing the Organ Shortage

The term minority often has an association with negative connotations. Hopefully, this is something that will change as our society grows. In light of this, it is important to note when the term minority is used within the text of this paper, it encompasses different groups. African Americans, Latinos, and the poor (indigent) are the biggest groups of minorities found in the United States. In researching this topic, the African American community makes up the larger portion of the minorities, therefore that demographic has much more support and education available to help with the problem of the organ shortage that is affecting America. Although many people choose not to donate their organs for various reasons, the rising trend seems to be that more minorities are in dire need of an organ transplant, yet the quantity of minority donors continues to diminish.

According to the Organ Procurement and Transplantation Network (OPTN) website, the waiting list as of early July indicates that well over ninety-eight thousand people are in need of some type of organ via transplantation. When those factors are broken down into categories by race, the results of those who are in need are: white—over fifty thousand, black—over thirty thousand, and Hispanic—over seventeen thousand. Combining the donations of cadaveric organs and those of living donors, the donation amount for the year 2008 is as follows: white donors—just over three thousand; black donors—right at six hundred; and Hispanic donors—slightly more than six hundred. These numbers clearly show that not only is the organ donation system in crisis mode, but the minority
population is especially at risk. “Indeed, studies show that the poor, the uneducated and minorities are less likely to consent to organ donation than affluent, educated whites. Meanwhile, blacks and Hispanics have higher diabetes rates…” (Hansen 166). The organ that is needed the most, among all the demographics, is the kidney. Currently the waiting list shows that the white population and the black population are running a close race with the need for a kidney transplant. The statistics for those waiting on a kidney transplant are: white—over thirty one thousand; black—just over twenty eight thousand; and Hispanic—slightly over fourteen thousand. In the article, “Who Gets the Organs? Experts Say Transplant Medicine Has a Race Problem”, Ben Whitford states that while a person’s ethnicity isn’t exactly the issue; African Americans are varied when it comes to genetic makeup:

Black and Hispanic people donate organs at the same rate as whites, but they are predisposed to organ-damaging diseases like diabetes, so that in spite of campaigns to promote organ donation in minority communities, there’s no way for minority donation alone to keep up the minority demand for organs (par 4).

In light of the circumstances surrounding the need for an increase in donations, some experts agree that there needs to be other areas looked into to boost the supply of transplantable organs and reduce the amount of people on the waiting list. One of these areas may be how patients end up on the waiting list, altogether. Dr. Denise Dudzinski,
of the University of Washington School of Medicine, offers some solutions for the problems that minorities face with the allocation process in the commentary piece, “Shifting to Other Justice Issues: Examining Listing Practices”. One of the proposed ideas is a motivational approach, which recognizes transplant teams who can develop listing criteria and make it equally available to all people in their community who are considering organ transplantation. Dudzinski also asks that we take a look at the method for which transplant patients are assessed. There are only a small percentage of patients who do not actually make it on the transplant list after evaluation; however they may wait for long periods of time for an organ. Dudzinski feels that perhaps due to relationships formed between these patients and the center from which they seek care, they may be listed out of a sense of duty, even if transplantation is not the best option. Social assessment as well as psychological assessments can help determine the patient’s eligibility as well (35). Dudzinski also states, “One way to insure just allocation of deceased donor organs is to ensure that psychosocial criteria are openly stated and consistently applied” (35). Another topic that has come into focus where the donation process is concerned is the criteria for donor matching. Could the shortage of transplantable organs be due to the need of organs and lack of suitable, healthy donors? It has been proven scientifically that ethnic factors play a role in how a donated organ reacts when transplanted into a receiving patient. It is important to take into consideration that there is a need for an organ, but the supply to collect from is diseased
by chronic renal conditions (diabetes, hypertension) and poorer health altogether (Whitford, par 4). Whitford’s research lead him to discover that the United Network for Organ Sharing (UNOS), established a more relaxed approach to the previously rigorous standards for matching transplantable organs with waiting recipients (par 5). Brian Hansen discusses this further by stating that, “Minorities vying for transplants under the old policy were frequently told that they did not qualify for organs recovered from Caucasian donors…less importance placed on HLA [human leukocyte antigen] matching, will result in some 200 additional kidney transplants annually for minority patients” (168).

It has been observed throughout the history of medicine that there is a distinct mistrust among the minority community, specifically African Americans, and how they relate to healthcare. The Tuskegee Syphilis Study is widely recognized as a possible origin for this current belief in modern medicine. This experiment began in the United States in 1932 and carried on for almost forty years. This research project was based on the observation of over four hundred African American males affected by syphilis. The premise of the study was to follow the pattern of the patients and how their bodies dealt with the disease by withholding the proper medication that could cure their condition (Everitt and Pickles 55). Although there are very few patients of this study alive today, the memories of those families carry on and the conviction this distrust was founded on is hard to dispute. Among other beliefs held by African Americans is one that if doctors
get consent for organ donation, the patient is more likely to be allowed to die in order for their organs to be acquired for transplantation (Hansen 167). Dr. Clive Callender, a board certified transplant surgeon and director of the Transplant Center at Howard University Hospital in Washington D.C., has spent his career in medicine trying to educate the minority population on the importance of organ donation within the African American community. Dr. Callender founded the National MOTTEP (Minorities Organ Tissue/Transplant Education Program). His extensive research in the area of minorities and organ donation lead him to the conclusion that there are certain explanations about why African Americans do not donate:

- a lack of awareness about renal disease and transplantation; religious beliefs and superstitions; distrust of the medical community; a fear that by signing an organ donor card, medical professionals would not try as hard to save them; and racism-the belief that their organs would only go to whites (Basu).

In a research study performed by Laura Siminoff, et al, a poll was conducted among a broad group of the population, including all ethnicities, sexes, and creeds. Amid all of the topics discussed in this study, it was found that African Americans wanted for their donated organs to go other African Americans, specifically (“Racial Disparities” 999). Another issue in question is the allocation process itself. Some experts’ opinion is that the allocation process is race oriented. Defending this issue are experts who deny that
racism is not possible due to the fact that all information in the allocation process is computer generated, however Dr. Callender feels that, “The computer may be colorblind, but the people who put the information into the computer are not…This is directly the consequence of institutionalized racism”(Whitford par 3). Dr. Callender said, “They [minorities] feel if…society has been discriminatory to [them] in life, why would it be any different in death?” (Hansen 167). Another study conducted by Laura Siminoff, et al in the Annals of Internal Medicine, cite that if it is unspecified that African Americans are not as probable to act in an unselfish manner “toward a medical system that has mistreated them, then public education efforts designed to solely increase cadaveric donation without addressing issues of trust and equity will not be as effective as possible” (Increasing 609).All of the information thus far has pointed to a need for an increase in education and awareness. Many believe that if the minority population were educated in the area of organ donation and transplantation, there would be an increased understanding and favorable recognition of the need for change. Among some of the concerns, it is believed that simply orating ones wishes to donate to their family would open doors that were previously closed. There are many educational programs in effect today. One example of this educational initiative, Dr. Callender formed-- The National MOTTEP, an organization that receives funding from the government. Dr. Callender states:

“I want people to go from not signing donor cards to signing them, to not being donors to becoming donors, in life and death. Our modus operandi goes into the community and educates and empowers community
members about how they are going to change the behaviors in their own community. Awareness is when you make people aware, but we want to take it a step beyond that. We want them to put their awareness into an action, so they will do something positive” (Basu).

The MOTTEP has sponsored the National Minority Awareness Day, held annually. This event is intended to improve not only awareness of the shortage of organ donors, but to alleviate fears connected with this issue. It is the aim of this movement to encourage living a healthy lifestyle, deterring disease, and signing donor cards (MOTTEP website). Perhaps another way to get the message across to minorities about the impending problems associated with the organ shortage is to utilize the experiences of professional athletes who have been affected by this issue. In the Black History month article on ESPN.com, the story of Walter Payton’s family shows how insight into this terrible epidemic can help increase awareness. In 1998, Walter Payton, award winning running back for the Chicago Bears, developed an uncommon disease of the liver that would require a transplant. He was subsequently placed on the waiting list; however, he died because of the delay in finding a matching donor. Prior to his death, he admitted that he did not know enough about organ donation. He began speaking on the topic to heighten awareness of the need for organs. His daughter, Britney, who was only fourteen when he died, began her own initiative. She was still a student
in high school when she formed the Youth for Life campaign. This campaign was aimed at teenagers in order to increase their understanding of organ donation. This project has helped the state of Illinois become one of the country’s leaders in organ donation. Wayne Drehs, of ESPN, has observed that perhaps, “Having a story of a celebrity like Payton or professional basketball player Alonzo Mourning, a transplant kidney recipient, or Sean Elliott, who received a kidney from his brother, can only help”.

It appears that the issue of minorities and the organ shortage is not going to go away. There seems that there will always be a need for more organs. However, by spreading the word through educational programs, or simply discussing wishes for donation with family members, the numbers of recipients on the waiting list may start to decline. Perhaps we will see a future where technological advancements in medicine will help with organ matching and rejection rates and a minority population that holds good health and awareness as its mainstay.