

Some of the Challenges of Encouraging Organ Donation Among Minority Populations

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Organ donation and organ allocation remain important issues for patients awaiting transplantation in the United States. The disparity between the number of deceased donors and the number of patients awaiting transplantation continues to widen each year. The number of deceased donors in the United States has remained stagnant at approximately 5,000 donors per year, while the waiting list for organs in 2004 exceeds 80,000 individuals. Each day in the United States 15 patients die while awaiting life-saving transplants. The method of allocation of these precious gifts is of importance to all patients, but is of particular importance to minorities. Although minorities are represented in all end-stage organ diseases, end-stage renal disease has by far the greatest impact on minorities. Diseases such as hypertension and diabetes, which can lead to end-stage renal disease and the need for transplantation, disproportionately affect minorities. Several key questions should be openly discussed and debated in regard to transplantation policy and minorities. Some of these questions might be: Is there proportionate representation of minorities on organ waiting lists? Does race impact organ availability? What are the reasons that waiting time is longer for minorities awaiting kidney transplantation? How can we increase organ availability for minorities? What should be the guiding principles of organ rationing?

For many highly specialized procedures in the United States, racial differences in access to effective medical procedures persist. Minorities are far less represented than their majority counterparts, even when adjustments are made for economic status and education. Coronary artery bypass surgery, total knee and hip replacement, cataract surgery, screening colonoscopy and mammography are examples of such procedures where disparities exist. Access remains a critical issue.

Two significant risk factors for renal disease, hypertension

and diabetes, disproportionately affect African Americans. It is estimated that more 30% of adult African Americans are hypertensive, compared to a 20% incidence in the majority population. More importantly the age of onset in African Americans is earlier, resulting in higher age-adjusted hypertension prevalence. This early onset subsequently leads to more target organ damage and greater overall mortality burden when compared with the majority white population. Although the difference is not as drastic with the incidence of diabetes, the risk of end-stage renal disease in African Americans with diabetes is three times as great as that of the majority population.

Due to the greater burden of disease, the incidence of end-stage renal disease is much higher in African Americans. Thirty-five percent of all patients awaiting kidney transplantation in the United States are African American. In some areas of the country, African Americans account for over 70% of the patients awaiting kidney transplantation. Thus, issues of organ allocation are of paramount importance to understand. Organ allocation begins with timely referral to transplant centers. In a study by Ayanian et al., they showed that despite equivalent desire for transplant, the number of patients referred for evaluation and the number of patients placed on the waiting list were significantly less for African Americans than for their majority white counterparts.¹ One recent proposal to level the playing field is for patients to be assigned waiting time from their initial diagnosis of renal dialysis and not with their referral to the transplant center.

This proposal, if implemented, may allow for those patients with less access to the referral process to gain a more equitable footing. However, there remains some opposition to this proposal in the transplant community. Not only must we provide better access to transplantation, but the method of allocation has great importance

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since the demand far outweighs the supply of deceased donor organs. For patients listed in 1997, African Americans waited an average of two-and-a-half years longer than their white counterparts on the waiting list. This disparity is most notably accounted for by the limited supply of genetically closely matched organs, and to some extent by the continued use of tissue type matching in the algorithm for kidney allocation. Traditionally it has been shown that in the prior era of immunosuppressant drugs, tissue type matching played a role in the longevity of functioning kidney transplants. As the immunosuppression drugs have improved, these differences have been lessened. Certain tissue types are much more common in the majority of white populations than in minority populations. Since the majority of deceased donors are Caucasian, this limits opportunities for closely matched organs in some instances. Over the years the preference given to tissue type matching has been reduced. The question remains: should we eliminate tissue type matching altogether and apply severity of illness and waiting time as the only factors for recipient selection in kidney transplant allocation? Previous studies have shown that the impact of elimination of tissue type matching reduces long-term kidney survival.³ It is my belief that this difference may be mitigated by utilizing different immunosuppressive strategies for African Americans than for their majority white counterparts.

Other issues of importance include increasing organ donation, especially in the minority population. The African American deceased organ donor consent rate is far less than it is in the white population. Boulware, et al. recently studied racial and gender issues relating to donation in a Baltimore community.² Their results suggest that mistrust of hospitals and concerns about racial discrimination in hospitals accounted for the signif-

icant differences in willingness to donate between non-Hispanic blacks and whites. Black males were particularly resistant to organ donation. White males were most likely to identify themselves as organ donors on a driver's license (65%), compared to white females (60%), black females (38%). Only 19% of black males indicated their willingness to donate. Ironically in the year 2003, in the service area of the greater metropolitan Washington, DC area, the percentages of actual deceased organ donation show great similarity to the data provided by Boulware and her colleagues. Of eligible African American families that were approached concerning organ donation the consent rate was 25%, compared to 60% for the Caucasian population.²

Targeted education in the minority community will likely provide greatest benefit to increasing organ donation in the minority population. Central figures of trust within minority communities can be used as advocates for dissemination of this critical information. Dissemination of information regarding the need for organ donation in the minority community will be more effective if simultaneous education about disease prevention occurs, especially in relation to hypertension and diabetes, which ravage our community. The future looks grim with almost 20% of minority group children facing obesity. More often than not, they will carry this problem into adulthood leading to a greater incidence of hypertension and diabetes. We must confront these lifestyle issues now by targeting exercise, nutrition and disease prevention in our children. These and other issues must get on the agenda in our organizations, community and political debates. We need to not only emphasize the needs of end-stage organ disease patients, but also preventive strategies for our communities.

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I, _____, have spoken to my family about organ and tissue donation. I wish to donate.
☐ Any needed organs and tissue ☐ Only the following organs and tissue _____

The following people have witnessed my commitment to be a donor.

Donor Signature _____ Date _____

Witness _____ Date _____

Witness _____ Date _____

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Fill out this donor card in the presence of two witnesses, preferably your next-of-kin, and sign your name in the space provided.