

ORGAN DONATION IN THE AFRICAN-AMERICAN POPULATION: A FRESH PERSPECTIVE WITH A SIMPLE SOLUTION

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Organ transplantation is seriously limited by a lack of available organs. This article focuses on the more pronounced lack of organ donation within the African-American population and discusses the consequences of this trend. The reasons for this population's continued reluctance to donate organs are reviewed in detail and current efforts to improve donation rates are outlined.

The solution proposed in this article is to acknowledge and use resources already active in the community in efforts to increase organ donation rates within the African-American population. Social workers, teachers, religious leaders, and transplant donors, recipients, and their families would all provide a crucial addition to the multidisciplinary team already involved with organ donation efforts. (*J Natl Med Assoc.* 1993;85:353-358.)

Key words • organ donation • organ transplantation
• African Americans

Since the beginning of organ transplantation in the United States in 1954, the number of available organs (donated organs) has been considerably lower than the number of patients waiting for organs (potential recipients). This lack of donated organs has been significantly more pronounced within the African-

American population. This underrepresentation of African-American organ donations has had and continues to have two primary ramifications: there is a disproportionately large number of African Americans waiting for organ transplantation, and there is a paucity in the number of potential African-American organs available for transplantation. A third concern is now becoming apparent—there is a decreased likelihood of successful transplantation due to poor tissue match between donors and African-American recipients.

This article summarizes the reasons that African Americans have traditionally been less willing and available to donate organs for transplantation, and proposes solutions by focusing on and reaching out to some important and heretofore untapped resources, eg, social workers, teachers, religious leaders, and other culturally sensitive or appropriate educators who work at a grass roots level in the community.

The fresh approach proposed in this article is a matter of expanding horizons and closing in on new frontiers that already exist. Such new approaches must be taken now because previous attempts have proven inadequate.

It is important to keep in mind that the key current factor limiting the number of possible transplants is the availability of donor organs.¹ In recent years, the demand for transplants has grown much faster than the supply of available organs. Since 1983, the gap between donors and the number of patients waiting for organs in the United States has widened from 1050 to 9903 in 1989. As of June 1991, more than 25 000 people are waiting for organs for transplantation and six people die each day because of this shortage.^{2,3} This article, however, focuses on the particularly severe lack of donors from the African-American population who represent 30% of those waiting for organs.

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We chose the African-American population as the focus for this article because this population is the largest minority group in the United States, comprising 12.3% of the total population.⁴ In addition, although there is relatively little information available regarding this phenomenon of a lack of minority donors, by far the most published research results available relate to the African-American population. One likely reason for this is that while blacks comprise about 12% of the population, they comprise almost 30% of the end-stage renal disease (ESRD) patients. Kidney dialysis is the most common treatment for ESRD patients, and many of these patients become candidates for kidney transplantation.

EFFECTS OF UNDERDONATION

The underrepresentation of African-American organ donors has had two primary results. The first is that there is a disproportionately large number of blacks waiting for organ transplantation. In kidney transplantation (which accounts for 75% of all organ transplants and about 84% of those awaiting a transplant), the probability of a match between the donor and recipient within the same racial group is greater than between racial groups.⁵ Previous work^{1-3,5,6} has suggested that in about 20% of the cases, African Americans waiting for organs would be better served by kidneys from other blacks. Special antigen match-ups between kidney donor and recipient pairs are necessary, and such match-ups are more likely to be found in other blacks. Because certain identified antigen frequencies of blacks are different from those of whites, blacks are likely to have less access to transplants under the organ distribution systems now used, which gives more weight to antigen matching.^{1,7} Such evidence makes the lack of African-American organ donations significant as there are relatively fewer organs available that are a good match to black patients awaiting transplantation. Taken together with the fact that blacks have a significantly higher predilection for high blood pressure and kidney failure, it is even more important that blacks become interested in organ donation.

Second, there is an overall reduction in the number of potential organs available. This observation is fairly self-explanatory and affects all organ transplantation: kidney, heart-lung, liver, pancreas, and lung. If African Americans comprise 12% of the United States population but, as reported in a 1987 Gallup Poll, only 11% are willing to donate organs (compared with 32% of whites), this is a large untapped pool of potential organs.⁶

Third, in kidney transplantation, a probable consequence of low African-American organ donation is that black recipients often do less well after transplantation. The reason for this is that mismatches, which can occur when blacks receive nonblack organs, are often associated with intense graft rejection and therefore may have less potential for successful outcomes⁵ (Dunston G. November 1990. Written communication). With increased black donors, it would be less likely that blacks would receive mismatched organs, and consequently, the best possible outcome would be assured. According to Dunston's previous hypothesis, 20% of blacks are more likely to have successful kidney transplants if they receive kidneys from black donors.⁵

REASONS FOR LOWER DONATION RATES BY BLACKS

The most in-depth look at the reasons for lower African-American donation rates has been done at the Howard University Hospital Transplant Center in Washington, DC.^{2,3,5} In a 1982 study undertaken at the Center, where the patient population is 95% black and the District's population is 70% black, 41 of 47 cadaveric organs (80%) used for kidney transplantation were donated by nonblacks.⁵ A pilot project was developed to look at the reasons for low African-American organ donations. As part of this study, discussions with 40 African-American men and women revealed the following seven reasons influencing the reluctance of blacks to donate organs:

- lack of awareness of transplantation,
- religious beliefs and misperceptions (superstitions),
- distrust of the medical community,
- racism,
- poor access to medical care,
- lack of appropriate organ procurement specialists, and
- intra-family relationships.

Lack of Awareness of Transplantation

One general theme that surfaced in the Pilot Project at Howard University Hospital was the lack of knowledge about kidney transplantation. Many times during the discussion, the need for improved communication and education about these areas was stressed. In addition, a significant lack (only 5% of total) was found in the percentage of black transplant coordinators in the United States.⁷ Because these coordinators are often responsible for educating the public, speaking with potential organ donor families, and in general increasing donor awareness, one can see a lack of ethnically

appropriate and sensitive community education. In a similar vein, another study⁶ found that nurses requesting organ donations needed to better understand and appreciate the black belief system and culture. These nurses can then develop more appropriate and acceptable educational materials and programs that focus on increasing the African-American community's knowledge and acceptance of organ donation.

A 1987 newspaper article entitled "Doctors Urging Blacks to Donate" cited in a 1986 Gallup survey of public attitude toward transplantation and organ donation that showed 34% of whites but only 16% of blacks were very willing to donate their organs.^{5,8} In the same article, Schulman was quoted as saying that she "did not feel that the black community has had the extensive amount of education and exposure" on the subject of organ transplantation. Educational materials are often not geared to target blacks through the media. Unfortunately, the written organ donation materials currently available do not adequately address the black population either.⁹

Religious Beliefs and Misperceptions (Superstitions)

The 1982 Pilot Project at Howard University also identified some religious beliefs that had negative implications for donations. "Here the belief was that the body must be kept intact for life after death."^{10,11} According to these authors, there is great concern among African Americans that in that great getting up morning, if they leave their organs behind, they won't have them for themselves. So when Jesus Christ comes again and they're raised up, they'll be deficient of these organs.

Another study¹ relates the religious link between African Americans and low organ donation rates to African and new world Indian beliefs that share strong beliefs in the afterlife. These beliefs consider the sacred and believe that the dead should not be molested in any way because their spirits will be angered. They are against receiving a cadaver organ because one would be indirectly responsible for the violation of the body, thus angering the donor's spirit.

Distrust of the Medical Community

The Howard University Hospital project saw this distrust manifested in a view that after making a commitment (to donate) by carrying a card stating this, the individual might not receive proper care in a hospital because the doctors will be so eager to pluck out their organs and give them to someone else.¹²

Of the many episodes that have contributed to this African-American distrust of the medical community, perhaps none is more appalling than the Tuskegee Syphilis Experiment in which the United States Public Health Service conducted a study of the effects of untreated syphilis on black men in Macon County, Alabama. With promises of meager benefits, more than 600 subjects "agreed" to participate in a study that had nothing to do with treatment.

No new drugs were tested (even after the advent of penicillin). It was a non-therapeutic experiment, aimed at compiling data on the effects of the spontaneous evolution of syphilis in black males.¹³

In a conversation with Robert Grant, Senior Coordinator of the Maryland Organ Procurement Center, he said that this trust issue was most important. He feels that after years of distrust, the fear remains that whites are taking something away from blacks, who then tended to be reluctant when asked to donate organs.

Racism

In the study at Howard University, there was considerable concern over the negative implications of cross race transplants. A significant number of respondents preferred not to cross racial barriers because they felt the black kidney was superior.⁸

This attitude was illustrated by Robert Grant of Maryland Organ Procurement Center in a humorous anecdote. He was attempting to obtain permission from a Navy family to donate their son's organs, but they would only consent if his organs went to another Navy person!

The following excerpt was taken from a journal article entitled "The Marketing of Organ Donation."¹⁴ This article also reported that black families will express their belief that organ donation only helps whites and that they are not inclined to cooperate to that end. "How widespread this attitude is impossible to say, but we can't be too surprised, that in a racially polarized society, altruism is bounded by the limits of racially defined communities even in the absence of specific racial hostility, black donor families may easily have a greater sense of alienation from and fear of the institutions asking them to donate their relative's organs."

Poor Access to Medical Care

The tendency of black individuals to use hospital clinics and emergency rooms rather than to visit a physician's office may result in an inadequate exchange of information between patients and health-care provid-

ers. Also, it has been reported that “inner city hospitals, usually noted for serving a higher minority population, are the lowest providers of transplant organs.”⁶

Lack of Appropriate Organ Procurement Specialists

A recent study at Howard University² observed that there is a need for transplant coordinators “who are ethnically appropriate and sensitive.” Since only 5% of transplant coordinators in America are black,⁷ there is a need to use these black coordinators to their fullest and also to educate other black health-care providers.^{2,3} Organ procurement specialists see a proportionately small number of black families, mainly due to the lack of referrals from hospital staff concerning possible black donors.¹⁵ In a conversation with Helen Michalisko, a clinical social worker with the heart transplant program at Johns Hopkins Hospital, she said that there are instances when both physicians and procurement coordinators might hesitate to approach an African-American donor family because they are uncomfortable and unfamiliar with the black way of reacting to the tragedy. She sees this “healthy reaction” as much more demonstrative and dramatic than the white way of reacting to grief and concludes that procurement personnel (who are almost always white) often just do not know how to deal with these differences and therefore do not approach the family.

Grant at the Maryland Organ Procurement Center said that this reluctance to donate is self-perpetuating. Ten years ago African Americans, as a result of many of the reasons described in this article, were much less likely to donate than whites. However, currently he sees this reluctance far less often but feels that procurement coordinators still assume they will get a refusal and often, therefore, do not approach the African-American family.

Intrafamily Relationships

Several sources^{14,15} suggest that low donation in black families is perhaps due to broken families, single-parent families, or even extended families, all of whom have lower organ donating traditions. Procurement specialists find it easier to obtain donations from tightly knit nuclear families.

RACE OR CLASS?

In the process of researching and writing this article, the authors could not help but wonder if this phenomenon of lower African-American organ donation is really an issue of race or class. We now conclude that it is

both. Issues of race and racism seem apparent when looking at: mistrust of the medical community, cultural and religious reasons for not donating, lack of appropriate organ procurement specialists, blacks and whites wanting to donate their organs only to their respective racial groups, and most perplexing, speculation that where racial differences are found in medical treatment, these differences could reflect the existence of a subconscious bias.^{14,15} The American Medical Association’s Council on Ethical and Judicial Affairs^{14,16} described this matter as a serious and troubling problem. “Despite the progress of the past 25 years, racial prejudice has not been entirely eliminated in this country.” They concluded that the health-care system, like all other elements of society, has not fully eradicated this prejudice.

However, we see class as an issue when looking at the lack of awareness about transplantation and donation, and access to medical care. It is possible, indeed probable, that at least part of the difference between whites and blacks is really a class-based rather than a race-based difference. Certainly class, especially as measured by education (and income), is correlated to attitudes toward transplantation and organ donation among whites.^{13,14} Ultimately, however, the fact that blacks comprise a substantially larger percentage of the lower and “truly disadvantaged” classes is the result of racism throughout the history of this country.

IMPLICATIONS AND EFFORTS TO IMPROVE DONATION RATES IN THE BLACK POPULATION

This article has dealt with a phenomenon that has important implications for a broad spectrum of health care and community workers, for as long as any segment of the total population is underrepresented in the donor pool, the number of possible life-saving transplants will be reduced. In addition to examining the reasons for lower black organ donation, we have also explored how this lack has been and continues to be addressed by a variety of programs.

Growing out of the study at Howard University, the DC Organ Donor Project was initiated to educate the black population at the grass roots level. Since the program’s inception in 1982, a local increase in the signing of organ donor cards by blacks has increased 30-fold, from 25 per month in 1982 to 750 per month in 1989.¹⁷ This success led to a partnership with the Dow Chemical Company called the Dow Take Initiative Program (DOWTIP), which used “principles of grass root mobilization at a national level.” A media

campaign using magazines such as *Ebony*, *Essence*, *Black Enterprise*, and *Black Health* was used to increase awareness about the necessity of black community involvement. In combination with TV/radio broadcasts and numerous community discussions, these magazine articles were key to an impressive increase in donor awareness from 10% in 1985 to 32% in 1990.^{2,3}

In the fall of 1989, the National Association for the Advancement of Colored People joined together with Dow in a nationally organized donor education program in the black community. Black clergy and several other social and transplantation organizations are involved in this program.

Another important element of the DC Organ Donor Project involved an education program through the DC Motor Vehicle Administration. Drivers seeking licenses are given information regarding transplantation and organ donor cards. Licenses may be stamped for those wishing to be classified as an organ donor. Since the program began in 1982, the number of people signing organ donor cards has increased as detailed previously.^{2,3,17}

The Maryland Organ Procurement Center in Baltimore is currently working with black transplant recipients and donor families to produce education/awareness messages for TV and radio.

One area that needs to be given more attention is that of financial accessibility for those in need of transplantation. In 1985, kidney transplantation gained coverage under Medicare. Still, there are large expenses such as transportation and outpatient drugs (which often cost more than \$5000 yearly) that are not covered past the first year and must influence treatment choices. While both dialysis and kidney transplants are covered by law under Medicare, for many people waiting for new hearts and livers, there are no options. Unless their insurance covers transplants or they qualify for Medicare, they must come up with as much as several hundred thousand dollars on their own or die.

It seems that this inequity of opportunity is currently being debated as evidenced by recent comments from the American Society of Transplant Surgery concerning a 1990 report from the Office of the Inspector General entitled "The Distribution of Organs for Transplantation: Expectations and Practices." The American Society of Transplant Surgery recommended that the report should better address the need to alleviate systemic defects in the Medicare and National Transplantation Acts that discourage some patients from accepting transplants for economic reasons, inadvertently resulting in inequitable distribution of organs. As indicated in a September 1990 letter from the president

of the American Society of Transplant Surgery, D.E. Sutherland, the Society continues to lobby Congress to make changes that will encourage patients from the lower socioeconomic strata to undergo transplantation.

As stated in the introduction, one of the purposes of this article is to inform and reach out to some heretofore untapped but fundamentally important resources in the community. Gaining support and participation from such groups as social workers, nurses, donor families, patients waiting for transplant, teachers and religious leaders will broaden the team addressing the organ donor issue and ultimately increase the likelihood of solving the biggest barrier to successful organ transplantation: the lack of organ donations in general and specifically the shortage of black donors. Teachers and religious leaders have diverse roles as spiritual teachers and sustainers within their communities and are in an ideal position to educate people at the grass roots level regarding the true facts as they relate to organ donation.

Perhaps most crucial is the role that social workers can take in this endeavor. It is this group of professionals who interact daily within the community as they work as counselors, agency workers, policymakers, social activists, child advocates, neighborhood clinic workers, community organizers, employee assistance program counselors, and workers in correctional institutions and within the schools. Another area of community interaction for the social worker is their many health-care environment roles such as talking to families and patients within the hospital, hospices, outpatient clinics, nursing homes, and rehabilitation programs. Social workers, together with teachers and religious leaders, have unique opportunities to inform people about the issue of organ donation and can make a major difference.

How can community educators best become involved in this venture to improve organ donation rates? The first step must be to demystify organ transplantation, which is often a subject of misperceptions. Lack of familiarity with organ transplantation often prevents organ donation. Second, African-American leaders need to encourage the African-American community to sign organ donation cards through the Department of Motor Vehicles. Third, through formal and informal means, African-American families need to be encouraged to discuss organ donation and transplantation. The ease and frequency of this activity will allow for success at the grass roots level, and increased donation rates will predictably follow. Fourth, preventive measures such as early detection and treatment of hypertension are important adjuncts to these efforts regarding transplantation and donor awareness. Finally,

whenever possible, these community educators should be ethnically appropriate or culturally sensitive individuals who have been trained to communicate and work with African-American individuals, families, and communities. It is important to point out that black teachers, nurses, social workers, and religious leaders can serve as primary or secondary educators (messengers).⁶ Moreover, patients—both donors and recipients—and their families should become part of the team, for they are in the best position to explain potential benefits. These individuals are surely the best ambassadors and disseminators of information regarding the realities of organ donation and transplantation.

CONCLUSION

This article has identified racial issues in donor organ availability and transplantation. Major differences in organ donation rates have been identified, along with their effects on transplantation in general and the degree of success of black recipients in particular. Efforts to alleviate this inequality have already begun but much more needs to be done.

Our proposal focuses on the use of resources that are already in place in the community but have heretofore been untapped in efforts to increase organ donation rates within the African-American population. These untapped resources—teachers, religious leaders, and social workers along with organ donors and their families—would provide a crucial addition to the many faceted team that is already involved with organ donation. Such efforts will open new frontiers that will pave the way to greater organ donor availability for all ethnic groups. Only then will organ donation allow the maximum benefit from technical and medical advances in transplantation, and in so doing, be made available to all on an equal basis.

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