Strategies To Facilitate Organ Donation among African Americans

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The greatest challenge for transplantation is the significant disparity in the number of organs available relative to the demand. African Americans in particular are disproportionately represented on the national transplant waiting list for a myriad of reasons. Although accounting for merely 13% of the national population (1), African Americans comprise 30% of the 123,000 waitlist candidates (2). The need among African Americans is considerably high because the incidence rate of ESRD is 3.4 times greater than that among Caucasians (3). This disparity is exacerbated by the disproportionate effect of certain health conditions, such as diabetes, hypertension, heart disease, and hepatitis, which increase the necessity for a transplant. When putting this in perspective, an astounding 94% of the African Americans on the waitlist are specifically awaiting a life-enhancing kidney transplant.

African Americans are also overrepresented among those in need of organs partly because of the difficulty in finding well-matched donors when compared with other racial/ethnic groups (4). This underrepresentation of African Americans in the donor pool speaks to the necessity of greater commitment to organ and tissue donation among African Americans (5). However, numerous barriers exist, and negative attitudes toward donation play a prominent role in the lack of donor registration (6,7). In this issue of CJASN, Locke et al. identify and prioritize strategies for increasing organ donation willingness and ultimately donor rates among African Americans (8). This thoughtfully designed study uses the novel formative research methodology of nominal group technique. This strategy is designed to stimulate the generation of ideas and gives guidance in the creative productivity of group discussion. In the approach taken by the authors of this study, four nominal group technique panel interviews were convened comprised of local Birmingham parishioners and clergy representing a diverse pool of Christian denominations. Participants were posed with a question (“What would make it easier for people to decide to become organ donors?”) and individually tasked with recording their responses, which were later discussed as a group, anonymously voted on, and prioritized. Panel discussions generated the following themes related to strategies for increasing organ donation among African Americans: provide more information about organ donation (including what is involved and how it helps others), better publicize the need for organ donation (including through the use of television advertisements, commercials, and seminars at work or school), and help overcome the lack of trust of the medical community.

There is no doubt that addressing these themes are critical to intervention development and overall educational efforts within the African-American community; however, many of the strategies detailed are not new to the field of organ donation. Over the last three decades, colleagues have studied ways to influence and effectively alter the modifiable barriers associated with organ donation among ethnic minority groups and African Americans in particular (9). Studies indicate that African Americans tend to be less knowledgeable about donation and/or transplantation than other racial/ethnic groups (10). Research clearly suggests that knowledge and awareness of organ donation are associated with the expression of written donation intentions and willingness to discuss intentions with family (9). More specifically, our work (11) has identified the types of knowledge that are more influential (knowledge of transplant allocation system and knowing a waitlist candidate or recipient) and less influential (i.e., knowledge of statistics, registration process, medical suitability, a donor/donor family) than others in the donation decision-making process. However, increased knowledge alone does not fix the problem. Well-cited theories in the field of behavioral sciences and health education clearly indicate that knowledge is necessary but not sufficient for most types of health behavior change, including organ and tissue donation (12).

Continuing with the theme of limited knowledge and the necessity for additional information, the results of Locke et al. (8) suggest the use of mass media as an approach to address the need for donation. Given the persuasive presence of media in the United States, this outlet is a very powerful resource that has been used for minority-focused donation-related education. Multiple studies have used campaigns to promote and educate about the topic of donation among minority populations, with a main outcome of either donor registration or family notification (13). In particular, minority-targeted campaigns using an interpersonal message have been shown to be more successful than those focusing on the general population (13). The National Minority Organ/Tissue Transplant Education Program

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pioneered early African-American educational efforts focusing on increasing knowledge and addressing concerns about premature death, fears related to racism, distrust of the health care system, and religious concerns. These television, print, and radio advertisements were distributed in 15 United States cities and later expanded to include other minority populations (14). Examples of statewide donor registry campaigns include the Lifebanc project (15) that distributed advertisements through local African-American community and faith-based organizations and a Michigan Department of Motor Vehicles study (16) that used mass media (billboard, bus advertisements, posters, and public service announcements), point-of-decision materials, and interpersonal messaging. On a smaller scale, Alvaro et al. (17) implemented a three-city Spanish-language media campaign that used personal stories from local transplant recipients and local Catholic bishops to convey positive donation messages. There are multiple other examples of mass media approaches to educate racial/ethnic minorities about organ and tissue donation (18). Although this is not a new approach, there is a need for more work to investigate how to maximize the utility of messages that seek to increase donation registration.

Aside from mass media, there are other mechanisms for increasing knowledge around the topic of organ and tissue donation. Some researchers have implemented creative strategies for education by using lay health workers, community members, peer leaders, and persons with large social networks. Interventions have been delivered in community settings (19), beauty salons (20), and churches (21) and have been successful in increasing awareness, willingness to donate, and registration on the state donor registry. This line of research offers fruitful direction to better understand the optimal settings in which to deliver donation-related education targeting communities of color.

The authors articulate the need for increased education surrounding the topic of living donation; however, their results do not explicitly speak to this issue. It is also unclear whether the authors are seeking to encourage living donation to strangers or to family members in need. Indeed, one of the greatest challenges of living donor transplant is that it requires a second, healthy person to participate in the process. The opportunity for living donation is often thwarted by preexisting health conditions. For example, African Americans have a 4-fold increased risk for renal disease, a 2-fold increased risk for diabetes, and increased rates of heart disease and cancer (22). Additional challenges associated with living donation stem from the ethical concerns associated with putting a healthy individual in a situation of surgical risk. Many ESRD patients have not considered living donation as an option because of distrust, fear of surgery, and not wanting to be a burden to others (23). For all of these reasons and others, instead of recruiting living donors, one strategy is to focus on educating ESRD patients about the importance of carefully weighing the advantages and disadvantages of living donor transplant within their own situations (24).

Religion and religious institutions maintain a prominent role in the lives of many African Americans (25). Moreover, there is compelling evidence that religious beliefs and misperceptions serve as prominent barriers to organ and tissue donation registration among many African Americans (6,26). However, it is not generally understood that most major religions support organ donation (27). Therefore, delivering interventions to promote organ donation in a religious context may be a successful education strategy (21,28). The authors of this article elected to draw from a pool of participants representing multiple Christian denominations. They cite a finding that a church-going population tends to exhibit greater health seeking behavior, have greater continuity with a health care provider, and may have greater exposure to health topics, such as organ donation (29). However, it is not clear that this finding applies to the present, highly selective sample of parishioners. Therefore, the authors do not have a strong justification for the decision to situate this study in a religious context. Indeed, given the well-documented religious barriers to donation, this study misses important opportunities to shed light on how religious beliefs may be incorporated into successful strategies to enhance uptake of organ and tissue donation among African Americans. For example, our findings suggest that participants tended to align their donation beliefs with what they thought their religious institution supported regarding donation (30). These data underscore the potential value of collaborating with religious institutions to generate successful strategies to encourage donation among African Americans. Ideally, the authors would have included an additional discussion question that addressed the role of religion in donation intentions.

Federal agencies (e.g., National Institute of Diabetes and Digestive and Kidney Diseases, Health Resources and Services Administration’s Division of Transplantation) have invested heavily in the development of successful interventions to improve commitment to organ and tissue donation, particularly among communities of color. As a result, the field has progressed greatly over the last three decades. The Locke et al. (8) article aligns with the existing body of research that supports the importance of increasing knowledge to improve public commitment to donation among communities of color. Future work should continue to move toward a deeper understanding of the messages, mechanisms for delivery, and settings for delivering the most efficacious donation education interventions for African Americans. Using this education to complement additional intervention efforts at higher levels of the social ecology (e.g., policy-level interventions) has the potential to increase donor registration, effect the donor pool, and increase access to transplant for patients in need.

Disclosures
None.

References

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