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# THE BLACK ORGAN AND TISSUE DONOR SHORTAGE: A REVIEW OF THE LITERATURE

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## Introduction

On April 16, 1999, the Department of Health and Human Services and the United Network for Organ Sharing (UNOS) announced that the number of organ donors increased 5.6 percent in 1998, the first substantial increase since 1995. Donation increases between 1997 and 1998 were substantial for whites (up 6.6 percent from 4,139 to 4,410 donors) and Hispanics (up 7.8 percent from 552 to 595 donors). However, the number of black donors remained relatively unchanged at 654 donors in 1998, and the number of Asian donors decreased by 8.4 percent from 107 to 98 donors (HRSA, April 16, 1999).

In April 1998, the Office of the Assistant Secretary for Planning and Evaluation, the National Institutes of Health, and the Agency for Health Care Policy and Research cosponsored a national conference, "Increasing Donation and Transplantation: The Challenge of Evaluation." The purpose of the conference was to identify methods to evaluate strategies designed to increase donation and transplantation. Despite the growing portfolio of funded activities, the effectiveness, replicability, transferability, and practicality of interventions that can serve as models have yet to be demonstrated.

A great deal of information about well-validated theories and models of health behavior change has been amassed in the public health and health education literature in the past decade. However, with few exceptions, this knowledge has not been applied and integrated into the design and evaluation of strategies for increasing organ and tissue donation among African Americans. The purpose of this article is to provide a foundation for understanding the social context of organ and tissue donation in the black community and the social science challenges confronting any effort to increase the participation of African Americans in donation programs.

## Background

There is a large body of literature on organ and tissue donation and transplantation in general. This review is limited in focus to those issues as they relate to African Americans. The literature is easily classified into three types. The first group includes articles that provide statistics or data to describe the problem ("*Descriptive Articles*"); the second group includes research that looks at why donation rates are low among

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African Americans (“*Explanatory Articles*”); and the third group is made up of articles that suggest strategies or approaches for increasing donation rates (“*Interventions and Evaluations*”).

### **Descriptive Articles**

In 1995, there were approximately 44,000 people on the United Network for Organ Sharing (UNOS) waiting list for organ donation (UNOS, 1997). On average, however, only about 6000 to 9000 individuals on that list are transplanted each year (Yuen, Burton, Chiraseveenuprapund, Elmore, Wong, Ozuah & Mulvihill, 1998). Consequently, a significant number of people on the list (e.g., 3500 in 1995) die each year while waiting for organs. The donor shortage is particularly problematic for blacks because of both a greater need for donated organs and lower organ donation rates among blacks compared to whites. In 1995, for example, African Americans comprised only 12% of the US population but they represented approximately 35% of the national waiting list for kidney transplants (UNOS, 1996). This increased need for kidneys is primarily due to a higher rate of end-stage renal disease in the black population, which is linked to a higher incidence of hypertension among blacks (USRDS, 1996). The African American kidney donation rate in that same year was only 11%, resulting in a large discrepancy between the number of African American donors and potential organ recipients (UNOS, 1996).

African Americans are far less likely to be transplanted, and significantly more likely to die while awaiting transplantation, compared to whites. In 1995, for example, only 23.1% of blacks (compared to 47.9% of whites) on the kidney transplant waiting list received a transplant (UNOS, 1997). These and other similar statistics point to a significant need for more donated organs from all types of donors. They also, however, illustrate the urgent need for more African American organ and tissue donors in particular. The significance of the mismatch between the number of African American donors and those needing transplants is that for many types of transplants, including kidney transplants, the likelihood of success is greatest when donor and patient are of the same ethnicity (Yancey, Coppo & Kawanishi, 1997).

### **Explanatory Articles**

In reviewing the literature on reasons for low donation rates among African Americans, it quickly became evident that Dr. Clive Callender and his colleagues from Howard University were not only pioneers in the field but continue to be the leading source of information about African Americans and organ donation. Of the 46 articles cited in this review, Callender is an author on 10, or more than 20%, of them. Callender’s work in this area began with a 1982 pilot study of 40 African American men and women in Washington, DC (Callender, Bayton, Yeager & Clark, 1982). That

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sample represents one of only 8 predominantly African American samples identified in this review that have been the subject of research on organ donation (see Table 1). Callender's research is widely quoted in studies describing the African American donor shortage (Daniels, Rene, Fish & Daniels, 1992; Toledo-Pereyra, 1992).

From focus group discussions conducted as part of the 1982 pilot study, Callender identified five major barriers to donation (Callender et al., 1982). They are: 1) lack of awareness about transplantation, including awareness about the effectiveness of transplantation, the donor shortage in general, and the disproportionately high need for African American donated organs; 2) religious myths and misperceptions about donation; 3) distrust of the medical community; 4) concerns about premature declaration of death for donors; and 5) racism, or concerns that donated organs will not be distributed fairly among blacks and whites.

Many of Callender's findings have been replicated by other researchers in the field (See Table 1). For example, Davidson and Devney (1991) and Sanders-Thompson (1993) identified religious issues and distrust of the medical community as significant factors influencing African Americans' donation decisions. Roberts (1988) surveyed 111 African Americans and found that the majority of non-donors were both uneducated about donation and transplantation procedures and unaware of the critical need for African American donors. Creecy and Wright (1990), in their survey of 217 African American high school and college students, found that willingness to consider donation was significantly associated with confidence in medical doctors, perceived need for transplant organs among African Americans, and perceived effectiveness of transplantation. Schutte and Kappel (1997) reported that understanding of the transplant system and concerns about the quality of medical care they would receive as donors were donation barriers for African Americans. In addition to knowledge about the transplant system, Rubens identified personal knowledge of someone who had received a transplant or signed an organ donor card as a factor influencing African American students' donation behavior (Rubens, 1996).

Only one study reported findings that contradicted Callender's. Yuen et al. (1998) did not discover religious, moral, or racial objections to donations in any racial group in their heterogeneous sample (n=163), and they reported an overwhelming level of support for organ donation from all racial groups. They did, however, document a significant difference in the rate of African Americans signing donor cards compared to all other racial groups. They attributed this difference to the fact that many African Americans in their sample did not have driver licenses. The authors also reported that African Americans in their sample were significantly more likely than others to report fears about receiving compromised medical care if they become organ donors. Tissue donation has generally been treated as a separate topic from organ donation. However, research on African Americans and tissue donation is scarce. Identified

**Table 1: Organ & Tissue Donation Research Utilizing African American Samples**

<b>Investigators</b>	<b>Sample Size</b>	<b>No. (%) African American</b>	<b>African-American Donation Barriers Identified</b>	<b>Strategies Evaluated</b>
Callender (1982)	40	40 (100%)	Transplant awareness; Religious myths and misperceptions; Distrust of medical community; Concerns about quality of medical care; Racism	Community-based, grass-roots approach using African American recipients, donors and families as health educators
Creecy & Wright (1990)	217	217 (100%)	Transplant awareness; Distrust of medical community	
Davidson & Devney (1991)	500	500 (100%)	Religious issues; Distrust of medical community	
Gentry, Brown-Holbert & Andrews (1997)	N/A (African American population targeted)			Use of African American health educators
Gutoski (1995)	8	8 (100%)	Distrust of medical community; Transplant awareness; Religious issues; Racism	
Kappel, Whitlock, Parks-Thomas, Hong & Freedman (1993)	N/A (African American population targeted)			Use of African American health educators
Roberts (1988)	111	111 (100%)	Transplant awareness	

**Table 1: Organ & Tissue Donation Research Utilizing African American Samples, Continued**

<b>Investigators</b>	<b>Sample Size</b>	<b>No. (%) African American</b>	<b>African-American Donation Barriers Identified</b>	<b>Strategies Evaluated</b>
Rubens (1996)	683	186 (27%)	Transplant awareness; Personal knowledge of transplant patient/donor	
Sanders-Thompson (1993)	56	56 (100%)	Religious issues; Distrust of medical community	
Schutte & Kappel (1997)	63	28 (44%)	Concerns @ quality of medical care; Transplant awareness	
Townsend, Rovelli & Schweizer (1990)	120	74 (62%)		Grass-roots approach to public education
Yancey (1996)	1000	1000 (100%)	Transplant awareness; Distrust of medical community; Religious issues; Racism; Fear of pain/debilitation	
Yuen, Burton, Chiraseveenu-prapund, Elmore, Wong, Ozuah & Mulvihill (1998)	163	47 (29%)	Concerns about quality of medical care	

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barriers are similar to those identified for organ donation (Yancey et al., 1997). For example, one study based on key informant interviews reported lack of knowledge about donor need among African Americans and of the donation process. Additionally, the legacy of Tuskegee (Thomas & Quinn, 1991; Thomas & Curran, 1999; Corbie-Smith, 1999) contributes to mistrust between African Americans and the biomedical research establishment. This situation complicates the patient/physician relationship and generates barriers to bone marrow donation among African Americans (Ross, 1996). Two other studies of bone marrow donation using African American samples reported barriers identical to Callender's: lack of awareness about transplantation; distrust of the medical establishment; religious beliefs; and racism (Gutoski, 1995; Yancey, 1996). Yancey also reported fear of pain and debilitation as a barrier unique to bone marrow donation. In summary, cultural beliefs, knowledge and the behavior of both the patient and the provider emerge as primary factors in the social context where African Americans make decisions about donation.

### **Interventions and Evaluations**

Research describing and evaluating strategies for increasing donation rates falls into three categories: 1) public education; 2) interventions targeted at health professionals, hospitals and organ procurement organizations; and 3) policy/legislative strategies.

In the literature on public education strategies, Callender once again emerges as the preeminent source. Based on his initial work with the DC Organ Donor Project, Callender established a community-based intervention, the National Minority Organ and Tissue Transplant Education Program (MOTTEP). His publications consistently confirm that a comprehensive, grass-roots approach to public health education can generate significant increases in transplant awareness, donation behavior, and donation rates among African Americans (Callender, 1987a; Callender, Bey, Miles & Yeager, 1995; Callender, Burston, Burton & Miles, 1996; Callender, Burston, Yeager & Miles, 1997; Callender, Hall, Yeager, Barber, Dunston & Pinn-Wiggings, 1991; Callender & Washington, 1997; Miles & Callender, 1997; Reitz & Callender, 1993). Central to this approach is the delivery of a message specifically tailored to the black community by black transplant recipients, donors and patients awaiting transplantation and their families.

Callender's view of an appropriate message is one that includes facts about transplantation as well as information about how each individual can impact the situation by changing his or her behavior, through signing a donor card, sharing that decision with family, and trying to live a healthier lifestyle (1987b). Other experts in transplantation have also recommended that messages address common fears and misconception about donation; suggest specific actions, such as signing a donor card or having

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discussions of organ donation with family members; and convey the knowledge that transplantation does save lives (Ganikos, McNeil, Braslow, Arkin, Klaus, Oberley & White, 1994). Moreover, because of the ever widening gap between the demand and supply for cadaveric kidneys, more experts are recommending education campaigns aimed at increasing living kidney donation (see e.g., Trollinger, Flores, Corkill, Ryan & Light, 1997).

Research investigating public education strategies targeting African Americans is limited, but the few studies that do exist support using an approach similar to Callender's. Townsend, Rovelli and Schweizer (1990) found that the use of small, informal discussion groups resulted in a significant increase in acceptance of organ donation from 20% to 60% in their sample of 120 mostly African American adults. They also reported an increase in reports of family discussions about donation following the intervention.

The use of African American organ requesters in a St. Louis hospital increased consent rates from 31% in 1988 to 48% in 1992 (Kappel, Whitlock, Parks-Thomas, Hong, & Freedman, 1993). Gentry, Brown-Holbert and Andrews (1997) also reported higher consent rates and donation rates among African Americans in their Texas sample after hiring an African American to spearhead a minority community education program and having an on-call African American coordinator.

Models of organ and tissue donor recruitment strategies share many common elements, including the delivery of targeted messages to minority communities by ethnically similar messengers and an emphasis on grass-roots programming (Yancey et al., 1997). During the period from 1993 to 1997, a 20% increase in bone marrow matching for African Americans was reported by the National Marrow Donor Program, suggesting that these types of recruitment strategies have been at least somewhat effective (Yancey et al., 1997).

Many researchers have suggested that public education is only part of the solution, and that health professionals, hospitals and organ procurement organizations represent other important intervention targets (Prottas & Batten, 1991). Anecdotal evidence suggests that asking rates for blacks are lower than for whites because of the expectation that consent will be denied. At least one study documented lower rates of request for blacks than whites (46% vs. 69%), suggesting that the difference was due to failure to identify blacks as potential donors (Hartwig, Hall, Hathaway & Gaber, 1993). In addition to accurately identifying potential donors, some researchers stress that hospital staff must approach families about donation in a culturally sensitive manner (Plawecki, Freiberg & Plawecki, 1989; Rosen, 1991; Wheeler & Cheung, 1996).

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Interventions targeting health professionals and organizations have been effective. Gravel and Szeman (1996), for example, reported significant improvements in the number of organ referrals, organ donations and tissue donations at a large Michigan medical center after implementation of a model designed to increase staff education and administrative involvement in transplantation. Similarly, a Texas medical center added in-house transplant coordinators to work with the nursing, physician and resident staff members. Efforts to facilitate identification and recruitment of donors demonstrated an increase in the African American consent rate from an average of 35% in 1993-1995 to 73% in 1996 (Shafer, Wood, Van Buren, Guerriero, Davis, Reyes, Sullivan & Levert-Cole, 1997).

### **Policy Interventions**

Different states and countries have implemented a range of policy interventions. At one end of the spectrum are policies that encourage individuals to make their own decisions regarding future use of their organs, as with the use of organ donor cards, and on the other end are policies that give physicians the power to take organs regardless of the wishes of the deceased or surviving family (Klenow & Youngs, 1995). Most research in this area is from countries other than the U.S. and evaluates the effectiveness of various national policies. For example, presumed consent policies, where physicians can remove organs for transplantation purposes unless the surviving family objects, were linked with higher donation rates in Austria and Belgium (Roels & DeMeester, 1997).

In the United States, forty-four states and the District of Columbia have some form of legislation on required request which mandates that hospitals must develop policies and procedures for identifying potential donors and making their families aware of the opportunity to donate (Beasley, Capossela, Brigham, Gunderson, Weber & Gortmaker, 1997). States have not uniformly implemented these laws, and their impact on donation rates has been minimal (Beasley et al., 1997).

The National Organ Transplant Act introduced organ allocation guidelines in the U.S. in 1984. Patients in need of a transplant are placed on a waiting list and accumulate points on the basis of waiting time, presensitization status, age (if less than 18 years old), and an antigenic profile similar to the donor (UNOS, 1995). Organs are given to the patient who has the highest number of points and resides in the local area of the donor. This holds true except in cases where a recipient can be found who is a complete antigen match with the donor. There have been many debates over the fairness of those guidelines in recent years. Experts are clearly divided about whether the organ allocation system places too much emphasis on efficiency compared to equity. One study explored public attitudes toward the trade-off between transplant efficiency and waiting time equity (Ubel, DeKay, Baron & Asch, 1996). The authors concluded



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that the majority of Americans feel that small differences in outcome, such as those between complete and partially matched kidney transplants, do not justify allocation policies that create significant discrepancies in waiting times for transplant candidates.

### **Acknowledgements**

Preparation of this manuscript was supported by a grant from the Carlos and Marguerite Mason Trust. Appreciation is expressed to the Advisory Council of the Georgia Leadership Commission on Organ, Tissue, Blood and Marrow Donation among African Americans for their helpful comments on an earlier version of this article.

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