

# AFRICAN AMERICANS' KNOWLEDGE ABOUT ORGAN DONATION: CLOSING THE GAP WITH MORE EFFECTIVE PERSUASIVE MESSAGE STRATEGIES

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In spite of increasing interest in the area of African Americans' willingness to donate organs, little empirical knowledge exists that can be used to create more effective public communication campaigns. In this study, 310 African Americans responded to seven knowledge items (based on myths and misconceptions about organ donation) shown in past studies to discriminate between donors and nondonors. The rate of accurate responses varied from 33% to 78% to individual knowledge items. Beliefs that the organ allocation system is inequitable (favoring whites and the rich) and the belief that donors pay extra medical bills strongly distinguished donors from nondonors. In addition, the information sources reported by African Americans willing to donate were more likely to include family members. Implications of these findings to the development of more effective organ donation campaigns targeting African Americans are offered. (*J Natl Med Assoc.* 2003;95:1066-1071.)

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**Key words:** organ donation ♦ African Americans  
♦ medical mistrust ♦ religiosity  
♦ organ donation model

African Americans have been the subject of increasing research attention in the area of organ donation with good reason: the discrepancy between the need for organ transplants and the supply of available organs is more acute in this population than in any other. Even when transplants occur, suboptimal tissue type matching resulting from transplanting organs from European

Americans means that transplants may be less successful than they would have been if a suitable African-American donor had been found. Closing this gap requires the creation of more effective outreach strategies and persuasive campaigns that specifically target salient issues for African Americans.

The reasons for African Americans' reluctance to donate have been the subject of considerable speculation. In addition to lack of awareness and lack of knowledge,<sup>1-3</sup> religion,<sup>1,3-8</sup> preference for directed donation,<sup>1,7,9</sup> medical mistrust,<sup>1,4-7,9-15</sup> and a desire to maintain bodily integrity<sup>11,14,16</sup> are the major reasons cited by researchers for African Americans' unwillingness to donate organs.

The majority of these reasons may prove to be very troublesome to researchers and practitioners attempting to create effective communication campaigns targeting African Americans' willingness to

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© 2003. From the School of Communication, Information, and Library Studies, Rutgers University (Morgan) and the New Jersey Organ and Tissue Sharing Network (Cannon). Send correspondence and reprint requests for *J Natl Med Assoc.* 2003;95:1066-1071 to: Susan E. Morgan, 4 Huntington Street, New Brunswick, NJ 08901-1071; phone: (732) 932-7500, ext. 8111; fax: (732) 932-3756; e-mail: semorgan@scils.rutgers.edu

donate organs. For example, even though religiosity negatively correlates with willingness to donate, no reasonable person would suggest trying to make the African-American community less religious. A less facetious example is the high rate of medical mistrust by African Americans. Centuries of medical abuse have created a deep-rooted and well-justified mistrust of physicians and hospitals. No campaign—no matter how well constructed—could undo this important reason for not donating organs. Spiritual misgivings, including the belief that a person might need all of their “parts” for an afterlife existence, may prove similarly difficult to change with a conventional organ-donation promotion campaign.

Although there are clearly many factors contributing to African Americans’ lack of willingness to donate organs, many of these factors might be heavily influenced by a lack of knowledge about organ donation. Belief in myths and misconceptions about organ donation among all populations has been shown to affect the willingness to donate, and this factor is nowhere more pronounced than in the African American community. Some researchers<sup>17,18</sup> have suggested that this lack of knowledge disguises itself as reluctance to donate on religious or spiritual grounds or as medical mistrust. However, field studies have yet to test whether these types of reasons cited for not signing an organ donor card evaporate in the face of increased knowledge about organ donation. Since the simplest reason may provide the best explanation for a phenomenon, we believe that a lack of specific knowledge about organ donation may be contributing heavily to the lack of organ donation willingness among African Americans.

It is possible that a contributing factor to African Americans’ unwillingness to donate organs is that they may have limited exposure to information about organ donation. Based on this premise, Harrington<sup>19</sup> and Kappel and colleagues<sup>20</sup> report that increasing the amount of information about organ donation through a variety of channels, including radio and television programming, billboards, church-based interventions, and educational curricula, resulted in dramatic increases in the rate of organ donation. However, because both community-based studies did not use control groups, it is scientifically impossible to establish a true causal relationship, though we do not question the value of these projects. Most laudable are both community groups’ commitment to creating multichannel, multimessage campaigns.

However, more empirical research is needed on which channels of information are the most effective for reaching African Americans with organ donation information. This knowledge could be used to create more persuasive campaigns targeting African Americans’ willingness to donate.

To create an effective, persuasive, informative campaign, researchers and practitioners should attend to both type and quantity of information sources<sup>21</sup> as well as the type of message. Message strategies should focus on precisely the type of knowledge lacking in a community, rather than simply “raising awareness” about organ donation<sup>22</sup>. Previous studies have shown that some types of knowledge can be low and yet not affect the willingness to donate, while other types of misconceptions can be critical to the decision to donate<sup>2,23</sup>. Therefore, the goal of this study is to pinpoint the types of misconceptions held by African Americans and to determine which of these is critical to the willingness to donate. Based on our findings, we recommend specific message strategies that should improve the rates of organ donation willingness in the African-American community.

## METHOD

Through the outreach, managers at the regional organ procurement organization in northern New Jersey, NAACP chapter presidents within New Jersey were asked to distribute surveys for members to complete. In addition, The Sharing Network’s African-American Planning Committee, along with various community partners, were asked to distribute surveys to African Americans in New Jersey. Three-hundred-ten complete surveys were collected. A total of \$300 in incentive funds was provided to the three people who collected the largest number of surveys.

## Demographics

The average education of respondents was a college degree, with a relatively high proportion reporting postgraduate degrees. Approximately 5.5% reported having less than a high school education, 15.8% had a high school diploma, 26.8% attended some college, 29.7% had a college degree, 6.1% had some graduate education, and 12.6% had a postgraduate degree. The mean household income was approximately \$58,000/year, and the average age was about 45 years. Female respondents (59.4%) outnumbered male respondents

**Table 1. Relationship of Individual Knowledge Questions to Signed Card Status**

Knowledge item	Total		Signed Organ Donor Card		$\chi^2$	p
	% Correct	% Incorrect	Card signed % Correct	No card % Correct		
Racial discrimination prevents minority patients from receiving the transplant they need.***	33.5	66.5	68.4	43.3	18.25	<0.001
It is possible for a brain-dead person to recover from their injuries.**	56.8	43.2	70.1	52.3	10.13	0.002
People who choose to donate a family member's organs end up paying extra medical bills.***	50.3	49.7	74.0	46.2	25.09	<0.001
A rich person has a better chance of getting an organ transplant than an ordinary working person.*	28.4	71.6	67.1	42.0	16.51	<0.001
Organs for transplant can be bought and sold on the black market in the U.S.***	46.8	53.2	69.7	49.0	13.82	<0.001
It is possible to have an open-casket funeral service following organ donation.	78.7	21.3	65.2	58.6	0.93	0.40
The need for organ donation in the African-American community is greater than in other racial/ethnic communities.**	66.5	33.5	70.2	54.9	6.77	0.01
High rates of hypertension and diabetes among African Americans leads to a higher need for organ donation.*	67.4	32.6	77.3	56.5	3.35	0.04
Have you discussed your decision to be/not be an organ donor with your family?***	51.9	48.1	76.8	44.7	32.66	<0.001
*** Significant at 0.001 level (two-tail)						
** Significant at 0.01 level (two-tail)						
* Significant at 0.05 level (one-tail)						

(40.6%). Based on the findings in the published literature, we can expect that the data may be somewhat skewed toward optimistic findings, because higher education, higher income, and being female are associated with more favorable attitudes toward donation and being more willing to sign an organ donor card.

### Knowledge Scales

The survey consisted of two sets of knowledge items. The first set of knowledge items is commonly used in studies of organ donation willingness and has shown to be a valid instrument<sup>24-25</sup>. The second set of items consisted of African-American specific knowledge: "The need for organ donation in the African-American community is greater than

**Table 2. Percentage of Respondents Receiving Information About Organ Donation From Specific Sources**

Source of information	% Receiving information from source			$\chi^2$	p
	Total %	% Signed card	% No card signed		
Television	38.4	33.1	41.9	2.48	0.12
Radio	17.7	16.1	18.8	0.37	0.65
Newspaper	31.3	30.6	31.7	0.04	0.90
Magazine	26.1	25.8	26.3	0.01	1.00
Church	27.4	27.4	27.4	0.00	1.00
Family	41.6	52.4	34.4	9.93	0.002
Work	30.3	36.3	26.3	3.48	0.08
DMV	39.0	43.5	36.0	1.77	0.19
Other	9.4	6.5	11.3	2.05	0.17

in other racial/ethnic communities” and “High rates of hypertension and diabetes among African Americans leads to a higher need for organ donation.” Since both scales rely on accuracy scores (true/false), these dichotomies do not lend themselves to reliability testing. However, based on past studies<sup>2</sup> as well as the current one, it is clear that the scales have both face and predictive validity.

### Information Sources

Respondents were asked to indicate all sources where they had obtained information about organ donation. Eight specific options were provided in addition to an “other” category. The specific options were television, radio, newspaper, magazines, church, family members, workplace, and driver’s license bureau.

## RESULTS

### Organ Donor Willingness

A total of 40% (n=124) of the sample had signed an organ donor card, while 60% (n=186) had not. Of those who had signed an organ donor card, 76.8% had talked to family members about their wishes to donate, while 44.7% of nondonors had done so.

### Knowledge About Organ Donation

The average number of knowledge items answered correctly was four out of eight questions (4.23). The average number of correct responses to the two African-American-specific knowledge questions was 1.34. The level of knowledge displayed by people who had already signed organ donor cards was significantly higher (an average of

5.14 correct responses) than those who had not signed a card (an average of 3.72 correct responses). Only one specific knowledge item did *not* distinguish donors from nondonors: the vast majority (almost 79%) of the entire sample was aware that it is possible to have an open-casket funeral following organ donation. Table 1 shows percentage of correct responses to each of the knowledge questions.

The number of correct responses to all other knowledge questions differed significantly by donor status. Five questions in particular strongly distinguished donors from nondonors: the belief that racial discrimination plays a role in organ allocation, the belief that organ donation is associated with additional medical costs, the belief that organ allocation is more likely to favor the rich over the poor, a misunderstanding of brain death, and the belief that a black market for organs exists in the U.S. These are clearly important knowledge items to target in future organ-donation promotion efforts in the African-American community since they clearly (and strongly) differentiate donors from nondonors.

### Sources of Information About Organ Donation

The average number of information sources was 2.6. Interestingly, the number of sources of information did not vary by donor status, though the specific types of sources did. People expressing a willingness to donate organs were much more likely to report receiving information about organ donation from family members than people without organ donor cards. The top five sources of information for organ donation cited by all respondents are family (42%), the department of motor

vehicles (39%), television (38%), newspaper (31%), and work (30%). Open-ended responses to the "other" category (9.4%) included community groups, friends, organ donor recipient, sororities/fraternities, and the regional organ procurement organization. However, the sources that appear to be the most *influential* in affecting organ donation willingness are family, the workplace, and television, though the last two sources approached but did not achieve statistical significance. Table 2 shows the percentage of respondents by donor category reporting having received information about organ donation from each source.

## DISCUSSION

A sample size of 300 African Americans constitutes one of the largest studies of the attitudes and behavioral norms of African Americans done to date, and the results are important to the advancement of the understanding of the reasons why African Americans are reluctant to donate. Moreover, this study provides some clear direction for the types of communication channels that can be used to improve the level of knowledge about organ donation in the African-American community.

These findings have important implications for reaching African Americans with messages about organ donation. First, it appears that family discussions may be the most influential source of information about organ donation. Given that social norms are also among the most powerful factors in decision-making about organ donation, promoting African-American family discussions about organ donation would be an important outreach strategy. Outreach campaigns in contexts where African Americans can receive information about organ donation where families are already together or in formats that are easily brought into the home may be the most effective. Thus, churches (where families are likely to worship together) could prove to be an important part of an outreach campaign. Moreover, church-based campaigns may do much to counter the belief that organ donation is against religious principles. This is underscored by the *negative* relationship between willingness to donate and religiosity. The good news is that when religious leaders are perceived as being in favor of donation, African Americans are significantly more likely to donate<sup>26</sup>.

Similar to churches, workplaces offer an opportunity to provide extended campaigns where detailed information could be distributed in pamphlet form

that employees could then bring home to facilitate family discussions. Tommy Thompson, director of Health and Human Services, has spearheaded an effort to promote workplace organ donation campaigns, but only 30% of this well-educated, high-income group report receiving information at work. Clearly, workplace campaigns may play an important role in improving rates of African-American donation, particularly if companies are chosen on the basis of the rate of minority employment.

Television campaigns may still be an important communication channel, because many families watch TV together. However, 30-second public service announcements (PSAs) are often limited in effectiveness (except for promoting simple awareness or very specific knowledge targets), and 20-minute news magazine segments produced by national broadcasters cannot be commissioned by organ-procurement organizations. The Coalition on Donation ([www.shareyourlife.org](http://www.shareyourlife.org)), which performs the outreach function for the United Network for Organ Sharing, is active in the construction of PSAs and other campaign materials. Unfortunately, the effectiveness of these campaign materials in creating national increases in the rates of signed donor cards or the rate of family discussions about donation has yet to be formally evaluated.

The traditional types of messages associated with persuasive health promotion campaigns should be squarely incorporated into all outreach strategies. African Americans who are not willing to be organ donors (and even many who are!) cite all-too-common myths and misconceptions about organ donation. Thus, a basic campaign targeting the increase of knowledge about organ donation is fully warranted. In particular, African Americans need to be reassured that the allocation system for organ transplantation is not biased against them on the basis of race or socioeconomic status. Outreach efforts by African-American transplant recipients may constitute an effective means of providing some of the reassurance the African-American community needs in order to increase the rate of organ donation. In addition, this type of personal, affective approach may be what is needed in order to improve general attitudes toward donation.

## CONCLUSION

There are many barriers to organ donation by African Americans that cannot be addressed through traditional campaigns. The desire for bod-

ily integrity, distrust of the medical system, and altruism are too deep-seated to be easily targeted by persuasive campaigns. However, this study suggests that a basic problem faced by the African-American community is lack of knowledge about organ donation. To the extent that African Americans refuse to donate organs based on myths and misconceptions about donation, lives are being needlessly lost. Of particular importance are knowledge questions that indicate a fundamental distrust of the system of organ allocation. Improving knowledge about the (albeit complex) procedures that accompany decisions on who receives donated organs is likely to result in increased rates of organ donation. We also expect that under conditions of improved knowledge about organ donation, fears about afterlife consequences or about the medical system will take a back seat to more altruistic motives to help others.

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