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## Distrust in the Healthcare System and Organ Donation Intentions Among African Americans

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### Abstract

The purpose of this study is to further understanding of the association between distrust in the healthcare system and written and verbal expressions of donation intentions among African Americans. We hypothesize that distrust in the healthcare system will be significantly, positively associated with both verbal and written donation intentions. Five hundred and eighty five participants completed a 98-item survey that included scales on distrust in the healthcare system and donation intentions. Bivariate analyses (*t*-tests, ANOVA, chi-square tests and odds ratios) were used to explore the extent to which donation intentions and distrust in the healthcare system varied by demographic characteristics and the association between the distrust in the healthcare system scale and verbal and written donation intentions. Separate logistic regressions were performed with each of the dependent variables to see if significant associations remained while controlling for confounders. Findings based on the multiple regression indicate that when controlling the participant's education level, distrust in the healthcare system was not significantly related to written donation intentions (OR = 1.04;  $P = .12$ ). When controlling for education level, health insurance status, Community Health Advocates group and marital status, distrust in the healthcare system was significantly associated with verbal donation intentions (OR = 1.08;  $P < 0.05$ ). Our results suggest that distrust in the healthcare system varies in the way that it is associated with donation intentions. Future organ donation studies should be conducted to determine the pathways through which distrust in the healthcare system impacts different types of organ donation intentions.

## Keywords

Organ donation; African American; Medical distrust; Disparities

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## Introduction

African Americans are disproportionately represented on the national transplant waiting list. While African Americans make up only 13% of the US population [1] they comprise nearly 30% of all candidates for organ transplantation [2]. There are several factors that contribute to this disparity. African Americans are disproportionately affected by health conditions, including diabetes and hypertension, that may warrant the need for transplants [3, 4].

While the demand for organ donations is high among African Americans, they have longer wait times to receive a transplant than Whites [5, 6]. Barriers to organ transplantation include African Americans' being less likely than Whites to be supportive of organ donation [7–10], to be referred and evaluated for transplant [6, 11], to be identified as a donor [7], and to consent to organ donation [12].

The literature highlights several barriers that contribute to African Americans' being less willing to donate than Whites [7–10]. Callendar [13] identified five of these major barriers to organ donation. They are: lack of awareness about transplantation, religious myths and misperceptions about donation, distrust of the medical community, concerns about premature declaration of death for donors, and racism [13]. The relationship between attitudes, beliefs and willingness to donate in particular have been widely researched [10, 14–16]. While the literature supports the notion that distrust of the medical community may be a barrier contributing to organ donation disparities [8, 10, 17–19], it has received less attention in empirical studies than the other identified barriers.

The legacy of historical medical abuses like the Tuskegee Syphilis Study contributes to African Americans' distrust of the medical and health systems although such abuses have gone on for over 100 years [20]. Medical distrust has been found to be associated with African Americans' willingness to participate in medical research [8, 21, 22], willingness to seek and accept health care [23], and adherence to medication [24]. Efforts have been made to increase the participation of African Americans in biomedical research. However, even after the National Institutes of Health (NIH) passed the Revitalization Act mandating the inclusion of women and minorities in clinical trials, minorities continue to be underrepresented in biomedical research [25–28].

Previous donation research has examined distrust in several ways including: cultural distrust, distrust in the organ procurement system and medical mistrust. For example, Terrell et al. [17] explored the relationship between motivation to volunteer, gender, and cultural distrust and the willingness of Blacks to donate their organs as well as the organs of relatives. In this study distrust was measured using Terrell and Terrell's cultural mistrust inventory (CMI) [29]. The CMI consists of 48-items designed to measure the extent to which Blacks trust Whites. They found that Blacks with high levels of cultural distrust were less willing to consent to organ donation and to permit the recovery of organs from relatives than Blacks with low levels of cultural distrust. This study has important limitations. This inventory measured Blacks' mistrust of Whites, and is not specific to an individual's mistrust of the medical system [29]. While both may be important to understanding organ donation intention, they may do so in different ways.

Next, medical distrust has been most often operationalized as a participant's perception of whether physicians would work to save an organ donor's life or whether the potential organ donor would be declared deceased prematurely in order to obtain the donor's organs [8, 9, 30–32]. These studies were most often group comparisons between African Americans and Whites and support the claim that African Americans are more distrustful of the organ procurement system than Whites. Yuen et al. found that African Americans were more likely to agree with the statement "Doctors would not try as hard to save me if they knew I was an organ donor" [31]. Similarly, McNamara et al. [9] found that minorities were significantly less likely than their White counterparts to endorse the belief that doctors put life-saving before organ procurement; a belief that was strongly related to willingness to donate organs. While these studies provide comparisons between two racial/ethnic groups [9, 31] they fail to recognize the heterogeneity among African Americans and the concomitant need to study them exclusively. Furthermore, these studies specifically examine distrust of the organ procurement system and not the healthcare system in general.

Lastly, one more recent study operationalized distrust as medical mistrust. Morgan et al. [33] examined the impact of traditional variables (knowledge, attitudes and social norms) compared to variables thought to be barriers to organ donation (medical mistrust, bodily integrity, and religiosity) among African Americans. Medical mistrust was measured using a five-item scale adapted from LaVeist et al. [34]. Their result that African Americans with lower levels of medical mistrust were more likely to have signed an organ donor card support previous findings. However, this study failed to consider the differential relationship that distrust may have with written and verbal donation intentions [33]. To our knowledge, no studies have focused on the relationship between distrust in the healthcare system and different ways of expressing donation intentions.

Examining the differences in verbal and written donation intentions is important because research suggests that having donation intentions does not always translate into the written expression of these intentions [35]. For example, in a study examining African Americans' expression of organ donation intentions, Wagstaff et al. [35] found that while many of their respondents were willing to donate, only 10% reported signing a donor card, and less than one quarter reported that they had indicated this intention on their licenses. Furthermore, many African Americans place great importance upon the role of the family in decisions regarding donation [32], and therefore, they may be more interested in expressing donation intentions verbally than in written form.

The distinction between written and verbal donation intentions is especially important given the passage of recent legislation. As of July 2008, 48 states had passed First Person Consent legislation, which prioritized donor designation indicated on a driver's license or an official signed donor card over consent from the donor's family in situations of possible deceased donation [36]. In other words, family members could no longer override an individual's documented decision of whether to donate. This documentation gives hospitals the legal authority to proceed with organ procurement without obtaining consent from the donor's family. This legislation is particularly important because when written documentation is available, the burden of the donation decision is removed from the donor's family. Given the change in legislation, it is vital to understand whether African Americans' distrust of the healthcare system is associated with verbal and written donation intentions independently.

The purpose of the current study is to further understanding of the association between distrust in the healthcare system and both written and verbal expressions of donation intentions among African American adults. We hypothesize that distrust in the healthcare system will be significantly, positively associated with both verbal and written donation intentions.

## Methods

The present study is part of a larger study that sought to test the effectiveness of a culturally-sensitive organ and tissue donation intervention for African American adults. The parent study used a randomized, pre-post design with a control group; data from the current study were collected during the baseline assessment (which occurred March to December 2009). Using a cross-sectional research design, the current study combined pre-intervention data from both intervention and control groups. Study protocols were reviewed and approved by Emory University's Institutional Review Board.

### Data Collection

Community Health Advocates (CHAs) were utilized to facilitate participant recruitment [37]. CHAs were selected based on demographic similarity to the target population, their ability to bring together a diverse group of people, their large social networks, and their ability to build trust with community members. In order to recruit such individuals, fliers were distributed to community-based organizations, local church-affiliated groups, hospitals, transplant centers, and surrounding dialysis clinics that detailed the opportunity to educate African Americans about the importance of organ donation. A total of 19 persons elected to become CHAs and underwent the necessary training.

To ensure diversity in our study sample, CHAs were tasked with individually recruiting a total of 32 participants from among members of their social networks (church, professional or community affiliations, family, friends, associates, etc.). They were provided with all necessary recruitment materials inclusive of talking points, personalized participant recruitment fliers, and tailored form letters that informed interested persons about the study. Participants were recruited with the understanding that they were participating in a 2 h, group, health-related discussion and would be compensated \$15 in appreciation for their time.

Participants were considered eligible if they self-identified as Black or African American (for the purpose of this study, the term "Black" includes people of African descent, regardless of cultural identification) and were 18 years of age or older. A total of 585 people completed the baseline questionnaire. The baseline assessment captured knowledge, attitudes, beliefs, and behaviors relative to donation, as well as demographic and behavioral characteristics, and was completed before the intervention materials were reviewed. Prospective participants read and signed the consent form, and completed the questionnaire independently.

### Measures

Participants completed a 98-item survey that included scales on distrust in the healthcare system and donation intentions. These scales are discussed below.

*Distrust in the healthcare system* was measured using a 5-item scale previously used in health research [34]. This scale examined participant attitudes regarding the existence of discrimination and racism within healthcare settings. Participants were asked to indicate their agreement with the statements using a 5-point scale from 1 (strongly disagree) to 5 (strongly agree), such that higher scores indicate more distrust of the healthcare system. Scores ranged from 5 to 25 ( $M = 14.0$ ,  $SD = 3.27$ ), and  $\alpha = .72$ .

*Donation intentions* were measured via three items that represent one's readiness to be designated as a donor on one's license, carry a donor card, and talk to family about one's wishes. Each of the three donation intention items had 5-item response options corresponding to each of the stages of change, theorized by the Transtheoretical Model and

Stages of Change [38] [from 1 (“I have not identified myself as an organ donor on my driver’s license and I don’t plan to do it any time soon”) to 5 (“The last time I renewed my driver’s license I designated myself as an organ donor, but I had done it before then”)]. We dichotomized the original 5-item response option scale into two categories (“Preaction” and “Action”). The response options corresponding to the Precontemplation, Contemplation and Preparation stages of change constituted the new “Preaction” phase and the response options corresponding to the Action and Maintenance stages of change constituted the “Action” phase.

Each of the three new dichotomized donation intention variables were then transformed into two new variables: verbal and written donation intentions. Verbal donation intentions consisted of the family communication item, and the written donation intentions variable consisted of the license and donor card items. For written donation intentions, participants who were categorized in the “Action” phase in *either* of the license or donor card items were categorized as “Action” while all others were categorized as being in the “Preaction” phase.

The last section of the questionnaire included demographic items (e.g., age, gender, ethnicity, education, income, health insurance, and marital status).

## Data Analysis

Data were analyzed using SPSS 18.0. We began by computing basic descriptive frequencies to summarize characteristics of the sample. Next, using bivariate correlations, independent sample t-tests, one-way Analysis of Variance (ANOVA) and  $\chi^2$  tests we explored the extent to which donation intentions and distrust in the healthcare system varied by demographic characteristics. Then, we calculated odds ratios to assess bivariate associations between the distrust in the healthcare system scale and verbal and written donation intentions.  $\chi^2$  tests were used to explore the association between individual distrust in the healthcare system scale items and the donation intention outcomes. Lastly, we performed separate logistic regressions with each of the dependent variables to see if significant bivariate associations remained while controlling for confounding variables. In addition, demographic variables that were found to be significant in the bivariate analyses were entered into the regression equation for each of the dependent variables. An  $\alpha$  of .05 was used to determine statistical significance.

## Results

Descriptive statistics of the sample are presented in Table 1. Participants were predominately female and self-identified as being Black/African-American. Over 40% graduated from college. Roughly 39% were married and more than three-quarters reported having health insurance. Participants ranged in age from 19 to 95 years ( $M = 46.26$  years,  $SD = 14.56$ ).

Our outcomes of interest were two types of donation intentions: written (identified on either driver’s license or donor card) and verbal (communicating donation intentions with family members). Of our sample, 251 respondents (42.9%) reported being in the Action phase of written donation intentions and 149 respondents (25.5%) reported being in the Action phase of verbal donation intentions.

We explored the associations between demographic variables and written and verbal donation intentions (Table 2). Education ( $\chi^2 = 11.82$ ,  $P < .01$ ) was associated with both written and verbal donation intentions ( $\chi^2 = 8.63$ ,  $P = .05$ ) and marital status ( $\chi^2 = 12.51$ ,  $P < .01$ ) and health insurance status ( $\chi^2 = 6.66$ ,  $P < .05$ ) were associated with verbal donation intentions. Healthcare system distrust was only significantly associated with verbal donation

intentions (OR = 1.08;  $P < .05$ ). No significant association was found between distrust in the healthcare system and written donation intention.

Because participants were nested within CHA, we wanted to assess whether all data points were independent. A  $\chi^2$  test was used to determine whether participants responded similarly with respect to the variables of interest when grouped by CHA. No significant difference was noted between CHA groups and written donation intentions. Therefore we did not control for CHA group in the logistic regression analysis for written donation intention. There was, however, a significant difference noted between CHA groups and verbal donation intentions ( $\chi^2 = 58.09$ ,  $P < .01$ ). As a result, the CHA variable was controlled for with regard to verbal donation intentions, and thus included in the regression model.

Among the individual distrust in the healthcare system scale items, “Hospitals want to know more than necessary” was significantly associated with both written ( $\chi^2 = 10.77$ ,  $P = 0.03$ ) and verbal donation intentions ( $\chi^2 = 10.08$ ,  $P = 0.04$ ). No other individual distrust in the healthcare system item was significantly associated with either type of donation intention.

Findings based on the logistic regression indicate that when controlling for the participant’s education level, distrust in the healthcare system was not significantly related to written donation intentions (OR = 1.04;  $P = .12$ ) (Table 3).

When controlling for education level, health insurance status, CHA group and marital status, distrust in the healthcare system was significantly associated with verbal donation intentions (OR = 1.08;  $P < 0.05$ ). Specifically, respondents who reported lower levels of distrust in the healthcare system were 1.08 times more likely to communicate their donation intentions with a family member than respondents who reported higher levels of medical distrust.

## Discussion

This study sought to explore how distrust in the healthcare system is associated with written and verbal donation intentions among African American adults. Our results suggest that distrust in the healthcare system varies in the way that it is associated with donation intentions. We hypothesized that distrust in the healthcare system would be significantly, positively associated with both verbal and written donation intentions. However, we only found significant associations with verbal donation intentions.

The nonsignificant finding between distrust and written donation intentions is contrary to other studies exploring the relationship between African Americans’ distrust and attitudes towards the healthcare system [17, 21–24, 33, 34, 39]. Specifically, our findings contradict previous studies using the same distrust in the healthcare system scale [34]. Morgan found that African Americans who had lower levels of medical mistrust were more likely to have signed a donor card than those with higher levels of medical mistrust [33]. Creating a written record of your donation intention is a very complex behavior, and our measure may not have adequately captured this complexity.

Further, between July 1, 1995 and July 1, 2005, to improve public education and awareness regarding anatomical gifts of human organs and tissues and to address the ever increasing need for donation for transplantation, Georgia law capped the license fee at \$8.00 for applicants who declared themselves to be organ donors at the time of obtaining or renewing a driver’s license [40]. The designation of organ donor on the driver’s license resulted in a reduced fee of approximately 50% in comparison to the standard driver’s license application fee. There has been much debate about whether financial incentives or compensation should be offered for living or deceased organ donation [41–45]. While the question of donation, “Do you want to be an organ donor?” and the discussion of license fees were not linked in



the Georgia license bureau, the reduced license fee, through past license applications or word of mouth by others, could be considered a financial incentive that may have coerced individuals into designating themselves as an organ donor who would not have without the reduced license fee. Almost half of the participants indicated that they are in the “Action” phase for written donation intentions. We are unable to identify whether there were any residual effects of this legislation on the participants in our research study.

However, our findings are particularly important given the passing of First Person Consent legislation in Georgia [36], which prioritizes written donation intentions documentation (driver’s license or official donor card) over the wishes of the individual’s family members. Given this context, our finding that distrust in the healthcare system was not significantly associated with written donation intention is promising for future organ donation work among African Americans. If distrust in the healthcare system is not a barrier to written forms of organ donation, we may need to explore what barriers are preventing African Americans from organ donation. Currently African Americans comprise roughly 30% of all individuals on national transplant waiting lists (as of May 28, 2010) but represent only 14% of organ donors [46].

In our study, African Americans with lower levels of distrust in the healthcare system were more likely to communicate their intentions to donate with a family member than respondents who reported higher levels of distrust. One possible explanation that may account for this finding is that if individuals are distrustful of the healthcare system they may not consider becoming an organ donor and therefore do not need to discuss donation with their family.

Additionally, there were several issues with the verbal donation intention item that warrant attention. First, the response options for the verbal donation intention item may have been unclearly worded. Specifically, the response-options did not specify whether the participant was supportive or unsupportive of organ donation. Instead the response options asked participants to indicate whether they had “talked to [their] family about organ donation.” This means that participants in the “Action” phase for verbal donation intention could either be intending to donate or not intending to donate but have discussed either of these intentions with their family. In contrast, if participants were in the “Action” phase for the written donation intention item, that participant was supportive of organ donation. Second, there may have been a floor effect for the verbal donation intention item. Specifically the five-item scale did not include a response option that allowed participants to indicate that they had no intention to discuss organ donation with their family at any point in time. The verbal donation intention item was not measured precisely and therefore limits the ease of the interpretation of our findings.

We also found that one item of the distrust in the healthcare system scale (“Hospitals want to know more than necessary”) was significantly related to both verbal and written donation intentions. None of the other individual items were found to be significantly associated with either verbal or written donation intentions. Qualitative research should be conducted to further explore the processes through which distrust in the healthcare system impacts African Americans’ donation intentions.

There are several limitations to this study. First, while this study provided valuable information on the relationship between distrust in the healthcare system and organ donation, our study sample was skewed toward more educated, higher income African American women—groups more favorable to toward donation [47–51]. Second, as is the case with other research studies, it is possible that different results may have been obtained from another sample. Finally, the cross-sectional attainment of the written and verbal

donation intention variables limits the ability to rule out unintentional and unmeasured third variable influences. Thus, no casual assertions can be made.

In spite of these limitations, our findings expand current understandings of the relationship between distrust in the healthcare system and different types of organ donation intentions. Efforts need to be made to address feelings of distrust in the healthcare system among Blacks in the United States. Interventions and outreach campaigns should include messaging regarding distrust within the healthcare system. Furthermore, efforts should be made within medical facilities to address distrust issues with the patients using these facilities. Finally future studies in the area of organ and tissue donation should be conducted to determine the pathways through which distrust in the healthcare system impacts different types of organ donation intentions.

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**Table 1**Demographic and donation intentions characteristics of study participants ( $N = 585$ )

Characteristics	<i>N</i>	%
Age	567	
Mean (range)	46.26 (19–95)	
Gender	585	
Female	405	69.2
Ethnicity	573	
Black/African American	499	87.1
Black caribbean	52	9.1
Other	22	3.8
Education level	569	
Less than high school	29	5.1
High school diploma/GED	224	39.4
College graduate	237	41.7
Professional degree	79	13.9
Employment status	570	
Unemployed	119	20.9
Retired	91	16.0
Part-time/full-time work	360	63.2
Household income	507	
Up to \$29,999	178	35.1
\$30,000–\$69,999	236	46.5
>\$70,000	93	18.3
Marital status	569	
Never married/single	210	36.9
Married	223	39.2
Divorced-separated	115	20.2
Widowed	21	3.7
Health insurance status	571	
Yes	447	76.4
Written donation intentions	585	
Preaction	334	57.1
Action	251	42.9
Verbal donation intentions	585	
Preaction	436	74.5
Action	149	25.5

**Table 2**Bivariate associations between demographics and written and verbal donation intentions ( $N = 585$ )

	Distrust in the healthcare system	Written donation intention	Verbal donation intention
Gender	$t = -3.124^{**}$		
Ethnicity			
Marital status			$\chi^2 = 12.51^{**}$
Health insurance status	$t = 2.555^*$		$\chi^2 = 6.66^{**}$
Education level		$\chi^2 = 11.82^{**}$	$\chi^2 = 8.63^*$

Empty cells are indicative of nonsignificant findings

\*  $P < 0.05$ ;\*\*  $P < 0.01$

**Table 3**Written and verbal donation intentions regressed on distrust in the healthcare system ( $N = 585$ )

	$\beta$	<i>P</i> value	OR
Written donation intentions regressed on			
Medical distrust	0.04	0.12	1.04
Education level	0.20	0.08	1.23
Verbal donation intentions regressed on			
Medical distrust	0.07	0.02	1.08
Education level	0.35	0.01	1.42
Health insurance	-0.62	0.03	0.54
CHA group	0.01	0.49	1.01
Marital status	0.03	0.82	1.03