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Understanding the Relationship between Knowledge and African Americans' Donation Decision-Making

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Abstract

Objectives—To explore the association between different types of knowledge related to donation and transplantation and the expression of donation intentions via one's driver's license, a donor card, or sharing one's wishes with family.

Methods—Cross-sectional data were gathered via self-administered questionnaire from 425 Black adults, age 18 years and older who were recruited from nine churches in a large metropolitan area in the southeast United States.

Results—Results indicate that knowledge of the allocation system and experiential knowledge of a transplant recipient are associated with donation intentions after controlling for age, gender, and highest level of education. However, the following types of knowledge were unrelated to donation intentions: donation-related statistics (including an understanding of African Americans' overrepresentation among those in need), the donation process, the process for determining medical suitability, and religious institutions' support for donation.

Conclusions—Findings suggest that the relationship between donation-related knowledge and donation intentions is complex and may depend on the specific type of knowledge being measured.

Practice Implications—Knowledge of the allocation system and experiential knowledge of a recipient may be critical aspects of the donation decision-making process. Research findings suggest the need for an educational approach that seeks to improve the specific types of knowledge that are most strongly associated with donation intentions.

1. INTRODUCTION

Organ and tissue transplantation has extended and saved lives, improved the quality of life for many, and decreased overall mortality from certain diseases and conditions. Transplantation has become a preferred therapy for many individuals with end-stage organ failure; however

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the gap in the number of organs needed and received continues to increase. This disparity makes the donor shortage the number one problem in transplantation today, and of particular concern is the effect the donor shortage has on racial/ethnic minorities [1]. While ethnic/racial minorities comprise approximately 25 percent of the U.S. population and 25 percent of organ donors, they account for more than half of the 91,000 persons awaiting transplants on the national transplant waiting list [2].

African Americans, in particular, are overrepresented on the organ transplant waiting list because they are disproportionately impacted by certain health conditions (e.g., diabetes, hypertension, heart disease, hepatitis) that potentially warrant the need for life saving transplants [3]. This disparity presents a paradox. While the African American need for transplantation is considerably high, organ and tissue donation rates are comparatively low. In 2006, African Americans accounted for 2,060 (14%) of both living and deceased donations compared to Whites' 10,191 donations (69%) [4]. Note, however, that there is a lack of research that explores racial differences in donation consent rates using multivariate analyses that control for demographic characteristics and health suitability. Nevertheless, the relatively low donation rates reflected in existing data may be due to a variety of factors including reduced health-related eligibility for living and deceased donation as a result of the disproportionate burden of chronic disease among African Americans, lack of information about donation, and negative attitudes towards donation among African Americans as compared to people of other racial/ethnic backgrounds [5,6]. Taken together, all of these factors contribute to African Americans spending more than twice the amount of time on the national transplant waiting list as compared to Whites [7–10].

1.1. Lack of Knowledge as a Barrier to Donation among African Americans

Reasons for the persistence of lower donation rates among African Americans, especially relative to those for Whites, have been well documented [3,11–17]. Over the past two decades, extensive research has been conducted to better understand the barriers to organ donation and to raise awareness and acceptance of organ donation and transplantation among African Americans [1,3,9,11–22].

Research clearly suggests that knowledge and awareness of the topic of donation and transplantation is associated with donation intentions [1,23–37]. Among African Americans in particular, studies using a composite measure of knowledge demonstrate that overall knowledge about organ donation is an important predictor of willingness to donate [6,26,38–41]. However, less research has explored how different types of knowledge relate to donation intentions among African Americans. There are different types of knowledge that are relevant to this issue: for example, knowledge of African Americans' overrepresentation on the transplant list, knowledge of the donation system, knowledge of the allocation system, knowledge of how to express donation intentions, and the personal knowledge of individuals who have been impacted by the donation and transplantation system. Successful intervention strategies would most effectively target those types of knowledge that are most strongly associated with donation intentions.

The purpose of the current study is to further understanding of the association between different types of knowledge and both written and verbal expressions of donation intentions. It is expected that findings will have important implications for the development of effective intervention messages targeting African Americans.

2. METHODS

2.1. Study Design

The present study is part of a larger study that seeks to test the effectiveness of a culturally-sensitive organ and tissue donation intervention for African American parishioners [33,34]. The parent study uses a randomized pre-post design with a control group; data from the current study were collected during the baseline assessment (which occurred June to September 2005). Thus, the current study utilizes a cross-sectional research design and combines data from both treatment groups.

2.2. Participant Recruitment and Data Collection

Through a process of networking with clergy (via telephone and face-to-face meetings) and talking to colleagues in the field to identify pastors who may be interested in the project we identified ten churches from which the pastors would be willing to participate in this project. All of the pastors who agreed to participate either sat on the project's Community Advisory Board or nominated a liaison to that board. Because we achieved our desired sample size after collecting data at nine churches, we opted not to collect data at the 10th church. The authors worked with the pastor of each church to identify a suitable date for data collection, then a church liaison handled the logistics of data collection.

Liaisons were charged with recruiting at least 55 participants into the study. To assist each of the liaisons with their recruitment strategy, a one-page description of the study was provided for inclusion in their church announcements, bulletins, and/or newsletters. Understanding that each church varied in size, we allowed liaisons to design their own recruitment strategy. Many of the liaisons chose to individually select parishioners at their respective churches who fit the inclusion criteria. Some established a sign-up sheet where parishioners would commit to participation by signing their name and agreeing to attend on the data collection date. Others decided to make recruitment announcements in the weeks preceding and on the day of data collection with the expectation that a sufficient number of volunteers would enroll in the study on the day of data collection. Using a combination of these methods, liaisons at each church recruited between 19 and 70 participants into the study. Participants were considered eligible if they self-identified as being of African descent, were 18 years of age or older, and did not reside in the same household. As a result of this process 425 participants completed the questionnaire.

Data were collected during after-church luncheons that were sponsored by the project. Project staff explained what participation in the study entailed and distributed a packet containing the consent form and questionnaire to each interested and eligible participant. Participants read and signed the written consent form and completed the survey on their own, except in several cases in which participants requested assistance. The surveys took approximately 15 minutes to complete. Participants returned their completed surveys to project staff and received their monetary incentive, which was either \$10 in cash or a \$10 donation being made to the church on their behalf. The decision of which participant option to take was a church-level decision made by the pastors prior to data collection so that all participants at the same church were given the same incentive option.

2.3. Measures

Participants completed an 89-item survey that measured beliefs and attitudes regarding donation and transplantation, knowledge and understanding of the donation and transplantation system, knowledge of people who were personally impacted by donation and/or transplantation, intentions to donate (based on willingness to be identified as a donor on one's license, on a donor card, or via sharing wishes with family), and demographic characteristics.

The knowledge scale had two components (see Appendix A for the knowledge scale). The first component was adapted from the work of Sander [30] and Weaver [42]. This scale consisted of 16 items that had true/false response options. We combined the items to create seven subscales that captured different dimensions of knowledge: general donation-related statistics (2 items), African American donation-related statistics (4 items), knowledge of the donation process (3 items), knowledge of the allocation system (1 item), knowledge of what signing a donor card means (3 items), knowledge of how medical suitability for donation is determined (2 items), and knowledge of religious institutions' objections to donation (1 item).

The second component measured experiential knowledge of people who were personally impacted by the donation and transplantation system, respondents were asked to respond "yes" or "no" to each of eight items that captured whether respondents knew people who had been impacted by the donation and transplantation system. We combined the items to create three subscales: personal knowledge of a donor or donor family member (3 items), personal knowledge of a person on a waiting list (2 items), and personal knowledge of an organ/tissue recipient (3 items). Since the knowledge scale relied on accuracy, no effort was made to demonstrate reliability of the items. Respondents' knowledge score on each of the 10 subscales represents the number of items they got correct within that subscale.

Drawing from existing measures in the research literature, we created a 24-item scale that captured attitudes and beliefs about donation and transplantation [6,30,43,44]. This scale included items that measured support for donation, willingness to donate to people of other racial/ethnic groups, religious objections to donation, concerns that donation might hasten death, trust in the donation and transplantation system, and perceptions of equality in the transplant system. Response options for these items ranged from 1 (strongly disagree) to 5 (strongly agree), such that higher scores indicate stronger personal religious support for organ and tissue donation. Total scores ranged from 52 to 120 ($M=94$, $SD=11.6$), and $\alpha=.94$.

Intentions to donate were measured via three items developed by the authors (one each for willingness to be designated as a donor on one's license, carry a donor card, and talk to family about one's wishes). We opted to explore the three intentions separately because there are different life experiences that influence which intention one might choose (e.g., one may not carry a driver's license at all). Additionally, two of these intentions involve written documentation of one's wishes while the third entails verbal communication only. It might be that some are not willing to provide written documentation of their wishes but would be open to verbally sharing their wishes. Exploring all three ways of expressing donation intentions provides one way to account for these nuances.

For each of the three questions, donation intentions were measured on a continuum based on the Transtheoretical Model and Stages of Change [45]. This theoretical framework suggests that people move along a continuum of readiness to engage in organ and tissue donation: precontemplation (having no intention to donate), contemplation (having thought about expressing donation intentions in the future), preparation (having plans to express donation intentions in the near future), action (having recently expressed donation intentions), and maintenance (having expressed donation intentions more than six months ago). Thus, for each of the three questions there were five response options, one each corresponding to the five stages of change (precontemplation, contemplation, preparation, action, and maintenance). The last section of the questionnaire included demographic items (e.g., age, gender, ethnicity, education, income, and marital status).

2.4. Statistical Analysis

Data were analyzed using SPSS 13.0. We began analyses by examining the frequency distribution of all relevant variables. Then, we explored the extent to which donation intentions

vary by demographic characteristics using bivariate correlations. Next, we conducted correlations to assess bivariate associations between the 10 knowledge subscales, attitudes towards donation, and donation intentions. Finally, we performed separate multiple regressions with each of the three dependent variables (intention to be identified as a donor on one's license, intention to carry a donor card, and intention to talk to one's family about one's wishes) to see if the significant bivariate correlations remained significant after controlling for age, gender, and education. Thus, in addition to the control variables, only those variables that were significant in the univariate analyses were entered into the regression equation for each dependent variable. An level of 5% was used to determine statistical significance.

3. RESULTS

3.1. Demographic Characteristics and Donation Intentions

Participants were predominantly female and self-identified as being Black/African American (Table 1). Approximately 1/3 of the sample had attended vocational school or some college, and another 1/3 had graduated from college. Almost half of the sample was married, and 2/3 of the sample was Baptist. Participants ranged in age from 19 to 88 ($M=48.95$, $SD=14.26$).

In terms of donation intentions, we explored the percentage of participants who self-reported that they expressed donation intentions for each of the three outcomes: 176 respondents (44%) reported that they are identified as a donor on their driver's license, 75 respondents (18%) reported that they carry a donor card, and 136 respondents (36%) reported having talked to family about their donation intentions within the past six months (Table 1).

Age was unrelated to feelings about carrying a donor card and discussing donation with family (both $ps > .10$). However, younger participants tended to be more ready to be designated as donors on their driver's licenses ($r = -.12$, $p < .05$). Household income was significantly related to donation intentions, such that higher incomes were associated with greater readiness to designate oneself as a donor on one's license ($r = .11$, $p < .05$), carry a donor card ($r = .12$, $p < .05$), and discuss donation with family ($r = .18$, $p < .01$). Education was highly associated with readiness to discuss donation with family ($r = .16$, $p < .01$) but unrelated to readiness to either designate oneself on one's license, or carry a donor card.

3.2. Knowledge and Attitudes

We found that more positive attitude and beliefs were associated with six types of knowledge: the donation process ($r = .34$, $p < .001$), general donation-related statistics ($r = .24$, $p < .001$), the allocation system ($r = .23$, $p < .001$), religious institutions objections to donation ($r = .17$, $p < .001$), personal knowledge of a recipient ($r = .15$, $p < .01$), and knowledge of how medical suitability is determined ($r = .13$, $p < .01$). Attitudes and beliefs were unrelated to personal knowledge of a donor or person on the waiting list to receive a kidney, knowledge of what it means to sign a donor card, or knowledge of African American donation-related statistics.

3.3. Knowledge and Donation Intentions

Results indicated that only three of the knowledge subscales were associated with intention to be designated as a donor on one's driver's license: knowledge of the donation process, knowledge of the allocation system, and experiential knowledge of a transplant recipient (Table 2). Knowledge of how medical suitability is determined, knowledge of the allocation system, and all three of the experiential knowledge variables were associated with intention to carry a donor card. Finally, only experiential knowledge of a transplant recipient and experiential knowledge of someone on the waiting list (or someone who died waiting) were associated with intention to talk to one's family about donation intentions (Table 2).

Findings based on the multiple regression indicate that knowledge of the allocation system remained significantly associated with both intentions to be identified as a donor on one's license and by carrying a donor card. Additionally, experiential knowledge of a transplant recipient remained significantly associated with all three dependent variables (Table 3).

4. DISCUSSION & CONCLUSION

4.1. Discussion

This study sought to explore how different types of knowledge are associated with donation intentions among African American adults. Results suggest that there is great variability in terms of how different types of knowledge are associated with both written and verbal expressions of donation intentions. Of the different types of knowledge, those that are most strongly associated with written donation intentions are knowledge of the allocation system and personal knowledge of a transplant recipient. Additionally, personal knowledge of a transplant recipient was also associated with verbal expression of donation intentions.

4.1.1. The Allocation System—Equity in the healthcare system has been widely studied and recognized as a significant barrier to the transplant and donation process [1,3,9,11–22, 33,34,46–48]. Specific to the African American population, a fear of racism in the healthcare system persists [1,3,11–14,51]. This fear of racism is a function of daily experiences of prejudice and discrimination as well as knowledge of a history of misuse by the medical community [52–55]. The Tuskegee syphilis study is often cited as a historical event that contributes to African Americans' distrust of the health care establishment [56–60]. It might be the case that this fear and distrust prevents many African Americans from getting necessary treatment, participating in medical research, signing living wills, and donating organs [51, 60–66]. Indeed, results of this study suggest that concerns about fairness in organ allocation may be central to the donation decision-making process among African Americans. It was those participants who more clearly understood how the organ allocation system works who were more willing to express written intentions to donate. These findings are consistent with other research that finds that knowledge of the organ allocation system is critical to donation decision-making [7,49–51]. Therefore, education that seeks to explain the role and function of the Organ Procurement and Transplantation Network could be useful in improving attitudes and increasing donation rates among this population [49,67,68].

4.1.2. Experiential Knowledge—Data also suggest that experiential knowledge of the transplant system also plays an important role in the expression of donation intentions. Findings from this study indicate that knowledge of a transplant recipient or knowledge of someone who has been on the transplant waiting list is associated with greater readiness to express written and verbal donation intentions. It might be that knowing someone with a positive outcome relative to transplantation increases the likelihood of people's wanting to become organ donors themselves, which is consistent with existing theories of observational learning [69]. This finding suggests that recipients' sharing of their personal stories may be an effective way to increase donation intentions among African Americans.

Community education programs might benefit from having organ recipients share their personal stories. However, this face-to-face contact may be expensive and labor-intensive to arrange. Thus, one could incorporate recipient stories into video footage that is disseminated to a broader audience. Recipients could share their stories in a manner such that those watching feel a close personal connection. This finding fits with the Transtheoretical Model and Stages of Change in that, in addition to the five stages, this framework proposes processes of change, which are overt and covert activities that help move individuals along the continuum of behavior change [45]. It might be that knowing a transplant recipient is an example of

consciousness raising, which is one of the ten theorized processes that have received the most empirical support. Several donation-related interventions were developed with the goal of consciousness raising [23,42,70,71]. For example, the Project ACTS: About Choices in Transplantation and Sharing intervention package includes a culturally-sensitive video in which living donors, donor families, and recipients talk candidly about their experience with donation and/or transplantation in order to create a personal connection. Nevertheless, more research is needed to evaluate the effectiveness of this intervention approach.

4.2. Limitations

This study suffers from limitations as does any other. One limitation of the study is that it used a convenience sample of Christian, African-American parishioners within metropolitan Atlanta. The intent of this study is not to generalize findings to African American parishioners in other locales. Nor can the findings be generalized to populations holding non-Christian religious beliefs and the non-church attending population. Because random sampling methods were not used, the extent to which findings generalize to the parishioners of the nine participating churches is questionable. Nevertheless, so little is known about what this group thinks and knows about donation and transplantation that this study represents an important first step towards generating new knowledge about this issue. Additionally, the cross-sectional nature of this study prevents us from assuming causality. Knowledge may cause stronger donation intentions, stronger donation intentions may cause one to seek out knowledge, or a third variable may cause this relationship.

Additionally, it might also be that the overrepresentation of women among our sample of parishioners impacted the findings, although it is notable that women tend to report higher rates of church attendance than men [44]. However, these findings further the development of knowledge of the attitudes, beliefs, and experiences of a particular group of individuals with the goal of developing intervention messages that positively impact their views on donation and transplantation. Such an intervention can be modified and transferred to other populations of African American parishioners contingent upon additional research on its effectiveness.

4.3. Conclusion

In order to increase support for organ donation among African Americans, there is a need to thoroughly understand how to impact what people think and know about donation and transplantation. Findings of this study suggest that knowledge of organ and tissue donation is very complex and is present in many different forms. Specifically knowledge of the allocation system and personal knowledge of a recipient are most significant with respect to expression of donation intentions.

4.3.1. The Role of Educators—It is important that public health professionals and educators craft messages that will explain the complexities of organ allocation in a way that the lay public understands. It might be helpful to explain how this system tries to be equitable, who gets the organs, how potential donors and recipients are identified, how the waitlist and prioritization works, and who the recovery physicians are and how they differ from regular medical staff. In addition, public health professionals must do a better job of creating opportunities for family donors and recipients to share their experiences about the donation/transplantation process. As our study has revealed, this aspect of experiential knowledge is very important in the donation decision process. By incorporating these educational efforts, we may move toward wider support for organ and tissue donation among African Americans.

4.4. Practice Implications

This study offers new direction for donation education efforts targeting African Americans. Previous research arguing for the need to address donation education may not be applicable to

the African-American, churchgoing population. Or it might be that such efforts are useful for promoting positive donation intentions through some mechanisms but not others. Knowledge of the allocation system and experiential knowledge are critical mechanisms. With this understanding, we can shape the development of effective, culturally-sensitive, intervention messages to promote these discussions within the African American community resulting in more effective, individual, community-based, and mass media outreach and education campaigns.

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Table 1
Demographic Characteristics of Study Participants (N=425)

	n (%)
Female	324 (77)
Ethnicity	
Black/African American	383 (93)
Black/Caribbean	16 (4)
Other	11 (3)
Highest level of education completed	
High school graduate	70 (17)
Vocational school or some college	132 (32)
College graduate	157 (32)
Some graduate school or graduate degree	53 (19)
Annual income	
Up to \$29,000	118 (31)
\$30,000 to \$69,000	169 (44)
\$70,000 or more	99 (26)
Marital status	
Never married	102 (25)
Married	184 (44)
Divorced/separated/widowed	128 (31)
Denomination	
Baptist	279 (66)
Lutheran	39 (9)
African Methodist Episcopal	77 (18)
Cosmopolitan Methodist Episcopal	30 (7)
Intention to be identified as a donor on one's driver's license	
Precontemplation	64 (16)
Contemplation	112 (29)
Preparation	38 (10)
Action	55 (14)
Maintenance	121 (31)
Intention to be identified as a donor on a donor card	
Precontemplation	104 (29)
Contemplation	140 (38)
Preparation	55 (15)
Action	6 (2)
Maintenance	59 (16)
Intention to talk to family concerning wishes	
Precontemplation	68 (18)
Contemplation	114 (30)
Preparation	57 (15)
Action	30 (8)
Maintenance	106 (28)

Appendix 1

Knowledge & Understanding of the Organ Donation System Questionnaire

	True	False
1. For most organs, the demand for transplants is higher than the availability.	T	F
2. A national computer system matches and distributes donated organs to persons who are the sickest and have been waiting the longest.	T	F
3. Organ and tissue donation disfigures the body so an open casket funeral is not possible.	T	F
4. People on the waiting list for a transplant die everyday because there are not enough organs available.	T	F
5. African Americans wait longer for kidney transplants than Caucasians.	T	F
6. Almost one-half of the persons waiting for transplants in the U.S. are from minority groups.	T	F
7. People can recover (get better) when they are brain dead.	T	F
8. A person can specify on a donor card what organs and tissues they want to donate.	T	F
9. In the state of Georgia, next of kin must give permission for donation to occur even if I sign a donor card.	T	F
10. Most major religions oppose organ and tissue donation.	T	F
11. Signing a donor card or indicating consent on my driver's license will not change the medical treatment I receive to save my life at the hospital	T	F
12. Anyone can decide to be a donor regardless of their age or medical condition.	T	F
13. Once a person has signed a donor card or indicated consent on their driver's license, they cannot change their mind about organ donation.	T	F
14. It is illegal to sell your organs in the United States.	T	F
15. A large percentage of people who need kidneys are African American.	T	F
16. What percent of the U.S. population is African American?		
☐ 7%		
☐ 13%		
☐ 20%		
☐ 35%		
17. What percent of participants waiting for a life-saving kidney in the U.S. are African American?		
☐ 7%		
☐ 13%		
☐ 20%		
☐ 35%		

Table 2
Correlations Between Knowledge Subscales and Donation Intentions

Type of knowledge	Intentions to be identified as a donor...		
	On one's driver's license	By carrying a donor card	By talking to family
General donation-related statistics			
African American donation-related statistics			
Knowledge of the donation process	.11 *		
Knowledge of how medical suitability is determined		.10 *	
Knowledge of what signing a donor card means			
Knowledge of religious institutions' support for donation			
Knowledge of the allocation system	.14 **	.12 *	
Experiential knowledge of a transplant recipient	.10 *	.19 ***	.19 ***
Experiential knowledge of someone on the waitlist or someone who died waiting		.14 **	.14 **
Experiential knowledge of a donor/donor family		.15 **	

Note. Empty cells are indicative of nonsignificant findings.

*
p < .05;

**
p < .01;

p < .001.

Table 3
Donation Intentions Regressed on Knowledge Subscales

Type of knowledge	Intentions to be identified as a donor...		
	On one's driver's license (β)	By carrying a donor card (β)	By talking to family (β)
Knowledge of the donation process	.08		
Knowledge of how medical suitability is determined		.08	
Knowledge of the allocation system	.11 [*]	.11 [*]	
Experiential knowledge of a transplant recipient	.11 [*]	.15 [*]	.14 ^{**}
Experiential knowledge of someone on the waitlist or someone who died waiting		.10	.10
Experiential knowledge of a donor/donor family		.05	
F	3.12 ^{**}	3.40 ^{**}	4.90 ^{***}

All models control for age, gender, and highest level of education. For each regression, only those knowledge subscales that were significant in the univariate analyses were entered into the equation; thus, empty cells indicate that the variable was not entered into that regression model.

*
p < .05;

**
p < .01;

p < .001.