

Correlates of support for living donation among African American adults

Context—Living donation is studied with much less intensity among African Americans than among the general population. Examination of barriers to living donation can lead to effective strategies to educate dialysis patients and their families about this alternative.

Objective—To explore the correlates of likelihood of becoming a living donor among community-recruited African American adults.

Design/Participants—Cross-sectional data were gathered via self-administered questionnaire from 425 African American adults, age 18 years and older, who were recruited from 9 churches in Atlanta.

Main Outcome Measures—Self-reported likelihood of becoming a living donor to a close family member, an extended family member or friend, or a stranger.

Results—More than three-quarters of participants were willing to act as living donors to a close family member or spouse and two-thirds to friends or extended family. For likelihood of donating to a friend or extended family member, only willingness to engage in deceased donation was significantly associated; to a stranger, both willingness to engage in deceased donation and attitudes toward donation were significantly associated. Knowledge of and personal experiences with donation and/or transplantation were not significantly associated with likelihood of any type of living donation.

Conclusions—Findings indicate widespread support for living donation to a close family member or spouse. These findings have important implications for dialysis patients who must decide whether to approach friends and/or family about the possibility of serving as a living donor and emphasize the need for interventions to help facilitate this process. (*Progress in Transplantation*. 2009;19:244-251)

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The number of patients who are in need of a life-saving transplant continues to grow at an alarming rate, and the gap between this need and the number of available organs is widening steadily. Not only is this disparity the No. 1 problem in transplantation today, but it is also particularly pronounced within the African American population.¹

In the state of Georgia, the median wait time for kidney transplantation is 1151 days for African Americans as opposed to 767 days for white patients. Even though African Americans comprise the majority of persons on the kidney waiting list (63%), they represent less than half of kidney transplant recipients.² The need for transplantation among African Americans is exceptionally high and is exacerbated by the low organ and tissue donation rates in Georgia and throughout the United States. Deceased donations account for more than 88% of transplants, whereas living donation rates remain markedly lower (11.5%).² Of the 106 living donor

transplants performed in Georgia in 2007, less than one-third (30) were to African American recipients.

The benefits of living donor transplantation, especially for patients with renal failure, are well documented.³⁻⁶ Compared with deceased donor transplantation, living donation is more cost-efficient and results in lower rates of acute rejection, improved graft survival, and enhanced long-term functioning.⁷⁻⁹ For patients with end-stage renal failure, a living kidney donor transplant can result in relief from the burden of dialysis and improved survival rates; 50% of living kidney donations are still functioning after 20 years versus the 10-year mean survival of deceased donor organs.¹⁰ However, the great challenge of living donation is that it requires a second, healthy person to undergo the donation surgery in order for the patient to receive a functioning organ.^{9,11-14} Living donors can be blood relatives or unrelated individuals and can donate an entire organ, such as a kidney, or a segment

of an organ, such as a lobe of a lung or segment of a liver or pancreas.

In the African American community, pre-existing health conditions such as diabetes, hypertension, and kidney disease are prevalent.^{15,16} African Americans represent 13% of the general population but more than one-third of those with renal disease.¹⁷ They are 7 times more likely than whites to have hypertension, 4 times more likely to be on dialysis,¹ and have consistently higher rates of heart disease and cancer.^{18,19} The possibility of living donation for African Americans has been thwarted by the presence of these health issues and others such as pancreas, bladder, or liver problems, unsuitable creatinine clearance, hepatitis, and high body mass indexes, all of which render potential living donors unsuitable.²⁰⁻²² Healthy potential African American living donors who do not have any of these ailments may still be unable to donate because of immunological incompatibilities with their potential recipient, such as a mismatch of ABO blood group or human leukocyte antigens, which are essential in the matching process.

Because of the lack of available donors, many African Americans live and die on dialysis; moreover, they do not have access to or do not choose to pursue transplantation.^{9,23,24} Much of this situation has to do with the patient's willingness to approach a loved one and accept his or her offer of an organ.^{8,25,26} Murray et al¹² reported that 60% of 115 patients from a dialysis clinic never talked with anyone about the possibility of living donation, and 80% actually refused to consider a transplant from a family member. Other researchers^{8,23,25,27} have similarly reported that many patients refuse to have potential matching donors evaluated and are not willing to actively pursue living donation as a treatment option. Numerous patients choose to continue dialysis because of concerns about harming the potential donor, possible resentment after donation, graft rejection, and feelings of indebtedness to the donor.^{8,9,25,27} As a result, patients who could potentially receive living donor transplants experience significantly diminished quality of life, may wait many years for a deceased donor's organ to become available, and could die before receiving a lifesaving organ.²⁸ Despite the disproportionate need among African Americans for transplants, living donation is a topic that is infrequently discussed and greatly understudied within that population.^{8,11,14,29-37}

African Americans should be taught about what it means to be a living donor, the evaluation process, and what to expect after donation, and they need to hear stories about the experiences of donors and their recipients.^{11,38-40} Such awareness and education could potentially benefit friends and family members who are currently on dialysis. It could make people more receptive to the idea of transplantation when and if

they are approached by friends and family members who are on dialysis. It could also increase the likelihood that friends and family members would approach their loved ones who are on dialysis about the possibility of living donation when the dialysis patient is unaware or unwilling to consider this option. However, before designing educational materials for African Americans, one must understand their knowledge, attitudes, and beliefs surrounding the topic of living donation. The purpose of the current study is to shed light on this issue by exploring the correlates of likelihood of becoming a living donor among community-recruited African American parishioners. Demographic characteristics, donation-related knowledge, and personal experiences are examined in relation to intentions with respect to living donation.

Methods

Study Design

This study is part of a larger study done to test the effectiveness of a culturally sensitive intervention in promoting organ and tissue donation among African American parishioners.⁴¹⁻⁴³ 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 June to September 2005). Using a cross-sectional research design, the current study combines preintervention data from both the intervention group and the control group. This study was approved by the institutional review board at Emory University.

By networking with clergy (via telephone and face-to-face meetings) and talking to colleagues in the field, we identified 9 churches that had pastors who were willing to participate in this project. Pastors who agreed to participate either served as members of the project's community advisory board or nominated a liaison to the board. In addition to participation on the community advisory board, the pastors agreed that their churches would serve as data collection sites for the project. Project staff 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. Using a combination of 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 another participant. As a result of this process, 425 participants completed the baseline 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 those instances in which participants requested assistance. The survey took approximately 15 minutes to complete. Participants returned their completed survey to project staff and received their monetary incentive, which was either \$10 in cash or having a \$10 donation made to the church on their behalf. The decision of which incentive option participants would receive was a church-level decision made by the pastors before data collection so that all participants at a given church were given the same incentive option.

Measures

Participants completed an 89-item survey that measured personal experiences with donation and/or transplantation; knowledge of the donation and transplantation system; attitudes and beliefs regarding donation and transplantation; willingness to have organs donated after death; likelihood that the participant would donate to a close family member, extended family member/friend, or stranger while living; and demographic characteristics (eg, age, sex, race/ethnicity, highest level of education, income, religious denomination, and marital status).

Personal experiences with donation and/or transplant were assessed with 3 items: "I know someone who donated an organ while living," "I know someone who donated an organ after death," and "I know someone who has received an organ transplant." Response options were "yes" and "no." Those participants who responded "yes" to at least 1 of these questions were identified as having a relevant personal experience. Of 415 participants responding, 242 (58%) were categorized as having reported a relevant personal experience, and 173 participants (42%) were not.

Knowledge of the donation and/or transplantation system was assessed with 15 true/false items. Sample items are "African Americans wait longer for kidney transplants than whites" and "Most major religions oppose organ and tissue donation." Knowledge scores were calculated for each participant by summing the number of items the participant got correct. Scores ranged from 0 to 15 (mean = 10.84, SD = 2.58).

By drawing from existing measures in the research literature, a 23-item scale was created that captured attitudes and beliefs about donation and transplantation.⁴⁴⁻⁴⁷ 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. On a 5-point Likert scale, the response options for these items ranged from 1 (strongly disagree) to 5 (strongly agree), such that higher scores indicated

more positive attitudes toward organ and tissue donation. Scores for the items were summed to create a total score; total scores ranged from 20 to 115 (mean = 86.89, SD = 14.47) because several participants exercised their right to omit items, and reliability was high (coefficient $\alpha = 0.87$), indicating that the items were generally measuring the same underlying construct.

One item ("I am willing to have organs donated after my death") measured willingness to consent to deceased donation, and response options ranged from 1 (strongly disagree) to 5 (strongly agree). Scores ranged from 1 to 5 (mean = 3.98, SD = 1.10).

Three items assessed likelihood of becoming a living donor from 1 (very unlikely) to 5 (very likely). The questions were "How likely is it that you would donate an organ to a family member or spouse?" "How likely is it that you would donate an organ to an extended family member or friend?" and "How likely is it that you would donate an organ to someone you've never met?" These 3 items were assessed independently.

Statistical Analysis

Data were analyzed by using SPSS 15.0 (SPSS, Chicago, Illinois). Analyses started with an examination of the frequency distributions of all demographic variables. The Cronbach α was calculated on the 23-item Attitudes and Beliefs Scale to determine the internal consistency of the instrument. Univariate analyses (χ^2 and Pearson correlation) were conducted on demographic variables to determine if they were associated with both the independent variables (attitudes, knowledge, and personal experiences) and the dependent variables (likelihood of living donation to various others) and might serve as confounders (extraneous factors that relate to both the dependent and independent variables, making them appear connected when their association is spurious and thus distorting results⁴⁸).

Next, the correlation between the independent variables and the dependent variables was explored. Finally, 3 separate multiple regressions were performed with each of the 3 dependent variables: likelihood of serving as a living donor for one's immediate family, for a friend or extended family member, or for a stranger. Only those independent and demographic variables that were significant in the univariate analyses were entered into the regression equation. The interrelationship between independent variables was explored to assess collinearity, of which none had correlations higher than 0.61. An α level of 0.05 was used to determine statistical significance.

Results

Demographic Characteristics and Likelihood of Living Donation

Participants were predominantly female (76%) and self-identified as being black/African American

Table 1 Demographic characteristics and intentions with respect to living donation

Characteristic	No. (%) of respondents ^a
Female	324 (76)
Ethnicity	
Black/African American	383 (93)
Black/Caribbean	16 (4)
Other	11 (3)
Highest level of education completed	
High school graduate or less	70 (17)
Vocational school or some college	132 (32)
2-year or 4-year college graduate	157 (38)
Some graduate school or graduate degree	53 (13)
Annual income	
≤\$29 000	118 (31)
\$30 000-\$69 000	169 (44)
≥\$70 000	99 (26)
Marital status	
Never married	102 (25)
Married	185 (44)
Divorced, separated, or widowed	128 (31)
Denomination	
Baptist	279 (66)
Lutheran	39 (9)
African Methodist Episcopal	77 (18)
Cosmopolitan Methodist Episcopal	30 (7)
Likelihood of donating to a close family member or spouse	
Likely	310 (76)
Neutral	60 (15)
Unlikely	38 (9)
Likelihood of donating to a friend or extended family member	
Likely	268 (67)
Neutral	91 (23)
Unlikely	42 (11)
Likelihood of donating to a stranger	
Likely	169 (42)
Neutral	166 (41)
Unlikely	66 (17)

^a Because of missing data, sample size ranges from 386 to 425.

(93%; Table 1). Approximately one-third of the sample had attended vocational school or some college, and another third had graduated from college. Almost half of the sample was married, and two-thirds of the sample was Baptist. Participants ranged in age from 19 to 88 years (mean = 48.95, SD = 14.26). Regarding the likelihood of engaging in living donation, more than three-quarters of participants reported that donating to a close family member would be likely (Table 1). Fewer participants reported that donating to a friend would be likely (67%), and even fewer reported that donating to a stranger would be likely (42%).

Univariate Analyses

Each of the demographic variables (age, sex, race/ethnicity, educational attainment, annual income,

marital status, and denomination) was explored in relation to the 3 dependent variables related to living donation. Results indicate that the sex of the respondent was associated with all 3 variables; women reported a higher likelihood of engaging in living donation than did men: $\chi^2_2 = 5.9$, $P = .05$ for donation to a close family member, $\chi^2_2 = 6.7$, $P = .03$ for donation to an extended family member/friend, and $\chi^2_2 = 9.0$, $P = .01$ for donation to a stranger. Additionally, participants with a college degree reported a significantly higher likelihood of donating to a close family member than did participants without a college degree ($\chi^2_2 = 8.8$, $P = .01$). Because the participant's sex and having a college degree were also associated with the primary independent variables of interest, they were entered into the regression models and treated as potential confounding variables. Differences in denomination, race/ethnicity, annual income, and marital status were not significantly associated with intentions with respect to living donation.

Univariate analyses indicated that donation-related knowledge, attitudes, and willingness to engage in deceased donation were not significantly associated with likelihood of living donation to a close family member. Personal experiences with donation and/or transplantation and knowledge of donation/transplantation were not associated with the likelihood of living donation across the 3 variables (Table 2). However, donation attitudes/beliefs and willingness to engage in deceased donation were significantly associated with likelihood of donating to an extended family member/friend and likelihood of donation to a stranger. The effect size (strength of the relationship between these variables) was larger for likelihood of living donation to a stranger (Table 2).

Multivariate Analyses

Finally, multivariate analyses were conducted (with sex and educational attainment of the respondent controlled for) to determine whether the relationships found in the univariate analyses would hold. First, because none of the univariate analyses revealed significant associations with likelihood of donation to a close family member, no multivariate analyses were conducted with this dependent variable. In the multivariate regression model of likelihood of living donation to a friend, only willingness to engage in deceased donation remained significantly associated. Finally, in the multivariate regression model of likelihood of living donation to a stranger, both attitudes toward donation and willingness to engage in deceased donation were associated with likelihood of donating (Table 3).

Discussion

In this study, we explored the relationship between donation knowledge and attitudes and the likelihood

Table 2 Pearson correlation testing the association between donation-related knowledge, attitudes, and experiences and intentions with respect to living donation^a

Donation-related knowledge, attitudes, and experiences	Type of living donation		
	To a close family member	To an extended family member/friend	To a stranger
Personal experiences with donation and/or transplantation			
Knowledge of donation and/or transplantation	0.09		
Attitudes and beliefs toward donation	0.09	0.17 (<i>P</i> = .001)	0.23 (<i>P</i> = .000)
Willingness to engage in deceased donation	0.10	0.21 (<i>P</i> = .000)	0.31 (<i>P</i> = .000)

^a Empty cells indicate nonsignificant findings.

of living donation. Living donation to a close family member showed widespread support. Most participants said that this type of donation was likely; thus, a ceiling effect may have prevented any of the independent variables from achieving a significant association with likelihood of donating to a close family member. In this case, a ceiling effect occurred because so many participants responded in the affirmative that the variability in the dependent variable was not sufficient to reveal associations with the independent variables.

Only willingness to engage in deceased donation was significantly associated with likelihood of donating to a friend or extended family member. It is likely that willingness to participate in deceased donation reflects one's openness to donation in general, as well as commitment to donation. Both willingness to engage in deceased donation and attitudes toward donation were significantly associated with likelihood of donating to a stranger. Thus, donation commitment and attitudes and beliefs about donation become more important in determining likelihood of donation as the distance between the donor and recipient increases. In other words, as one moves outside of one's immediate family and friends, and more selflessness is required for a decision to donate, attitudes and a general commitment to donation become more important in determining the likelihood of becoming a living donor.

Nevertheless it is unclear how much findings are attenuated given the high percentage of people who were willing to donate to a friend, which reduces the variability in responses. This finding suggests that donating to a friend or stranger requires more thought and may be perceived as being more of a sacrifice than donating to a close family member. Interestingly, knowledge of and personal experiences with donation and/or transplantation were not significantly associated with likelihood of any type of living donation.

Although variability in knowledge scores was good, with participants responding to all questions, this knowledge was not significantly associated with

donation attitudes or intentions with respect to living donation. These findings are consistent with results of previous research^{8,43} that indicate that general knowledge is not the primary factor in a person's decision making about donation. Among African Americans, in particular, studies have often used the composite measure of "knowledge" to represent a collection of awareness and understandings of donation facts and processes.^{46,49-52} Our previous research has suggested that the expression "knowledge" has many complex components, and how different types of knowledge are associated with deceased donation intentions varies widely.⁴³ The same may also be true for living donation intentions. Specific types of knowledge (ie, experiential knowledge, knowledge of the allocation system) may influence an individual's willingness to engage in living donation. Thus, interventions that continue to concentrate on donation education with a focus on the broad spectrum of knowledge may be ineffective.

In some respects, the study findings are encouraging. They provide some evidence of a willingness of family members and friends to serve as living donors for their loved ones. If African American dialysis patients can overcome their concerns with approaching family members and making donation requests, they may encounter much less resistance than imagined. However, refusal to approach family members is a real impediment.^{26,53} Many patients are consistently reluctant to engage in these discussions for a myriad of reasons: (1) not wanting to be a burden and have anyone suffer unnecessarily for them, (2) not wanting to feel a sense of indebtedness to another, and (3) concerns for a loved one's risks of surgery and increased risk for future kidney disease.^{9,12,23,27} Because of these concerns, family and friends are most often the ones initiating these important living donation conversations rather than the dialysis patients themselves.^{8,11,13,54} With additional education, dialysis patients may be better willing and able to broach these difficult conversations.

Table 3 Intentions with respect to living donation regressed on donation-related knowledge, attitudes, and experiences (N = 425)

Donation-related knowledge, attitudes, and experiences	β^a	
	To an extended family member or friend (4, 377) ^b	To a stranger
Personal experiences with donation and/or transplantation		
Knowledge of donation and/or transplantation		
Attitudes and beliefs toward donation	.08	.12 ($P = .05$)
Willingness to engage in deceased donation	.16 ($P = .009$)	.25 ($P = .000$)
Sex	-.14 ($P = .007$)	-.13 ($P = .01$)
Education	.00	-.10 ($P = .04$)
Adjusted r^2	.05	.12
F	6.49 ($P = .000$)	13.56 ($P = .000$)

^a All models control for sex and educational attainment. For each regression, only those independent variables 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.

^b Degrees of freedom.

Limitations

This study involved a multidominational convenience sample of Christian, African American parishioners in Atlanta. Thus, this study was not designed to generalize findings to African American parishioners in other locales, to those holding non-Christian religious beliefs, or to African Americans who do not attend church. The overrepresentation of women among our sample of parishioners may have affected the findings, although it is understandable that because women tend to report higher rates of church attendance than men, it is natural to expect that a sample of churchgoers would have a larger representation of women.⁴⁴

Furthermore, participants' self-reported attitudes and donation intentions may be biased. Social desirability bias, in particular may have affected self-reported donation intentions. Asking a hypothetical question gauging the interest in donation may have inadvertently increased the possibility of receiving a favorable response. Given this limitation, what participants said they are likely to do in this survey may differ from what they would actually do if a family member approached them about undergoing living donation. In addition, because of the cross-sectional nature of this study, causality cannot be assessed. Additionally, although a degree of likelihood is necessary for a person to designate himself or herself as a potential living donor, such a designation alone is not sufficient to make someone an actual donor. Issues of medical suitability are equally important in the donation process and play a major role in a person's ability to act as a living donor.

Conclusions

Although more research is needed in this area, our data have shown that willingness to be a deceased donor is most strongly associated with intentions with respect to living donation. It might be that when

people have positive attitudes and agree with the concept of donation, they do not differentiate between the options of living or deceased donation. This finding raises the possibility that generating support for organ donation in general may translate into support for both deceased and living donation. It is unclear whether this finding would hold among other ethnic groups, thus additional research in this area is greatly needed.

The topic of living donation is studied with much less intensity among African Americans than among the general population. Not only are African Americans overrepresented on the transplant waiting list, but dialysis patients also are insufficiently educated about their treatment options.⁵⁵ Although numerous studies have been conducted to identify barriers specific to donation among African Americans,^{9,11,12,23,26,39,53,56,57} few interventions have been developed to address their concerns and apprehensions specifically related to living donation. These concerns (eg, personal/donor health after donation and reluctance to accept family members as donors^{6,9,11,12}) are not well understood. Given the reluctance of dialysis patients to approach family members, staff members at dialysis clinics are encouraged to serve as liaisons between patients and patients' families. Development of interventions to educate dialysis staff about approaching patients and patients about approaching family members about the possibility of living donation are recommended.

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