

Moving beyond Attitudinal Barriers: Understanding African Americans' Support for Organ and Tissue Donation

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Purpose: African Americans are disproportionately represented among individuals in need of an organ transplant, due in part to low donation rates in this population. The research literature has focused on attitudinal barriers to donation; however, the current study explores individual experiences and values that contribute to supportive attitudes toward organ and tissue donation.

Procedures: Focus group participants were 26 African-American clergymen and 42 African-American parishioners recruited from seven Christian churches in the metro Atlanta area.

Findings: Although a large number of participants had previous exposure to organ and tissue donation and transplantation, the majority of these experiences were negative, and participants felt a general fear and lack of knowledge about the process of donation and transplantation. Despite these negative experiences, respondents reported personal values (e.g., the desire to help others and acceptance of group responsibility) and religious values (e.g., the desire to carry out God's will and to have faith in God) that contribute to supportive attitudes toward organ and tissue donation.

Conclusion: An understanding of supportive attitudes toward donation may help improve the development of effective culturally sensitive intervention messages targeting the African-American religious community with the ultimate goal of increasing the pool of organs available for transplantation.

Key words: organ and tissue donation ■ African Americans ■ transplantation ■ clergy ■ kidney

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With the success of organ transplantation, it has become the therapy of choice for many individuals with end-stage organ failure. There has been a resulting increase in the need for donated organs; however, the number of organs available for transplant in no way meets the current need. In 2003, only 25,448 transplant procedures were performed while nearly 6,300 individuals died awaiting donor organs that never became available.¹ As of March 2004, almost 85,000 individuals await a life-saving organ, and nearly 27% of these individuals are African-American (note that we use the term "African-American" to include black Americans of African, Caribbean and Hispanic cultural backgrounds).¹ A variety of factors, one of which is low donation rates, contribute to African Americans' overrepresentation among those who are in need of a transplant.²⁻⁴

The literature is replete with studies of negative attitudes toward organ donation, many of which appear to be shared by African Americans. A common perception exists that signing a donor card or designating organ donor status on a driver's license may result in a decrease in the quality of medical care received and possibly even the premature declaration of death.^{5,6} This general distrust of the medical community is reportedly one of the main reasons for many African Americans' lack of desire to become organ donors.^{3,4,7-11,12} Strident public squabbles about organ allocation, lurid melodramas about transplantation,¹³ and a concern of fairness in the allocation system^{4,5} are additional negative concerns contributing to low donation rates.

Oftentimes, the attitudinal barriers reported are based on religious beliefs and fears, such as the fear of mutilation and a belief in the need to keep the body intact for the afterlife.^{3,7,8,12,14,15} For example, in one study, participants' perceived importance of spirituality and religion were inversely associated with their willingness to become a deceased donor.¹⁶ In a qualitative study, respondents stated that religious beliefs did not have a significant impact on their decision to donate, yet many of them believed that they needed their organs for resurrection and that by speaking of

death they would bring death to fruition.⁹ Moreover, there is some evidence that religious objections act as a greater barrier to donation among African Americans than whites.¹⁰ These findings underscore the influential role that religious beliefs have on donation decision-making, particularly among African Americans. However, beyond an understanding of the desire to keep one's body intact for the afterlife, there is little in-depth understanding of how religious attitudes and beliefs influence donation decision-making. Moreover, the quantitative literature focuses on religion as a barrier to donation; thus, there is little understanding of how these attitudes and beliefs may also support donation.

In summary, much of the research to date has focused on the barriers to donation, in part because of the low donation rates among African Americans. Nevertheless, it is notable that not all attitudes toward donation among African Americans are negative. There are some individuals who support donation and have made a conscious decision to communicate this decision to others (e.g., by sharing their wishes with family or carrying a donor card). Others support donation but may not have properly communicated this desire to their close friends and family for fear of negative backlash. Finally, some individuals have a neutral stance toward donation simply because they haven't thought about it or perhaps hold conflicting positive and negative views. Nevertheless, human behavior cannot be fully understood in the context of a purely negative frame of reference.¹⁷ Understanding supportive attitudes toward organ and tissue donation among African Americans is necessary for the development of effective intervention messages. Thus, to extend the current literature beyond the focus on barriers to donation, this study will further the understanding of how respondents' experiences and values contribute to supportive attitudes toward organ and tissue donation.

This study is guided by three research questions:

- a) What are respondents' experiences with organ and tissue donation and transplantation?
- b) What personal values and belief systems lend themselves to supportive attitudes toward organ and tissue donation?
- c) What religious values and belief systems lend themselves to supportive attitudes toward organ and tissue donation? It is expected that the answers to these questions in conjunction with what is known about the barriers to donation will be useful toward the development of effective interventions.

METHODS

The current study is the first phase of a larger study that seeks to test the effectiveness of a culturally sensitive organ and tissue donation intervention for African-American clergy and parishioners. This initial phase of the study did not seek to impact views on donation. Instead, it simply sought to understand what individuals' views are. Because we are seeking to tailor the intervention to address religious concerns with donation, we needed to recruit into this study churches that held similar belief systems. Thus, we opted to focus our efforts on the religious denominations within the Christian faith with the understanding that an intervention that is tailored for individuals of other religious affiliations (e.g., Islam) may include different messages. It is for this reason only Christian-based churches are included in this study.

To recruit churches into the study, we generated a list of 112 Christian-based churches with African-American pastors in the greater Atlanta area and talked to colleagues in the field to identify pastors who may be interested in the project. Through a process of networking with clergy (via telephone and face-to-face meetings), eight pastors agreed to participate in the study by joining our community advisory board. A liaison was identified at each church to help us identify clergy and families that met the eligibility criteria for

Table 1. Demographic Characteristics of Participating Churches

Church	Denomination	Approximate Church Membership Size	Median Income ¹
1	United Methodist	150	\$17,857
2	African Methodist Episcopal	200	\$19,438
3	Baptist	200	\$19,530
4	African Methodist Episcopal	100	\$34,052
5	African Methodist Episcopal	1,000	\$36,769
6	Nondenominational	5,000	\$43,780
7	Baptist	500	\$51,915

¹ In 1999 for the zip code in which the church resides.

participation in the study. Because of logistical constraints, only seven of the churches were able to participate in this phase of the study. Both clergy and parishioners were recruited from these seven churches to participate in this phase of the study. Focus group participants were 26 African-American clergy and 42 African-American parishioners who resided in the greater Atlanta area. The denominations of most of these churches were African Methodist Episcopal or Baptist. Churches ranged in size from 100 to 5,000, and the median income for the county in which the church resides varied from approximately \$18,000 to \$52,000 (Table 1).

Data Collection

Four focus groups with clergy were convened during February and March 2003. Respondents were eligible to participate if they were ordained ministers in one of the seven participating churches. Each discussion was facilitated by an African-American professional with training and experience conducting focus groups. Facilitators followed a focus group guide with a standard introduction and opening question, discussion topics and probes, although the order of discussing the topics varied across focus groups. Focus group discussions included events in the media relevant to organ and tissue donation and transplantation, knowledge of organ and tissue donation, personal views and experiences surrounding organ and tissue donation, and religious beliefs surrounding donation and transplantation (Table 2). Each focus group discussion was audio-recorded, and a second African-American facilitator took notes on key issues that arose during the discussion. Respondents were offered a brief break with light refreshments approximately halfway through the discussion. Each focus group was subsequently transcribed verbatim. After each focus group, respondents completed a brief questionnaire that measured attitudes and beliefs surrounding organ donation and transplantation,¹⁸ personal experiences with organ and tissue donation and transplantation, knowledge of community projects on minority organ and tissue donation, and demographic information. Because of the qualitative focus of this phase of the study, we opted to have respondents complete the questionnaire after the focus group had been conducted to maintain the integrity of the qualitative data (thereby minimizing the possibility that items on the questionnaire would shape how respondents discuss the topic). Respondents were offered a \$100 monetary incentive. This study was conducted with the approval of the Emory University Institutional Review Board.

Ten focus groups with parishioners were convened between March and September 2003. One family was represented at each focus group for a total of 10 families. Each focus group consisted of

three-to-seven people that represented at least three generations within that family so that we would hear a broad range of views on this topic. At least one family member was a member of one of the seven participating churches. The same individuals who facilitated the clergy focus groups also facilitated the family focus groups. The focus group guide was similar to that used with the clergy focus groups with the addition of questions on the generational influences on personal views surrounding donation and transplantation (although these data are not reported in the current study). The same data collection procedures were used as with the clergy focus groups, and parishioners completed the same questionnaire as was completed by the clergy. Upon completion of the questionnaire, respondents were offered a \$75 monetary incentive.

Data Analysis

Data were analyzed according to procedures outlined in Patton.¹⁹ Each focus group transcript was read carefully for the purpose of creating a coding structure that would provide a meaningful framework to capture respondents' attitudes, beliefs and experiences. Once a structure had been agreed upon among the three members of the analysis team, the data were coded, and the codes were entered into *The Ethnograph*.²⁰ Next, the analysis team identified the codes that were relevant to each research question and analyzed the data separately by research question. This process involved reading the coded text and identifying salient themes that were relevant to each research question. Once the analysis team had identified the salient themes, a fourth individual reread the coded text for the purpose of validating and modifying the salient themes that had been identified by the analysis team. These themes are presented below separately by research question.

RESULTS

Description of Focus Group Participants

Among the 26 individuals who participated in the clergy focus groups, respondents tended to be female and in the 45–54 age category (Table 3). All of the clergy self-identified as being black/African-American with the exception of one individual, who self-identified as black/Hispanic. Most clergy had a college degree or had at least started work towards a graduate or professional degree. Half of respondents had an annual gross income of at least \$35,000, and over half were married. Based on the questionnaire data, they had moderately positive attitudes toward organ donation and transplantation; scores ranged from 23–33 on a 10-item scale with a possible range

of 10–40 ($M=28.62$; $SD=3.22$). Of the 21 individuals who answered this question on the questionnaire, 17 (81%) expressed interest in serving as a donor, and 10 people (48%) expressed this interest on their driver's license. Only four respondents (15%) indicated that they carry a donor card.

Among the 42 individuals who participated in the family focus groups, an overwhelming majority of respondents were female (Table 3). All parishioners self-identified as being black/African-American. Because we sought respondents representing different generations, their ages ranged greatly from 18 years to over 85. Respondents tended to be high-school graduates, many of whom pursued vocational or technical school beyond high school. Almost half of respondents had an annual gross income of over \$50,000, and their marital status varied greatly as well. Based on the questionnaire data, they had moderately positive attitudes toward organ donation and transplantation as well; scores ranged from 18–38 on a 10-item scale with a possible range of 10–40 ($M=28.71$; $SD=4.46$). Thirty-four respondents (81%) expressed interest in serving as a donor, and 15 people (36%) expressed this interest on their

driver's license. Only 11 respondents (26%) indicated that they carry a donor card.

1. What Are Respondents' Experiences with Organ and Tissue Donation and Transplantation?

Based on the questionnaire data, a large number of respondents reported some level of exposure to organ and tissue donation and transplantation through friends, family members and colleagues who needed or received organs. For example, the majority of participating clergy knew someone on dialysis, knew of someone who had been a recipient or knew someone who had served as a donor (Table 4). Similarly, the majority of the parishioners knew someone on dialysis or knew of someone who had been a recipient. However, in comparison to the clergy, few parishioners knew someone who had served as a donor (62% for clergy and 38% for parishioners) (Table 4).

Friends/Family Awaiting Transplant

The qualitative data support the contention that respondents had a variety of meaningful experiences

Table 2. Discussion Guide for Clergy and Family Focus Groups

1. *Opening Question*
As you know, the purpose of this study is to learn more about your views and experiences with organ and tissue donation. But before we get to those issues, I wonder if you could tell me what you think the major issues are surrounding organ and tissue donation.
2. *Media*
Next, I'd like for you to tell me what you've heard in the media on the subject of organ and tissue donation or transplantation. Is there anything that immediately comes to mind?
3. *Knowledge of Organ and Tissue Donation*
Now I'd like to go around the room and have each person tell me what he or she knows about organ and tissue donation. I'm not looking for more than a few sentences here.
4. *Personal Views Surrounding Organ and Tissue Donation*
Tell me about your personal views on organ and tissue donation and transplantation.
5. *Personal Experiences Surrounding Organ and Tissue Donation*
Tell me about your personal experiences with organ and tissue donation and transplantation.
6. *Myths and Fears*
What do you think about the statement, "African Americans don't donate"?
- 7a. *Church View of Organ Donation (This section was for clergy only)*
Tell me about your church's views on organ and tissue donation and transplantation.
- 7b. *Generational Influences on Personal Views (This section was for families only)*
We think that people's views on organ and tissue donation and transplantation are in part shaped by the era in which they were raised. So, someone born at a time when transplantation was not an option might have different views towards it than someone born when transplantation is a relatively common occurrence. Please tell me how much you heard about organ donation and transplantation when you were growing up.
8. *Other Questions or Concerns*
Is there anything else that you would like to share with the group about your views on organ and tissue donation and transplantation?

surrounding donation and transplantation, although most of them were negative. Respondents described situations in which people they knew were waiting on organs, died waiting to receive an organ or died after an unsuccessful transplant. For example, one parishioner described a friend of hers who was waiting to receive a kidney transplant:

And the other guy I know is my age... Well he started out with kidney cancer in one of his kidneys, and he lost that one. And now he's lost both of his kidneys. I don't know whether he had cancer to lose the other one, but he's lost both kidneys now. And he's on dialysis and he had had a procedure done, and he was doing the treatments at home but he got real bad infected and I think he had to go back and start getting—going back to the dialysis center to get them. But uh, he's on the list. You know, he has to go every, I think three times a week for the, uh, dialysis, but he seems to be doing pretty good.

She went on to describe how knowing this person and one other friend of hers who had an unsuccessful transplant caused her to be more accepting of donation:

...but I think it brought us more sense of awareness, you know, cause we actually knowing somebody, you know, than just hearing about it. You actually know of some of the experiences that they are going through, some of the treatment they are having. And I think it gives you a little more to think about, even in the prospect of the same thing could happen to you later in life, you know. And I guess that one thing makes me more ready to be a donor because you never know what could happen to you, and I'm sure if you needed an organ you would want someone to donate if it was going to save your life. You would want somebody to donate.

One member of the clergy described having two family members who died on the waiting list:

My, uh, father and my ...paternal grandmother...so they, they both died waiting on the list. We wanted to give. I said they could test us but they couldn't do it. Wouldn't match.

Unsuccessful Transplants

Other respondents described painful experiences in which friends or family members died after unsuccessful transplants. In some situations, respondents described long periods of waiting to receive a transplant (which is typical because the median waiting time is four years for African Americans awaiting kid-

neys¹), only to ultimately see their friend or relative die. For example, one member of the clergy stated:

My cousin was the longest recipient. She received a kidney once, Alicia did. She just died last week and her funeral was this week, but she's been on dialysis for years and years. The kidney she had implanted...it stopped functioning...

Although not a personal experience, many respondents discussed a recent media event in which an adolescent girl died after having received a heart-lung transplant from a donor with an incompatible blood type. Respondents raised numerous questions about how such a medical error could have occurred. Some respondents felt that the widespread media attention that this situation received will deter people from wanting to donate. A discussion among clergy illustrates this position:

Well, the medical team admitted that they made an error. They gave her a heart and lung with the wrong blood type.

Amen.

And so then when they tried to go in and redo it and give her the right one, her body was so weak that it rejected it and so she died. But that, uh, in itself would frighten so many people that the medical team, although they admitted making the mistake, made that mistake and you, you... You know millions, everyone in America probably heard this story and that's really going to, uh, cause some thinking now before anyone wants to donate or receive an organ.

However, other respondents felt that there are no guarantees that a transplant will be successful and that this situation was probably atypical. One member of the clergy stated:

I think I kind of look at it in the eyes of the question of how many number of transplants take place on a—let's just say a yearly basis—and how many times this kind of thing happens within that context. Maybe not this large, but something probably happens at some point in time but in relation to the number of transplants that actually take place. I would imagine that this is a rather small. It's no less tragic because it affects this family...

Successful Transplants

Many respondents described painful experiences of hearing about or personally knowing friends and family members needing organs or having unsuc-

cessful transplants. Others described more positive experiences in which a friend, family member or church member received a life-saving transplant and is now doing well. One parishioner stated:

So then I talked to someone...a conversation that I've had with a church member who recently received a kidney transplant a couple years ago and that how he would not be here if it wasn't for that transplant.

Another parishioner described having a friend who received a liver transplant and how seeing his recovery after the transplant has impacted her decision to donate:

Um, the second person received a liver, and like I say he was at the point of death and he got his call on Father's Day that, uh, they had a liver for him and he just immediately started to come back after he got his liver, uh, transplant. And now he's just thriving, he's gained a lot of weight and he's just doing everything and he goes out and he promotes organ donations. He's even been here at St. Luke for a health fair that we had and um, it was him that—on both people—that made me decide to be um an organ donor after seeing their quality of life change so, I just couldn't help but help other people who needed the help...

Lack of Exposure to the Donation/Transplantation System

Most of the experiences that respondents reported involved people who were not close enough to the respondent for her/him to see firsthand how the process of recovering and transplanting organs operates. Thus, despite these experiences, respondents reported a general fear and lack of knowledge about the process of donation and transplantation. Respondents raised questions about how to specify who will receive their organs should they agree to donate, when and where organs are recovered from a donor who has been in a fatal car accident, how to get on the waiting list for transplantation, and how to actually receive a transplant. One parishioner illustrates this sentiment:

Well now, being a donor, I would like to know the process so that maybe I can educate my family that, this is what's going to happen should something happen to me. Because right now it's just down on my driver's license that I'm a donor. That, that, that's all it is. I don't have any information as to, like my sister was saying, which parts? All parts? Any parts? What time, when, who, how? You know, there are a lot of unanswered question around the act itself.

Respondents generally acknowledged that this lack of exposure to the donation and transplantation system contributed to negative feelings toward donation. In addition to impacting their own personal views on donation, respondents argued that this fear of the unknown probably contributed to negative views towards donation among African Americans in general.

In summary, respondents reported a variety of experiences with organ donation and transplantation, though many of them were negative. It may be that these largely negative experiences, coupled with fear and a lack of knowledge about the process of organ recovery and allocation contributes to negative attitudes and beliefs that some African Americans hold towards organ and tissue donation. However, many respondents held views that were supportive of donation. The remainder of the paper will explore how respondents' values and belief systems lend themselves to supportive attitudes toward organ and tissue donation.

2. What Personal Values and Belief Systems Lend Themselves to Supportive Attitudes toward Organ and Tissue Donation?

Many of the negative beliefs that are reported in the literature were also discussed by respondents in the current study. Respondents expressed grave concerns that being identified as a potential donor would impact the quality of medical care received and ultimately hasten their death. Many respondents were skeptical about donation because of concerns of race and class-based inequalities in the allocation system. Additionally, respondents reported concerns of being mutilated and the need to have their body intact to get into Heaven. However, respondents' views were not one-dimensional. They held complex values and beliefs that accommodated many of the negative views described above while also embracing supportive views toward organ and tissue donation.

Desire to Help Others

Respondents repeatedly expressed altruistic motives for donation. The desire to help others was the most commonly reported motivation for agreeing to serve as a donor. One parishioner stated:

But I just felt like, you know, this is...if they can use any part of my body, I don't need it. My soul will be resting someplace else. That body they can do whatever they want to with it, you know. So I just decided, you know what? That's why I just decided to be a donor and let them use what part they can to help someone else.

However, respondents had mixed motivations for identifying themselves as an organ donor on their drivers' licenses. At the time of this writing there exists a Georgia law discounting drivers' licenses by \$7 (i.e., \$8 instead of \$15 for those who do not agree to be an organ donor) for those individuals who agreed to identify themselves as an organ donor. Thus, some respondents acknowledged that they were identified as an organ donor on their drivers' licenses simply to get the discount. One 21-year-old respondent stated:

I know when I went with a group of my friends, everybody that she asked it was just, like 'organ donor?' Everybody does that face like, 'hmmm'... Everybody does that face like, 'hmmm... well, it's money off, so OK,' whereas, we're still not thinking about it. We just know that we're getting \$10 off.

However, older respondents described how their motivation changed over time (given that the ques-

tion of whether to serve as an organ donation is posed every four years during license renewal) from simply wanting the discount to having a sincere desire to help others.

I told you in the past, when I found out the license were \$8, I said, I'm going to pay this \$8 just to get my license cheaper, opposed to \$10 or \$15. But I have truly taken a look at the need of saving lives, and my, my organ and body parts won't do me any good in the ground, but they'll do somebody else some good. So since our last discussion, I've been talking with my family members telling them that I am a true organ donor so they can know, because people's lives are just...people are dying everyday because the lack of organs.

Finally, although some respondents were interested in donating only to certain segments of the population, others countered with the view that one should want to donate regardless of who the recipient is.

Table 3. Clergy and Family Member Demographic Characteristics

Characteristic	Clergy (N=26) n (%)	Family Members (N=42) n (%)
<i>Gender</i>		
Male	12 (46)	8 (19)
Female	14 (54)	34 (81)
<i>Age</i>		
18-34	1 (4)	11 (26)
35-54	14 (54)	19 (46)
55-74	10 (39)	6 (14)
75 and over	0 (0)	3 (7)
<i>Formal Education</i>		
Less than high school/high school	2 (8)	15 (36)
Vocational or technical beyond high school	3 (12)	6 (14)
Some college/college degree	10 (38)	12 (29)
Some graduate work/graduate or professional degree or beyond	11 (42)	6 (15)
<i>Household Income</i>		
Less than \$10,000	1 (4)	10 (24)
\$10,000-\$19,999	0 (0)	5 (12)
\$20,000-\$34,999	6 (23)	6 (14)
\$35,000-\$50,000	5 (19)	2 (5)
Over \$50,000	8 (31)	18 (43)
<i>Marital Status</i>		
Never married	2 (8)	13 (31)
Married	16 (62)	17 (41)
Divorced or Separated	1 (4)	7 (17)
Widowed	1 (4)	4 (10)
Other	1 (4)	0 (0)
Ns vary due to missing data.		

Below is the discourse between two parishioners:

I would want to know who I'm giving it to and who's giving it to me if I needed it.

Well, then, you're not giving it truly from your heart. When you give an organ, you're doing it to help somebody. You shouldn't be worrying about who gets it, just that it's somebody that's really needing it. At least that's the way I feel about it.

Family Generosity

The value of helping family was an important aspect of respondents' desire to help others. There was general consensus among clergy and parishioner respondents that they would be willing to serve as a living donor for a family member in need of a transplant. In fact, for some respondents, they held negative views toward donation in general, with the exception of when a family member was in need. One parishioner stated, "You just don't give your organs unless it's your immediate family...". Another parishioner stated:

Well, I think that if I was already passed on, I wouldn't care who received it. But if I was giving an organ and I was alive, I probably would only do it for a family member so of course they would be African-American.

Allegiance to the African-American Community

In addition to the desire to help family, many respondents felt a sense of responsibility to helping the African-American community. This sense of group responsibility served as a strong motivation for agreeing to serve as a donor. In fact, some respondents were only interested in donation to the extent that they could be assured that their organs would go to someone black. One parishioner stated:

I wouldn't mind if my organs were donated to a black person or minority person, but what are those chances that they would get them? You know because blacks are always put down, always put down anyhow, and we're always on the bottom of the list as far as organ donors.

Other respondents were aware of the shortage of organs available for transplant and the large number of African Americans who are awaiting transplants. From this knowledge, these respondents felt a personal responsibility to increase the number of organs that are available for transplant among African Americans.

...My oldest received it [a kidney] from my youngest brother. But, uh, I was on board with organ donation prior to that because I was familiar with the disproportionate numbers there were with respect to need among black folks and availability and that's just always been, I mean once I became aware of it, it just became a, a concern. And that's not to exclude the racism issue, or the class issue, but still there's this, "are we doing what needs to be done on our end to ensure that there's availability while we're working on these other problems?"

Many respondents expressed an interest in donating for the purpose of helping not only African Americans but also poor people. There was a general consensus that blacks and poor people don't have equal access to organ transplants, thus, many respondents wanted to donate specifically to help those that are underserved. One respondent explained:

"So me myself, I'd love to donate an organ or tissue to um, anybody black that needs help or poor white people needs help because all us equal in some ways..."

In summary, altruistic motives strongly contributed to respondents' supportive attitudes towards donation. Respondents talked a lot about wanting to help others but later became more specific about who it was they were most interested in helping through donation. The current study revealed a genuine interest in helping others due to family generosity and an allegiance to the African-American community. Nevertheless, this altruism appears to be driven by yet another motivation: Christian values and beliefs.

3. What Religious Values and Belief Systems Lend Themselves to Supportive Attitudes toward Organ and Tissue Donation?

Being a Blessing to Others

Most respondents held conflicting views in which they felt that donation was the right thing to do but also had concerns about the fairness of the allocation system. Much more so than the clergy, the parishioners discussed how their Christianity helps them to resolve these conflicting views. A commonly held belief was that living a Christian life was founded on the principle of being a blessing to others. Some respondents equated organ donation to the ultimate sacrifice that Christ made for the sake of mankind. Thus, for some, the general interest in donation was rooted in their Christian values. One

parishioner articulated the position that donation was a way to bless someone else:

If you think about it, you know, if you can help someone and someone can use something and you're dead, you know, I mean it's a blessing, that someone could use your eyes or whatever, they couldn't see or whatever, and you are dead. And it is something to think about.

Another parishioner expressed a similar belief:

... we [African Methodist Episcopal] encourage organ donations in our particular, our congregation, because we really embrace that...doing unto others as you would have them do unto you...and to address the needs of others.... But I see more from of a spiritual standpoint which is...whether or not we believe that God will provide, and that what you do for others you reap what you sow and we constantly look at ways to be a blessing to someone else.

One parishioner went so far as to quote a well-known religious hymn, "If I can help somebody" by stating that "my living will not be in vain if I am able to help somebody."

Fulfilling God's Will

Respondents indicated that being a blessing to others is in line with the will of God. Thus, donation is in line with God's will, and the Lord will meet the needs of anyone who was willing to donate. One parishioner stated:

I have never seen anything from, um, my religious beliefs saying that you couldn't or you shouldn't. I haven't seen anything. As a matter of fact, contrary, I would say that it would say to donate only because the Lord is going to provide, if you want to go from a

spirituality point of view, that He will provide for you and the person that you have donated something to.

Others argued that since God created our body and it is His, it is our responsibility to put it to good use:

...because I think that's what God would want us to do. Um, our body is not ours anyway...I mean it's not ours. I think you know, you know He, He created us. I think that we, we have to give back and I think what better way to do it than to help someone else.

Physical Bodies Not Needed in the Afterlife

Finally, there were a fair number of respondents who clearly articulated that organs would not be needed in the afterlife. It was clear in their minds that since their spiritual selves (not their physical bodies) would go to Heaven, their organs would not be needed.

Also, I'm very clear on what my stand is when it comes to Christ, and I trust that He don't need not one of them parts for me to further this eternal life, if you would. So I'm just real clear about it.

Similarly, clergy generally felt that they wouldn't need any body parts in the afterlife. Moreover, one minister in particular felt that they had not done a good job of communicating this to parishioners:

We haven't done a good job, our parishioners haven't done a good job of understanding that it has nothing to do with resurrection or the hereafter. I mean we see it, and I think we perhaps see it because we attach it to the Jesus thought, but the resurrection is a spirit thing. We won't be, we won't have this kind of...we won't look this way in the uh,

Table 4. Clergy and Family Member Experiences with Organ and Tissue Donation and Transplantation

Experience	Yes n (%)	No n (%)
Clergy (N=26)		
Knows someone who is on dialysis	21 (81)	4 (15)
Knows of someone who has been a recipient	20 (77)	6 (23)
Knows someone who has served as a donor	16 (62)	10 (38)
Knows someone who died waiting on the organ transplant list	7 (27)	18 (69)
Family members (N=42)		
Knows someone who is on dialysis	33 (79)	8 (19)
Knows of someone who has been a recipient	36 (86)	5 (12)
Knows someone who has served as a donor	16 (38)	26 (62)
Knows someone who died waiting on the organ transplant list	10 (24)	31 (74)

Ns vary by question due to missing data

in the rapture. And that's part maybe what we haven't done in the church is help folks understand, that um, you go back to dust and so these body parts you think you're going to need later on you're not going to need.

Nevertheless, clergy remained more cautious than the parishioners in their statements about the stance that their religion and spirituality takes on donation. They indicated that donation and/or transplantation are not contrary to the will of God but that the church does not articulate a formal position on the matter.

I haven't heard, heard any of the scriptures...But I believe if you look at the Bible in its totality, you certainly can put in there that this [donation] is not contrary to the will of God.

Thus, respondents hold views towards donation that are more supportive than what the statistics on donation would have us to believe. For those respondents who have spent time thinking about this issue, there is a weighing of their concerns about inequalities in the transplantation system against altruistic motives and religious ideals that cause them to have a neutral stance toward donation. However, in the case of donation, a neutral stance ultimately translates into a lack of consent to donation because of family members' tendency to err on the side of caution when having to make the decision of whether to donate the organs of a deceased family member who held conflicting views on donation.

DISCUSSION

In this study of African-American clergy and parishioner families, we identified several values and belief systems as underpinnings of support toward organ and tissue donation, even in the face of conflicted views and experiences. While several of the stories of donation and transplantation as described by our respondents resulted in negative outcomes, such as death while waiting for a transplant or rejection of the organ after a transplant, such experiences did not necessarily color their attitudes in a negative manner regarding donation. Rather, for some, their experiences resulted in increased awareness of the need for donation. Perhaps such awareness resulted from their personal connections with others in need as those individuals held out hope for life-saving or life-enhancing transplants. Personal values that respondents articulated include the desire to help others or altruism; family generosity, especially regarding living donation; and an allegiance to the African-American community as a whole. Religious values described were a sense of being a blessing to others, donation as a fulfillment of

God's will and the belief that physical bodies are not needed in the afterlife.

Altruism

The organ donation and transplant system within the United States is founded on the principle of altruism: "an unselfish concern for the welfare of others; selflessness."²¹ According to published polls and surveys, the majority of Americans support organ donation as a means to save a life or help someone else.⁸⁻¹⁰ The current study of African Americans shows support for these views. Many respondents felt that it was their duty to help others regardless of personal benefit, especially those in need of a transplant within their family or their community. They held these views while acknowledging their mistrust of the medical community and the institutionalized racism that exists in the system as has been described in previous studies.^{2,3,5-7,9} Respondents repeatedly indicated that because of the existence of racism and discrimination, they felt more comfortable donating to family, other African Americans and poor people.

Nevertheless, many respondents wanted to donate to whomever was in need and felt it their duty to increase the number of organs available for transplant. Altruism as described by study participants may be seen as a reflection of the sense of community that many African Americans feel and may be manifested in the desire to take food to shut-ins, drive a friend to the doctor or church, or give clothes to those in need. Several respondents see donation in a similar vein, helping others within their community—even if conditional because of the societal and medical context in which the transplantation system plays out.

Religious Beliefs

The focus of religious beliefs in previous studies has been on religion as a barrier to donation—namely, the concern about mutilation of the body or the belief that the body must be whole in order to get into Heaven. However, in Thompson's study, her respondents denied that religious beliefs had a significant impact on the decision to donate.⁹ Rather, they "knew of no religious prohibitions or scriptures that were relevant in predominantly African-American religions" and further indicated that "rationales for nondonation could be extrapolated from religious teaching if a justification were sought."⁹

The current study illuminates the positive influence that religious or spiritual beliefs may have as a foundation for attitudes toward donation among African Americans. In the focus groups, respondents were asked to describe their personal views on organ and tissue donation and transplantation as well as how their personal beliefs fit with their religious

beliefs. The clergy were asked about their churches' views on organ and tissue donation, what their religions say about organ donation, and what the Bible states. From these statements, their religious and spiritual beliefs emerged. Several participants equated organ donation to the ultimate sacrifice that Christ made for mankind. Thus, organ donation offered a sense of fulfillment of what God would want His people to do.

Many of our respondents believed that one's whole body is not needed for eternal life. They repeatedly expressed the belief that the body serves its purpose on Earth, then afterwards, it is a spiritual body. While the investigators acknowledge that there were discussions of fears of body desecration and a desire for one's body to be whole, this study demonstrates that this commonly held belief that serves to discredit donation within the African-American community is not the only religious belief that shapes donation decision-making. Indeed, it was the respondents' desire to help others that stood out in the data most prominently as a religious view that shaped their views on donation.

Limitations

This study suffers from limitations as does any other. One limitation of the study is the potential that the focus group setting contributed to respondents engaging in socially desirable responding. Views on donation that were not well-developed at the beginning of the focus group may have been swayed, particularly to support donation, by the end of the focus group because of particularly influential family members. Moreover, the researchers explained that the purpose of this phase of the study was to understand respondents' attitudes, beliefs and experiences, but they could no doubt surmise that the overall purpose of the study was to positively impact views on donation. Although the moderators worked hard to create a neutral atmosphere that respected all views on donation, it is unclear to what extent respondents felt pressured to make positive statements about donation and transplantation.

Additionally, this study is limited to a sample of Christian African-American clergy and parishioner families within metropolitan Atlanta. The intent of this study is not to generalize findings to African-American clergy and parishioners in other locales—nor can the findings be generalized to populations holding non-Christian religious beliefs and the nonchurch-attending population. Moreover, by virtue of their willingness to volunteer, it might be that the pastors participating in this study are more open to discussing donation (not necessarily more supportive though) as compared to pastors who did not agree to participate in the study. It might also be that the over-

representation 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.²² 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 clergy and parishioners contingent upon additional research on its effectiveness. Additionally, much of the negative sentiment towards donation expressed by our respondents is similar to what has been found in previous studies, which provides some evidence that selection bias may have been minimal in our sample.^{3,4,6,7-11,12}

Implications for Future Research

Current findings agree with previous study findings that becoming informed about organ donation and having discussions with one's family regarding organ donation and other end-of-life decisions should be a major component of organ donation public education campaigns regardless of the specific community.^{2-7,9-17} But it is shortsighted to develop these messages exclusively from negative belief systems. This study has shown that not *all* attitudes regarding donation within the African-American community are negative. These findings support those of a telephone survey, conducted in 1995, of 12,000 African-American households in Georgia.²³ This study found that 86.6% of the respondents were in favor of donation with 65% "somewhat" or "very likely" to donate at the time of their own deaths and 74% "somewhat" or "very likely" to donate organs of their loved ones upon death.²³ The most frequent reason cited among those respondents in favor of donation was the ability to help others through donation.

Perhaps the previous literature has focused on negative views towards donation because of an underlying assumption that African Americans don't donate. Indeed, this is not the case. At least in the case of living donation, they donate at rates that parallel their representation in the population (around 12%)¹, but this rate does not match the level of need for organs among African Americans. Thus, understanding factors that contribute to support for donation is a different point of reference taken from many studies in the literature that will lead to a better understanding of donation decision-making. Developing and testing of culturally sensitive interventional materials for clergy and parishioners and incorporating the influence of religion and personal experiences on attitudes regarding donation are the next phases of this study. While this phase of the

study did not include a call for action, such as signing a donor card or having discussions regarding donation with one's family, those endpoints would be a measure to test the effectiveness of the newly developed materials.

CONCLUSIONS

The authors acknowledge that within the complexities of discussions around donation and transplantation, dichotomous, conflicting views may emerge. The purpose of this study was to move beyond what we know about negative views to an understanding of why many African Americans are supportive of donation. This somewhat unusual perspective comes at the recommendation of one of the elder clergy on our community advisory board. In an intense discussion of how to shape the intervention message, he stated that "Somehow we must eliminate the negatives and accentuate the positives. Somehow we must eradicate the negatives and get beyond this thinking. People are sick while we're here discussing." We agree with this position and hope to advance current understanding of supportive attitudes toward donation. With this understanding, we can shape the development of effective culturally sensitive intervention messages within the African-American religious community, resulting in more effective, individual, community-based, and mass media outreach and education campaigns.

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