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Understanding the Role of Clergy in African American Organ and Tissue Donation Decision-Making

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Abstract

Objectives—To describe and understand the attitudes, beliefs, and experiences towards organ and tissue donation among African American clergy in Atlanta, Georgia, USA. The secondary objective is to understand what messages clergy are providing to their parishioners relative to organ and tissue donation, and what their perceived role is in donation education.

Design—A qualitative study in which African American clergy ($n = 26$) participated in four focus groups.

Results—African American clergy, though generally supportive of organ and tissue donation in principle, have serious reservations about donation due to perceived inequalities in the donation and transplantation system. The clergy did not personally hold religious concerns about donation, but expressed that these concerns were a major barrier to donation among their parishioners. None of the clergy knew the written position that their religion took on donation; they acknowledged the need for more education for them and their parishioners on this topic. They also felt that as religious leaders, they could play an important role in promoting organ and tissue donation among African American parishioners.

Conclusions—African American clergy and religious leaders may play an important role towards improving willingness to donate among African American parishioners, but more education and advocacy is needed to prepare them for this role.

Keywords

Organ and Tissue Donation; African Americans; Transplantation; Clergy; Kidney

Introduction

Transplantation continues to be the therapy of choice for many individuals with end-stage organ failure. New advances in the field of transplantation have extended and saved lives, improved the quality of life for many, and decreased overall mortality from certain diseases and conditions. However, these medical advances are tempered by the considerable gap in the number of organs needed, and the number of organs received. Around the globe, 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 ethnic minorities (Callender & Hall 2001; Rudge *et al.* 2003). In the US, there are more than 90,000 persons on the national transplant waiting list, and ethnic minorities account for nearly half of those awaiting transplants (UNOS 2006). Similar statistics are seen among ethnic minorities in other countries, such as the UK (Randhawa 2004; UK Transplant 2005). It is thought that if accessing the transplant waiting list were not so difficult for many ethnic minorities (due to financial constraints, poor access, distrust of the medical establishment, and lack of knowledge and awareness of available treatment options), then the number of people on the waiting list would be even greater (Baker 1999; Callender & Miles 2001; Randhawa 2004).

African Americans, in particular, are over-represented on the transplant waiting list because they are disproportionately impacted by certain health conditions that potentially warrant the need for life saving transplants (Durand *et al.* 2002). Such conditions include diabetes, hypertension, heart disease, hepatitis, glaucoma, blood dyscrasias, and other conditions for which transplantation is a viable option. Additionally, the process of blood and tissue typing dictates that opportunities for genetically compatible matches are increased within one's own ethnic group (UNOS 2004), yet donation rates among ethnic minorities are low. For example, in the UK, while 39% of patients of South Asian origin and 22% of Black Caribbean patients are blood type B, only 7% of kidney donors are of the same blood type, which decreases the likelihood of matching among these patients. These very same candidates make up 20% of the waitlist, while donors of the same ethnicity only account for 2.0% (1.2% South Asian; 0.8% Black Caribbean) of the donor pool (UK Transplant 2005). This disparity is also seen in the US. Whereas in 2005, African Americans accounted for 14% of both living and deceased kidney donations compared to Whites (69%), they accounted for 35% of those on the wait list to receive a kidney compared to Whites (40%) (OPTN 2006a). A similar pattern exists among other organs though it is less pronounced. It is clear that while donation rates achieve population parity (i.e. approximately 13% of the US population is African American), they in no way meet the need for organs and tissues among African Americans. Overall, these low donation rates are probably a result of negative attitudes towards donation among ethnic minorities compared to other groups (Bayton *et al.* 1989; McNamara *et al.* 1999; Davis & Randhawa 2004). Taken together, all these factors contribute to ethnic minorities spending up to twice the amount of time on the transplant waiting list compared to people of other groups (Louis *et al.* 1997; Rozon-Solomon & Burrows 1999; Young & Gaston 2002; Randhawa 2004; Danovitch *et al.* 2005). One way to decrease wait time for ethnic minorities is to increase the number of ethnic minority donors.

Religion and Organ Donation

A considerable amount of research has been conducted over the past two decades to understand the disparity in organ and tissue donation among ethnic minorities. Numerous studies have explored the cultural reasons for this difference by focusing on barriers to donation specifically among African Americans (Callender 1982, 1987, 1995; Hall *et al.* 1991; Toledo-Pereya 1992; Thompson 1993; Sanders 1995; Siminoff & Strum 2000; Callender & Miles 2001; Boulware *et al.* 2002a, b; Callender *et al.* 2002a, b; Durand *et al.* 2002; Atkins *et al.* 2003; Gaston *et al.* 2003; Wolfe 2003; Danovitch *et al.* 2005; Davis *et al.* 2005). This research has found five general areas that explain the reluctance to donate among African Americans: (1) lack of knowledge and awareness of the topic; (2) distrust of the medical community; (3) fear of premature death; (4) concerns about racism; and (5) religious beliefs and superstitions. Such factors are hypothesized to influence donation decisions among other ethnic groups as well (Darr & Randhawa 1999; Lam & McCullough 2000; Bhengu & Uys 2004; Davis & Randhawa 2004, 2006). For example, research

suggests that Black Caribbeans in the UK also have the same concerns about equality in organ allocation and end-of-life treatment among those identified as potential donors (Davis & Randhawa 2004). Regarding religious beliefs and superstitions, African Americans, South Asians and Chinese share many of the same sentiments in wanting to ‘remain whole’ when they transition to heaven (Callender 1987; Kometsi & Louw 1999; Darr & Randhawa 1999), and fear that organ donation mutilates the body, inhibiting an open casket funeral (DeLong 1990; Darr & Randhawa 1999; Gillmann 1999; Boulware *et al.* 2002a, b; Durand *et al.* 2002). Regardless of what religious affiliation an individual holds, when religious perspectives on organ donation are unknown, most often an unsupportive stance is taken (Gallagher, 1998; Bhengu 2004). To the contrary, almost all major religions not only support donation, but many have supportive policy statements about it (Gallagher 1998). Overcoming these religious myths and spiritual concerns is integral to efforts to improve donation rates among ethnic minority populations.

Specific to African Americans, a full understanding of how religious beliefs may shape donation decision-making requires an understanding of the historical importance of religion and religious institutions among African Americans. It is argued that the process of capture, enslavement, and forced labor destroyed the social cohesion that previously existed through traditional African systems of kinship and other forms of organized social life, and that the Christian religion soon provided a new basis for social cohesion (Frazier 1969). Most slaves found that Christianity offered a new orientation towards the world, and saw value in adapting this new religion to fit their psychological and social needs (Frazier 1969). Thus, with its foundation in slavery, Black churches (i.e. those churches that are primarily comprised of people of African descent including African Americans, Afro-Caribbeans, and Black Hispanics) and religious leaders have risen to prominence in the African American community; it is argued that Black churches have had more influence on people of African descent than any other single institution (Lincoln & Mamiya 1990; Foster & Smith 2003). Theorists contend that even after slavery, Black churches are unrivaled as centers of power, given their role as (1) a central meeting place, (2) a platform for the exchange of ideas, (3) a place of employment resources, (4) an educational institution, and (5) a gathering place for youth (Foster & Smith 2003). Although the influence of religion has diminished, and there has been an erosion in the central importance of Black churches over the years since slavery, it is clear that religion and religious institutions maintain a prominent role among African Americans. Thus, it is conceivable that religious beliefs might shape attitudes towards organ and tissue donation and other health decisions, particularly among African Americans.

Clergy and Donation Decision-Making

In a similar vein, clergy and other religious leaders have achieved positions of power and leadership among African Americans (Davis *et al.* 2005). They are in a position to provide guidance and support in the everyday lives of their congregants, but particularly during times of tragedy. An important role of clergy has been to support congregants during times of grieving and when making end-of-life decisions. While medical staff are important in the identification and referral of possible organ donors, they are often not the primary sources of emotional support for the family. Rather, members of the faith community, such as hospital chaplains and church pastors, serve as the primary sources of emotional support for families in times of crisis, grief, and stress. They are frequently able to provide compassion, support, and sensitivity in otherwise difficult situations. Gillman (1999) argues that refusal to donate often occurs in times when either the emotional or spiritual concerns of the family are downplayed or ignored. Additionally, many parishioners are misinformed or even unaware of the position their faith takes on organ donation; few parishioners are aware that most faith organizations consider organ donation a beneficial treatment option for end-stage organ failure (Gillman 1999; O’Connell 2001). Therefore, in addition to emotional support, it

would be helpful to have clergy provide clarification on religious beliefs during times in which parishioners are faced with donation decisions (Gillman 1999). Indeed, research suggests that clergy may be useful in helping parishioners work through religious issues, promoting family discussion around organ donation, and providing reassurance of what their faith believes about organ donation (DeLong 1990; Gallagher 1997; Gillman 1999). It is for this reason, many argue for the importance of pastoral caregivers towards influencing the shortage of organ donors (Gallagher 1997).

Purpose of Study

However, little is known about what African American clergy think and know about organ and tissue donation. Even less is known about the messages they convey to their parishioners about organ and tissue donation. With the exception of Davis *et al.* (2005), there has been little exploration of feelings towards donation among African American clergy. The current study utilizes qualitative research methods to obtain a rich description of the attitudes, beliefs, and experiences of African American clergy relative to organ and tissue donation. Specifically, this study addresses (1) attitudes and beliefs surrounding donation decision-making; (2) messages that African American clergy deliver to their parishioners about donation decision-making; and (3) how African American clergy perceive the role of the church and pastor in donation decision-making. It is intended that these results will be able to assist public health professionals in developing culturally appropriate programs, health messages, and other communication efforts that aim to educate and increase organ donation rates among African Americans.

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 individuals' views. As the study desires to tailor the intervention to address religious concerns with donation, churches that held similar belief systems were recruited into this study. Thus, efforts were focused on the religious denominations within the Christian faith, understanding that an intervention 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.

Upon approval of the study by the Emory University Institutional Review Board, recruitment efforts ensued. To recruit churches into the study, a list of 112 Christian-based churches with African American pastors in the greater Atlanta area was generated, and conversations were held with colleagues in the field to identify pastors who may be interested in the project. By networking with clergy (via telephone and face-to-face meetings), pastors from eight churches were recruited to join the study's Community Advisory Board. Additionally, each pastor was asked to participate in a focus group of ordained ministers who held positions of leadership in their respective churches. Unfortunately, due to logistical constraints, one of the eight churches was unable to participate in the focus group phase of the study.

The focus group methodology was used to create an exchange of ideas among clergy that may not otherwise emerge in individual interviews or surveys. By conducting focus groups, characteristics most salient to clergy, emotional value associated with those characteristics, and how clergy differ on key issues, can be identified. A total of 26 African American clergy residing in the greater Atlanta area participated in focus group sessions. There were seven participating churches: three African Methodist Episcopal, two Baptist, one United

Methodist and one Non-denominational. Churches ranged in size from 100 to 5,000 congregants. The median household income for the counties in which the churches reside ranged from approximately \$18,000 to \$52,000 (see Table 1).

Data Collection

Four clergy focus groups were convened during February and March 2003. Clergy participants were limited to those ordained ministers of the seven churches. Focus group discussions were convened in a conference room on Emory University's campus. Duration of the discussions was two hours, and half-way through, respondents were offered a short break with light refreshments. All discussions were facilitated by an African American professional with training and experience in conducting focus groups. A second African American facilitator was present to take field notes on key issues that arose during the discussion. Facilitators followed an interview guide that included a standard introduction and opening question, discussion topics, and probes. Discussions included events in the media relevant to organ and tissue donation and transplantation, knowledge of organ and tissue donation, personal views and experiences with organ and tissue donation, and religious beliefs surrounding donation and transplantation (see Table 2). Each focus group discussion was audio-recorded and transcribed verbatim.

After each focus group, participants completed a brief questionnaire that measured attitudes, beliefs, experiences, and knowledge about donation and transplantation (data not presented), as well as demographic characteristics. Due to the qualitative focus of this phase of the study, it was decided that questionnaires would be completed after the focus group in order to maintain the integrity of the qualitative data, thereby minimizing the possibility that items on the questionnaire would shape how respondents discuss the topic. Participants were offered a \$100 monetary incentive for their participation in the study.

Data Analysis

Data were analyzed according to qualitative research procedures as outlined by Patton (2002). Each focus group transcript was read carefully for the purpose of creating a coding structure that would provide a meaningful framework to capture participants' attitudes, beliefs, and experiences. Once a structure was agreed upon among the three members of the analysis team, the data were coded and the codes were entered into *The Ethnograph* (Qualis Research Associates 1998), a qualitative data management software tool. The analysis team then 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 relevant to each research question. Once the analysis team identified the salient themes, a fourth individual reread the coded text for the purpose of validating and modifying the salient themes identified by the analysis team. These themes are presented in the following section.

Results

Among the 26 individuals who participated in the focus groups, approximately half were female ($n = 14$). Almost all participants self-identified as being Black/African American ($n = 25$); however one person identified as being Black/Hispanic. Participants ranged in age from 25 to 74 years (mean = 45–54, SD = 0.99). In terms of formal education, six had completed college, and an additional six had completed a graduate degree. When asked, 'Are you personally interested in being an organ donor?' 17 respondents answered favorably. Ten participants answered 'yes' to being recognized as a donor on their driver's license, and four respondents indicated that they carry a donor card.

Concerns about System Inequalities

Clergy were generally supportive of the idea of organ and tissue donation; however, their willingness to identify themselves as potential donors was influenced by their concerns about inequalities in the donation and transplantation system. Clergy repeatedly expressed concerns that ethnicity and class-based inequalities prohibit everyone from having equal access to organs. They felt that those who are disenfranchised, such as African Americans and the poor, do not have a fair and equitable opportunity to participate in the transplantation system due to ethnicity and class-based discrimination. Furthermore, they expressed the concern that even when African Americans donate their organs, these donated organs go to people of other ethnicities. One participant stated:

I still think it's a racial thing too because most Black people feel that they're never going to get an organ anyway because the organs are going to go to those people with money, or those people who know someone, or White people, and many of them just feel that you know, they would be providing for other groups rather than people in the community.

Participants expressed that system inequalities were a serious concern. For some, this concern was so great that they would only agree to donate if they could specify the ethnicity of the potential recipient (i.e. direct donation). However, there were no discussions of how this same process could further disadvantage African Americans if people of other ethnicities were given this same liberty.

While some participants acknowledged the system inequalities, they still felt the need to donate—either because of a responsibility to the African American community or a responsibility to God. During one focus group, the question was raised, ‘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?’ Some participants felt that if the organ shortage were eliminated by increasing the number of African American donors, then the system inequalities would be minimized. Others felt there was a Christian responsibility to donate that was more important than any concerns about system inequalities. Instead of focusing attention on the inequalities, these participants were more concerned about the greater good that could result from being a donor. One participant, borrowing words from a well-known gospel composition, stated:

If I could do anything to help somebody then I figure that my living is not really in vain. Even after I’m gone, it’s not going to profit me anything. I can’t take nothing with me cause it’s a spiritual transformation. Everything I got God gave it to me and if I can help somebody else, even after I’m gone I’m still helping someone else to live a more fruitful life.

Religious Myths Relative to Organ Donation

The clergy agreed that religious myths were a major barrier to organ and tissue donation in the African American community. Participants expressed that they heard of people wanting to return to heaven as they were created, out of concern that the physical body would be needed. They explained that many people believe, ‘as God created us, that’s how we should remain’. While the vast majority of the clergy themselves denounced this view, they felt that people continue to perpetuate this myth in the name of God without a full understanding of scripture. The clergy participants generally viewed death as a spiritual transformation; therefore, donating an organ would not interfere with the after life.

They don’t understand or don’t believe that this [organ donation] is something God will want them to do. God gave them this body and somehow they, or we, believe that we’re going to need it all the way into heaven, take everything with us.

The clergy felt there are aspects of the Bible that are commonly misunderstood relative to this issue of resurrection. For example, in reading the Apostle's Creed, the clergy talk of 'resurrection of the body'. If not properly explained, parishioners may believe that this passage refers to resurrection of the physical body, when the true intent of the passage is to refer to resurrection of the body of Christ.

Clergy expressed that in addition to Biblical misunderstanding, religious myths are continually perpetuated in that some people fail to see how these myths run counter to other religious and spiritual teachings. The clergy argued that 'people will hear what they want to hear'. For example, the clergy believed most of their parishioners *do* understand that people's physical bodies 'go back to dust'; also, parishioners understand on some level that their physical bodies will not go to heaven. As one participant stated, 'They're [the physical bodies] not going to be there [in heaven] because these bodies are going back to the dirt. Earth to earth, ashes to ashes, dust to dust'. This pastor shared that people hear these words at funerals all the time and generally agree with this contention. At the same time, many African Americans believe their physical bodies will be needed in heaven without critically analyzing how these two beliefs are inconsistent with each other.

It must be noted that none of the clergy were aware of the formal positions that their respective denominations have on the issue of organ and tissue donation, although each of the denominations represented in this study were supportive of organ and tissue donation. Participants felt that although the Bible did not directly address the issue, it certainly did not oppose the idea of donation. Indeed, several participants argued that biblical teachings to help others are in and of themselves supportive of organ and tissue donation.

Um, I don't know that I know of any place in the Bible that is contrary to this. I can't speak of any particular scripture that speaks for it specifically, but I think the idea is that we help each other.

General Lack of Knowledge about Organ and Tissue Donation

The clergy acknowledged that the African American religious leadership has done a poor job of educating its parishioners about the need for organ and tissue donation. They felt that parishioners' reluctance to donate was a function of their lack of knowledge of how the process of organ and tissue donation and transplantation works; thus, the clergy believed any effort to improve donation rates among African Americans would have to start with education. It was thought that education on this topic could help people move past the historical distrust that they have in the medical establishment. Participants cited the Tuskegee experiment as having laid a foundation for this distrust, although certainly medical experimentation on people of African descent had existed long before then (Gamble 1997).

Aside from parishioner lack of knowledge, the clergy felt that they, themselves, had not been educated on the topic of organ and tissue donation. While they understood the religious and spiritual aspects of death, they did not understand how the donation and transplantation system operated. This lack of understanding of the process fueled fear and perpetuated feelings of distrust of the medical establishment. For example, clergy expressed a fear of dying prematurely, if agreeing to serve as an organ donor. Several clergy were adamant about not being 'rushed off the scene' once health care professionals learned that they were potential donors. One participant reconciled this dilemma by agreeing to share his wishes to be an organ donor with his wife and mother, but would not indicate his decision on his license for fear that paramedics will hasten his death in the event of an automobile accident. This fear is perpetuated by a lack of understanding of the donation process, and the two different medical teams who care for patients and those that recover organs.

With all of the lack of education (among both parishioners and clergy), focus group participants consistently agreed that the church could do a better job of teaching the spiritual aspects of death and the resurrection in order to dispel some of the religious myths that keep parishioners from wanting to serve as donors.

The Role of the Church and the Clergy

Participants generally agreed that it was the responsibility of the church leadership to educate parishioners to make informed decisions about organ and tissue donation. However, clergy acknowledged that churches have less influence over the African American community than it had in the past. Clergy talked about the secularization of the African American community, such that the church is no longer a central resource for information, nor is the pastor highly influential in the personal decisions that parishioners make. They concede that the decision of whether to be a donor is a personal one, and they respected their parishioners' autonomy to make this decision. Nevertheless, the clergy agreed that parishioners do maintain some level of trust in their pastors and respect for their views. Thus, the church could play an important role in educating parishioners on this issue, and the clergy, in particular, are an important vehicle for delivering this information.

One participant stated:

I think it's the church's role to try to start to dispel those myths because people keep them going in the name of the word of God. They say, "no, the Bible says "So what does the Bible really say? And that could be something that the church could help with.

Why clergy have not spent more time discussing donation is complex and goes beyond their own lack of education. Participants repeatedly argued that organ and tissue donation is only one component of a wellness message that needed to be taught to their congregants. The clergy argued that they, themselves, needed to model how to live a healthy lifestyle in addition to educating their parishioners about how to do so. The clergy did not feel they currently did a good job of preaching wellness.

So I think we need to educate people on all of those aspects of being holistic and taking care of your body so that you don't get in that process [of needing an organ]. I'm going to tell people "O.K., if you stop eating all that fried chicken, chitterlings, pork chops, you know, then a lot of these things won't happen to you".

However, the clergy expressed it is difficult to deliver health-related messages because of the pastor's own competing priorities (e.g. they face a constant pressure to meet the church's fiscal responsibilities), and fear that the parishioners may not want the church 'prying' into their health behaviors (e.g. eating habits, cigarette use, and alcohol consumption). The clergy feel that the desire for privacy and extremely busy schedules contribute to poor attendance at health fairs and other events that seek to raise awareness of health-related issues. Thus, the clergy felt conflicted: they felt it their responsibility to move beyond religious and spiritual education to health education, but they had questions about how to do so effectively. The clergy did not, however, feel that they held sole responsibility for educating their parishioners on health-related topics. They felt that it was a joint responsibility shared by the church, the government, health care industry, and, in the case of organ donation, the transplant community, to deliver this education. Participants conveyed the point that as religious leaders, they were willing to play their part.

Discussion

Using qualitative research methods, this study found that African American clergy, though generally supportive of organ and tissue donation in principle, have serious reservations

about being willing to serve as donors due to perceived inequalities in the donation and transplantation system. It also found that religious concerns continue to be a major barrier to donation among parishioners, though this is less of an issue among clergy. Despite that clergy perceive themselves as holding a potentially important role in educating parishioners on the topic of organ and tissue donation, they generally lack knowledge and awareness on this issue.

System Inequalities

Research generally finds that concern about system inequalities is a key factor that impacts donation decisions among African Americans (Louis *et al.* 1997; Siminoff *et al.* 1999; Callender *et al.* 2002; Durand *et al.* 2002; Siminoff *et al.* 2003; Terrell *et al.* 2004; Arriola *et al.* 2005) and ethnic minorities in other countries, such as the UK (Randhawa 2004). However, the current study findings are of particular concern because the individuals under study are the religious leaders in the African American community. These leaders are the individuals to which many African Americans turn to for guidance and support when making difficult life decisions, including those related to organ and tissue donation. In all likelihood, in the absence of knowledge of what position their denomination takes on the issue of organ and tissue donation, clergy may resort to their own values and belief systems, in conjunction with Biblical teachings to advise parishioners on how to proceed. Data from the current study suggest that among those clergy participating in this study, this advice is not likely to take on a message with strong support for donation. Instead, participants in the current study may be likely to help their parishioners arrive at their own decision through a careful weighing of the advantages of donation alongside the parishioners' concerns about system inequalities.

Addressing both clergy and parishioner concerns about inequalities in the US transplant system is difficult in part, because of the paradoxical nature of the situation: data clearly show that ethnic minorities are not transplanted at rates equal to that of Whites (OPTN 2005b), yet ethnic minorities must still be encouraged to donate in order to increase the donor pool, and ultimately improve access to organs among all patients. Public health interventions that seek to address this paradox might: (a) highlight the overrepresentation of ethnic minorities awaiting transplant, (b) demonstrate that inequalities in the transplant system reflect inequalities in the larger health care system, and (c) discuss policy-level interventions that are being carried out to improve equal access to care in the transplant system and in the health care system more generally. An educational campaign that addresses these points might be effective at addressing people's concerns about inequalities while not discounting the legitimacy of these concerns.

The Role of Religion

The finding that religious views are a major barrier to donation among parishioners (as reported by clergy) underscores the importance of collaborating with religious leaders to influence parishioner views on donation. Clergy in our study tend not to personally hold these beliefs, which is consistent with quantitative studies of religious leadership (Gallagher 1996; Davis *et al.* 2005). However, studies conducted in the US (Callendar *et al.* 2002a, b) and internationally (Darr & Randhawa 1999; Lam & McCullough 2000; Bhengu & Uys 2004) continue to find that religious beliefs are a major barrier to donation, particular among ethnic minorities. Many of the concerns expressed by African American Christians revolve around the belief that in order to be resurrected after the Second Coming of Christ, the body must be intact (Callender *et al.* 1987, 2002a, b; Youngner 1992; Sanders 1995). Ethnic minorities residing in the UK have expressed concern that organ donation can interfere in situations in which it is God's will for death (Davis & Randhawa 2006), and that they are unsure of the stance their religion takes on organ and tissue donation (Darr & Randhawa

1999). These findings suggest that teaching clergy and other religious leaders about what stance their religious organization takes and how to talk to parishioners about organ and tissue donation may be a useful point of intervention. Clergy have the potential to influence their parishioners through sermons, pastoral counseling, and Bible study classes. Because of this influence, they are also able to educate their parishioners by clarifying religious misconceptions, fears of mutilation, and issues of mistrust with the medical system (Atkins *et al.* 2003; Rumsey *et al.* 2003; Davis *et al.* 2005).

However, involving clergy in such teachings first requires delivering education to them related to organ and tissue donation. There is a need to create educational materials that provide general information about the donation and transplantation system, and provide specific examples of how to incorporate Biblical teachings into messages that support donation. One example of how this might be carried out is a *Clergy Resource Manual* that was compiled by the LifeGift Organ Donation Center of Houston (2002). This manual was created specifically for African American clergy of all faiths, religions, persuasions and denominations. The resource guide provides a Biblical perspective helping clergy champion the cause of saving lives and improving health through organ and tissue donation. Clergy are made aware of the successes of transplantation, the increasing need for organs and tissues, and the growing loss of life due to families' refusal to consent donation. This manual includes bulletin inserts, biblical references, sermon ideas and sample sermons that can be readily incorporated into existing teachings. Although this particular manual has not been systematically evaluated to the knowledge of the study authors, there is great potential for this type of educational resource to better equip clergy with the instrumental tools to have a positive influence on parishioner views towards donation.

Limitations

This study, similar to any other study, has limitations. 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 and vocal discussion participants. 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 within metropolitan Atlanta. The intent of this study is not to generalize findings to African American clergy in other locales. Nor can the findings be generalized to leaders of non-Christian religious organizations. Moreover, by virtue of their willingness to volunteer, it might be that the pastors participating in this study are more open to discussing donation, though not necessarily more supportive, compared to pastors who did not agree to participate in the study. 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.

Conclusions

African American clergy and religious leaders may play an important role towards improving willingness to donate among African American parishioners, but more education and advocacy is needed to prepare them for this role. This education must start with an understanding of the position taken on this issue by each relevant religious organization. It must also include an understanding of how the donation and transplantation system works. Surely, addressing concerns about system inequalities is difficult. Nevertheless, messages delivered to clergy must emphasize the need to support efforts to increase the donor pool despite the existence of inequalities in the US transplant system and the larger health care system as a whole. It is expected that targeted messages to clergy and religious leaders, taken together with community-wide education and awareness, and political advocacy may make an important contribution towards improving the health of patients with end-stage organ failure.

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Table 1

Demographic characteristics of participating churches

Church	Denomination	Aproximate church membership size	Median income ^a
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	1000	\$36,769
6	Non-denominational	5000	\$43,780
7	Baptist	500	\$51,915

^aIn 1999 for the zip code in which the church resides.

Table 2

Discussion guide for clergy focus groups

Clergy discussion guide	
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 <i>you</i> 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 that, 'African American's don't donate'?
7	Church view of organ donation Tell me about your church's views on organ and tissue donation and transplantation.
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?