A Mosque-Based Qualitative Study on American Muslim Women’s Organ Donation Beliefs

Rosie Duivenbode, MD, MSc1, Stephen Hall, MPH1,2, and Aasim I. Padela, MD, MSc1,2

Abstract

Introduction: Detailed studies on the associations between religious beliefs and organ donation attitudes among religious minorities remain wanting. Although Muslims appear to have low rates of support for donation, how these behaviors relate to religious frameworks requires further investigation. Methods: We sought to explore the relationship between religious beliefs (Islam) and organ donation attitudes through focus groups with 43 Muslim women from 5 Chicago-area mosques. Purposive selection of mosques generated near-equal representation of Arabs, South Asians, and African Americans, as well as diversity in education and income. Using the theory of planned behavior as our conceptual framework, we expanded the traditional normative domain to include religiously informed beliefs. Findings: We found that the relationship between religious beliefs and Muslim attitudes toward organ donation is more complex than commonly perceived. Regarding the Islamic ethicolegal permissibility of organ donation, participants expressed a range of normative beliefs. Furthermore, participants voiced concerns beyond religious permissibility, including anxieties over modesty violations during the donation process, as well as concerns about purported black market organ trade and medical risks to donors. Discussion: Given that participants raised religious, societal, and biomedical concerns regarding organ donation, our findings suggest that effective educational programs should involve nuanced curricula that teach to the plurality of Islamic ethicolegal opinions and discuss transplantation processes within the United States.

Keywords

religion, Islam, tissue and organ procurement, community health, theory of planned behavior

Introduction

American Muslims are a diverse and growing population, numbering approximately 3.5 million and growing.1 They include African Americans, Arab Americans, and South Asian Americans. National data demonstrate that these communities have high rates of diabetes and hypertension that increase risk of kidney failure and thus convey greater needs for kidney transplantation.2-5 The disparity between supply and demand for organs is well known. The situation for ethnic and racial minorities is even more dire, as not only do biological factors make finding appropriate matches more difficult, organ donors rarely come from such backgrounds.6 As a result, one may hypothesize that, among the American Muslim community, organ donation is a pressing concern.

The decision to become a donor is, among other factors, influenced by religious beliefs.7 Although national databases do not record religious affiliation alongside organ donation statistics, empirical research demonstrates that organ donation raises theological and ethical concerns.8,9 Among Muslims globally, research notes controversy over organ donation. For example, while over 95% of the general American population supports organ donation, the support in some Muslim majority countries is as low as 57% (Turkey).10,11

Among diasporic Muslim communities, similar qualms exist. For example, one study of Muslim UK, US, and Canada residents reported that only 39% believed organ donation to be compatible with their religion.12 In addition, they found that those with higher levels of religiosity were less likely to hold positive views, suggesting that religious practice and values contribute to low donation rates. In the United States, a representative population-based study of Arabs in Michigan found that only 35% of respondents held deceased organ

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donation to always be ethically justified and that Muslim Arabs were approximately 1.5 times less likely to support organ donation when compared with their Christian counterparts. A mosque-based survey of 93 Arab, South Asian, and African American Muslims confirmed low rates of support for donation as only 39% agreed that deceased organ donation was ethically justified. These data signify that American Muslims, similar to their counterparts globally, may be hesitant to donate their organs.

The available literature thus documents comparatively low levels of support for organ donation among Muslims worldwide. Yet, at the same time, how religion implicates these rates is somewhat unclear. For example, a study in Malaysia found that being Muslim was associated with a reluctance to donate, yet only 8.4% indicated this reluctance stemmed from religious beliefs. These ambiguous quantitative data are supported by qualitative work from Pakistan, which found that both negative and positive attitudes toward organ donation were framed within religious paradigms by the local Muslim population. Detailed studies on the associations between religiosity and organ donation attitudes among Muslim minorities remain wanting.

To explore the relationship between religion and Muslim attitudes toward organ donation in greater depth, this study examined organ donation beliefs among American Muslim women through focus groups. We chose to focus on women because previous research, in both minority and majority populations, has demonstrated that their attitudes toward organ transplantation might differ from men. For example, women play central roles in seeking and communicating information regarding organ donation within family networks, are more likely to have favorable attitudes toward organ donation, and are more likely to donate their organs. More specifically, anthropological research in Egypt has shown that Muslim women place their responsibility toward family members at the center of their deliberations on organ transplantation. Thus, Muslim women potentially represent an important stakeholder group for community-based educational interventions.

**Methods**

**Theoretical Framework**

The theory of planned behavior (TPB) provided a conceptual framework for examining organ donation beliefs, generating interview questions, and performing qualitative content analyses. The TPB asserts that the most proximate and strongest predictor of behavior is intention. Behavioral intention, in turn, is informed by (1) outcome expectations and associated overall attitude toward the behavior, (2) the perceived normative expectations of others regarding the behavior and the associated motivation to comply, and (3) the individual’s perceived control over performing the action. Given the potential significance of religion to Muslim attitudes, the normative domain was expanded to include religiously informed ideas addressing the questions “How do I believe God views my donating my organs?” and “How important is it to me that I act according to God’s approval or disapproval of my donating my organs?”

**Study Setting and Design**

Set in greater Chicago, home to over 400,000 Muslims, the study utilized a community-engaged approach and was approved by the institutional review board of University of Chicago. The data reported in this article were collected as part of a larger study on American Muslim women’s religious beliefs, attitudes, and behaviors regarding breast cancer screening using a phenomenological approach.

**Participant Recruitment and Data Collection**

With the help of a multisectoral community advisory board, we identified mosques and established partnerships for data collection. We recruited self-identified Muslim, English-speaking women older than 40 years from 5 mosques between August 2013 and January 2014. Sites were purposively selected to achieve geographical diversity and near-equal representation of Arabs, South Asians, and African Americans. Recruitment primarily took place in person via recruitment tables during mosque events. Subsequent focus groups were held at these mosques and approximately 30 minutes of discussion time was devoted to the topic of organ donation. All focus groups were conducted in English and moderated by a trained Muslim female research assistant. Focus group questions were formulated by drawing upon existing literature on Muslim attitudes toward organ donation and TPB constructs (see Table 1).

**Table 1. Focus Group Interview Guide.**

<table>
<thead>
<tr>
<th>Theme</th>
<th>Example Questions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Introduction</td>
<td>Tell me what you know about organ donation.</td>
</tr>
<tr>
<td>Normative</td>
<td>In your understanding of Islam, is it permissible? How did you come to this view?</td>
</tr>
<tr>
<td>Control</td>
<td>If you needed an organ, does it matter who it comes from?</td>
</tr>
</tbody>
</table>

**Focus Group Interview Guide.**

Probe: Family member, person of the same religion, person of the same ethnicity

Follow-up: Of these, whose opinion is most important?
Participant sociodemographic characteristics and religiosity were obtained prior to the focus groups.

Data Analysis

Focus groups were audio-recorded and transcribed. Using the framework method and a deductive approach, we drafted an initial codebook using TPB and interview questions. After an initial reading of the data by 2 analysts, the codebook was jointly reviewed by 3 other researchers familiar with the data in order to assess the accuracy of code definitions. Thereafter, each focus group was independently coded by 2 researchers and emergent themes were added as branch nodes of the TPB-based domains within the codebook. After coding was complete, the 2 analysts, along with the principal investigator, reviewed interview summaries by code for validity, resolved disagreements in coding via consensus building, and grouped codes into higher order conceptual themes. NVivo 10 software facilitated data analysis.

First, to categorize the significance of beliefs, we termed a belief as salient when it was discussed during 3 or more focus groups. Furthermore, we categorized a belief as dominant when it was discussed by half or more participants in a focus group. Second, although several themes reflect religiously informed ideas, these themes were not restricted to normative beliefs within the TPB framework. Rather, some notions mapped onto behavioral beliefs. Since our aim was to explore religious beliefs in depth, and by doing so better inform educational interventions, we decided to overlay TPB domains with impact domains. In other words, did the belief relate to the donor (ie, donor-level impact), relate to the person who received the donated organ (ie, recipient), or to larger societal effects? Alternatively, did the belief extend to the afterlife?

Results

We recruited 59 participants, of which 43 participated in 5 focus groups (Table 2). There were 16 South Asian, 14 Arab, and 9 African American participants. The majority (32 participants) were Sunni Muslims.

In total, 25 themes were identified across 5 focus groups; 13 themes were classified as salient and 4 as dominant (Table 3). In what follows we report on beliefs using the impact framing noted above for it foregrounds concerns that must be addressed within the context of religiously tailored educational interventions.

Society and Recipient

Beliefs about the society and recipient fell within the behavioral and control domains of TPB (Table 3). Several participants expressed positivity toward the act of donating an organ, which was viewed as a contribution to society by either saving a life or by helping other people (5 focus groups, 18 participants). This is illustrated by the statement that you “do it and save somebody’s life, that’s the objective.” This belief was generally held regardless of who would be receiving the organ (4 focus groups, 9 participants). One African American participant reaffirmed this by saying, “I would prefer [to donate to] anybody that needs it.” Despite this general positivity, some participants expressed concerns about potential ethical and legal violations associated with organ transplantation, such as organ sale and theft (3 focus groups; 11 participants), and over the medical uncertainties and risks of organ donation and transplantation (1 focus group, 4 participants).

Donor

Beliefs about the donor crossed all 3 TPB domains (Table 3). Within the donor impact domain, distinctions were made between blood/tissue donation and solid organ donation. The donation of tissue was generally viewed as easy to perform (3 focus groups, 7 participants) and harmless, or even beneficial to the donor’s health (4 focus groups, 7 participants). Conversely, when discussing solid organ donation, participants expressed concerns about the potential health risks to the donor (3 focus groups, 4 participants) and worried about the possibility of the

<table>
<thead>
<tr>
<th>Table 2. Participant Characteristics.</th>
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<tbody>
<tr>
<td>Characteristic</td>
</tr>
<tr>
<td>I. Participants (N = 43)</td>
</tr>
<tr>
<td>Islamic Foundation (IF)</td>
</tr>
<tr>
<td>Orland Park Prayer Center (OPPC)</td>
</tr>
<tr>
<td>Mosque Foundation (MF)</td>
</tr>
<tr>
<td>Muslim Education Center (MEC)</td>
</tr>
<tr>
<td>Nigerian Islamic Association (NIA)</td>
</tr>
<tr>
<td>II. Sociodemographic information</td>
</tr>
<tr>
<td>Racial/ethnic background (N = 39)</td>
</tr>
<tr>
<td>African American/black</td>
</tr>
<tr>
<td>South Asian</td>
</tr>
<tr>
<td>Arab/Arab American</td>
</tr>
<tr>
<td>Age, mean (range; N = 43)</td>
</tr>
<tr>
<td>Highest level of education (N = 40)</td>
</tr>
<tr>
<td>High school/GED (or lower)</td>
</tr>
<tr>
<td>Associates</td>
</tr>
<tr>
<td>Bachelors</td>
</tr>
<tr>
<td>Advanced degree (master’s or higher)</td>
</tr>
<tr>
<td>Immigrant status (N = 43)</td>
</tr>
<tr>
<td>Immigrated as an adult</td>
</tr>
<tr>
<td>Born in the United States</td>
</tr>
<tr>
<td>Immigrated as a child</td>
</tr>
<tr>
<td>Annual household income (N = 35)</td>
</tr>
<tr>
<td>Less than $50 000</td>
</tr>
<tr>
<td>$50 001-$100 000</td>
</tr>
<tr>
<td>Over $100 001</td>
</tr>
<tr>
<td>III. Religiosity</td>
</tr>
<tr>
<td>Islamic affiliation (N = 32)</td>
</tr>
<tr>
<td>Sunni</td>
</tr>
<tr>
<td>Rating of religiosity on 1-10 scale (N = 39)</td>
</tr>
<tr>
<td>Mean (range)</td>
</tr>
<tr>
<td>Wear Hijab (N = 41)</td>
</tr>
</tbody>
</table>

Abbreviation: GED, General Educational Development.
donor’s body being treated disrespectfully (2 focus groups, 8 participants).

**Afterlife**

Beliefs that specifically impact the afterlife were grouped into Islamic ethicolegal considerations, modesty requirements, and the donor’s culpability for the deeds of the recipient.

**Ethicolegal considerations:** “Is it still controversial that we cannot donate our organs?” The religious ethicolegal considerations of organ donation (ie, Is it permissible under Islamic law to donate organs?) were exclusively expressed as normative beliefs. We identified 4 principal beliefs: (1) I am uncertain whether organ donation is religiously permissible, (2) living organ donation is religiously permissible, (3) deceased organ donation is religiously impermissible, and (4) there is a plurality of views on the religious permissibility of organ donation.

The participants who held the first belief expressed they did not know exactly what the normative religious position on organ donation was (3 focus groups, 7 participants). Illustratively, one South Asian participant said, “I don’t know, according to Islam—or is it still controversial that we cannot donate organs?”

Among those who perceived to know the religious rulings, living organ donation was generally thought of as religiously permissible (3 focus groups, 7 participants), while deceased organ donation as religiously impermissible (4 focus groups, 9 participants). A South Asian participant explained issues surrounding deceased donation, as distinct from living donation, in the following way:

But the thing is, they say when you die, don’t even put the fly on the body because, the body is hurt. You don’t even put the hot water on when they bath or wash it, so that’s why they say you have to be very respectful even when a person has died. You don’t give them pain or anything so [it’s impermissible] if they cut the body and take it’s. [organs]

Lastly, some women shared that they were aware of multiple opinions on the matter (3 focus groups, 6 participants).
For example, one woman said, “I’m saying different scholars said different opinions.” Interestingly, this understanding of legal plurality resulted in 2 different, almost opposing, attitudes. From this plurality, one woman concluded organ donation warrants a case-by-case assessment:

I really think in Islam, not all—even fatwas (religious juridical opinions) and a lot of things are not given on blanket [statements]. You can’t give a general fatwa on a lot of things because a lot of these types of cases, organ issues, I mean I think a lot of it is case by case and when there is a case and you go to the scholar or you go to the Imam (religious leader). . . .

Conversely, a different woman insisted that the scholars need to make a uniform conclusion on the matter. She said, “Imams, they’re the ones that are supposed to be more educated, so they probably should research these new topics, ( . . . ) somebody should be dealing with this and letting the community [know]—so we are not so ( . . . ) lost when the topic comes.”

In addition to these 4 beliefs about the ethicolegal permissibility of organ donation, the entire group demonstrated a high motivation to comply with religious guidelines. They expressed this motivation by stating that it is important to know the religious rulings (4 focus groups, 8 participants) and that this knowledge would result in their compliance (3 focus groups, 7 participants). For example, one Arab woman said, “I know this is something ( . . . ) if Allah will reward me for it, I will do it without thinking.”

Modesty requirements: “We are talking about our ‘awrah being exposed”. As mentioned above, some women expressed the behavioral belief that their body might be treated disrespectfully (2 focus groups, 8 participants). Some worried that body parts would be “played with” or mutilated. Yet, others focused on religious modesty guidelines. An Arab woman summarized this latter concern as follows: “We are talking about our ‘awrah (part of the body one is religiously required to cover) being exposed knowing that when after we have our coffin (muharam, male blood relations).”

Responsibility for deeds of the recipient: “On the Day of Judgment, all our organs speak”. An emergent theme that, given the elaborate discussion of it in one of the focus groups, is important to note is the worry among participants about their moral liability for deeds that the organ recipient may perform with the donated organ. They referenced the Quranic idea (24:24, 41:20, and 36:65) that one’s organs will testify for (or against) you on the Day of Judgment. A participant clarified, “The eyes—you know, you avoid certain things here. You’re not allowed to see this. Maybe it’s a non-Muslim or anybody else; he [the recipient] sees what you [the donor] shouldn’t see.” And another added: “I agree with her that on the Day of Judgment, all our organs speak to—Will tell what’s right and the bad deeds you did.” Yet, this idea was not shared by all in the group: 3 participants agreed with the premise, while 3 participants disagreed. One woman argued, “Allah knows that for 50 years what’s yours. For 20 [years], it [the donated organ] was somebody else. Allah knows everything.”

Discussion

This study demonstrates that the relationship between religious beliefs and Muslim attitudes toward organ donation is nuanced. First, we found that religious normative beliefs are not uniform or univocal. Some participants believed living organ donation to be generally permissible, but deceased donation to be religiously impermissible. Others were uncertain about whether organ donation is religiously permissible, and yet another group held there to be a plurality of views advanced by Islamic scholars. Second, we identified that Muslim women have additional concerns, apart from the ethicolegal permissibility of organ donation. These include religion-related anxieties about the potential violation of modesty requirements, as well as larger sociopolitical and medical concerns, such as donation contributing to black market organ trade and the personal health risks donation conveys. Lastly, despite their concerns, participants generally affirmed the societal benefit that organ donation provides. In what follows we highlight the religion-related findings and educational implications of our data.

The normative beliefs voiced by participants reflect the range of Islamic juridical opinions on organ donation. These scholarly debates can be grouped into 3 broad positions.25 The first ethicolegal position is that organ donation/transplantation is categorically impermissible, because it violates the sanctity and dignity of the body (hurma and karâma). The second, and arguably more prevalent, opinion states that although organ donation is impermissible in principle, it is conditionally permitted on the basis of dire necessity (darûra) because of the life threat and harms posed by organ failure. Lastly, there is a group of scholars who permit, and sometimes encourage, organ donation based on the public benefit (masâla) it offers. Although only a small subgroup of participants was aware of these 3 distinct camps, the diversity of normative positions voiced by participants map onto these 3 broad positions. This finding points toward the key role juridical perspectives have on the community’s views on organ donation and signals the need for comprehensive educational resources to help guide community members work through the plurality of the Islamic bioethical stances.

Alongside normative religious beliefs, multiple behavioral and control beliefs inform the intention to donate in the community. Two specifically religion-related behavioral beliefs we discovered were the perceived risk of violating religious modesty requirements during the live and deceased organ donation process, and the concern of being morally culpable for the organ recipient’s deeds on the Day of Judgment. Another qualitative study among Muslims in West London (United Kingdom) reported a similar concern over “organs acting as witnesses” on the Day of Judgment.26 Our finding regarding the importance of maintaining modesty requirements has not been reported elsewhere and may have surfaced within our
study because we conducted focus groups exclusively with women and hosted them within the religious setting of a mosque. Future research is needed to confirm and explicate this finding further. Critically, these sorts of concerns are, to our knowledge, not addressed by jurists within their religious edicts. Yet, if the community on-the-ground has such concerns it behooves religious scholars to speak to these issues in their religious writings. Furthermore, educational programs and behavioral change interventions might be made more effective when they account for these barrier beliefs in their curriculum.

The TPB has shown to be helpful not just in understanding antecedent beliefs for a range of health behaviors, including deceased and living organ donation intentions, but also for informing effective, tailored behavioral interventions that target specific health behaviors within different communities and cultures. The educational implications of our findings, the identified behavioral, normative, and control beliefs (Table 3) are manifold and can help improve organ donation education for Muslim communities.

Conventionally, organ donation–related interventions aim at improving organ donation rates by increasing knowledge and awareness about the societal need for organ donation and by allaying concerns about the donation process. Within minority communities, such interventions also often “humanize” the problem by discussing the acute need for organs within these communities, and within religious communities (particularly among Muslims), interventions incorporate the permissible rulings on donation. Accordingly, interventions are almost always implemented in a unidirectional (ie, encouraging organ donation/transplantation) manner and do not account for the diverse communal narratives and plurality of religious rulings surrounding the matter. For example, interventions that sought to change Muslim attitudes and behaviors by highlighting the scholarly views of permissibility have proven ineffective.

Rather than focusing on the merit of one scholarly position, our findings suggest the need for nuanced education that teaches the plurality of Islamic ethicolegal opinions because community members will likely voice their own understandings of various scholarly positions. By acknowledging the diversity of views, and presenting the religious grounding for each of them, greater trust would be generated and myths and misunderstandings removed. Additionally, persuasion theories suggest that, in areas of controversy, discussing multiple sides of an issue is more effective educational strategy. Moreover, educational efforts should also address other theological and ethical concerns beyond permissibility, for example, moral culpability of the donor on the Day of Judgment and modesty concerns. Given the ethicolegal and theological concerns Muslims have, it is important that health professionals partner with religious authorities in conducting educational interventions. Finally, since participants expressed an awareness of the ethical and legal violations associated with organ transplantation abroad, for example, organ black markets, it may be prudent for educational program efforts to discuss how organ transplantation is organized and how the body is cared for during the donation and transplantation processes within the United States.

Although our findings are significant, they should be interpreted in light of several limitations. Although the use of mosque-based sampling allowed us to reach participants who had strong religious identities and came from different racial and ethnic backgrounds, it did introduce selection bias. We only recruited women aged 40 years and older because data were collected as part of a larger study on breast cancer screening attitudes. It is possible that American Muslim men, younger individuals, those with less prominent religious identities, and those without English literacy may hold different beliefs. Hence, our findings might not be fully generalizable to American Muslims. Nonetheless, because nearly 50% of American Muslims attend mosque once a week, and 87% of American Muslims are English literate, we believe that our work legitimately represents the views of a significant cross section of American Muslims and reveals considerations that are important for organ donation professionals to address in their educational efforts. Aside from sampling, our qualitative methods introduce some limitations. For one we chose a focus group method and within that context devoted only part of the group to the topic of organ donation. As such, personal narratives might not have been fully captured and more in-depth studies via individual interviews may build upon, and clarify, our results. However, given that many of the beliefs presented were deemed salient due to their presence in 3 or more focus groups, this consistency of beliefs provides a basis for advancing culturally sensitive approaches to organ donation within the broader American Muslim population.

Authors’ Note
The data that support the findings of this study are available on request from the corresponding author AIP. The data are not publicly available due to their containing information that could compromise the trust of community partners and privacy of research participants. This article was presented in partial form at the 10th annual conference of the Society for the Study of Muslim Ethics, Louisville, KY.

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