Study protocol for ‘Informing American Muslims about Organ Donation (I AM a LD)’: A Randomized Controlled Cross-Over Trial Evaluating the Effect of Religiously-Tailored Health Education

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ABSTRACT

Background: American Muslims tend to hold more negative attitudes towards organ donation than other American populations, and these attitudes are contributed to by gaps in biomedical and religious knowledge. As a result, there is significant need for religiously-tailored health education on organ donation within this community. Thus our study sought to test the effectiveness of a mosque-based, religiously-tailored health education program that addressed biomedical and religious knowledge gaps regarding living organ donation amongst Muslim Americans.

Methods: A randomized, controlled, cross-over trial of religiously-tailored educational workshops held at four mosques in Washington D.C. and Chicagoland. Mosques are randomized into early and late intervention arms and participants are recruited at worship services and other mosque events. The primary study outcomes are changes in biomedical and religious knowledge regarding living organ donation. Secondary outcomes include change in procedural knowledge about the process and types of living organ donation, beliefs regarding organ donation, and religious knowledge regarding end-of-life care.

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1. Introduction

1.1 Background and rationale

The disparity between supply and demand for life-saving and/or life-sustaining organs is well-known and contributes to over 140 people on the waiting list dying per week in the United States (U.S. Department of Health and Human Services, 2013). The situation for

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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 (Health Resources and Services Administration). Illustratively, while 35,905 African Americans and 10,233 Asians are currently on the transplant waiting list, there were only 575 and 306 living donors from each community respectively in 2018 (Health Resources and Services Administration). The numbers of deceased organ donors from each group was similarly small, with 1,728 Black and 250 Asian donors. Consequently, there is a critical need for targeted programs that increase awareness about organ transplantation processes and disparities among minority communities. At the same time, such programming needs to be tailored to the specific cultural values and knowledge gaps that shape these communities’ experiences and attitudes.

The American Muslim population, currently numbering between 5 and 7 million and expected to double in number by 2030, is one such minority community that might benefit from tailored educational interventions (Pew Research Center, 2011a). American Muslims are primarily represented by indigenous African Americans, Arab Americans, and South Asian Americans (The Muslim West Facts Project, 2009; Smith, 2002). While there is scant data at a national level on Muslim Americans, research demonstrates that individuals from the ethnic/racial sub communities of Muslim Americans disproportionately suffer from higher rates of diabetes and hypertension which, ultimately, are risk factors for kidney failure and thus American Muslims have a potential greater need of kidney transplant (Burt et al., 1995; Centers for Disease Control and Prevention, 2014; Dallo & Borrell, 2006; National Kidney Foundation, 2015; Jaber et al., 2003; Jaber, Slaughter, & Grunberger, 1995; Jamil et al., 2008; Mohanty, 2005; Santos-Longhurst, 2014; National Center for Health Statistics, 2016). As a result, among the Muslim American community, organ donation represents a pressing concern.

Although organ transplantation might be a community health need, American Muslims tend to hold negative attitudes towards organ donation. While over 95% of the American population supports organ donation, reported support among American Muslims is much lower. For example, our representative population-based study of 1,016 Arab Americans living in Southeast Michigan found that only 35% of respondents considered deceased organ donation always to be justified, with 20% considering it never to be justified. In this study, Muslims were approximately 1.5 times less likely to support organ donation than their Christian counterparts (Padela, Rasheed, Warren, Choi, & Mathur, 2011). Our subsequent survey of 93 Arab, South Asian and African American Muslims recruited from Michigan-based mosques found that only 39% agreed that deceased donation was justified (Padela & Zaganjor, 2014). A community-based survey of 227 Muslim Americans in Chicago reported a similarly low rate of support, with only 51% of respondents willing to donate their organs (Hafzalah, Azzam, Testa, & Hoehn, 2014). This general lack of acceptability of organ donation is also found in other diasporic Muslim communities, for example in the United Kingdom and Australia (Karim, Jandu, & Sharif, 2013; Sharif et al., 2011; Sheikh & Dhami, 2000; Wakefield, Reid, & Homewood, 2011).

The negative attitudes toward organ transplantation in Muslim communities are impacted by both biomedical and religious knowledge gaps. Our own (soon to be published) data from focus group interviews with 43 Arab, South Asian, and African American Muslims in Greater Chicago, revealed a general lack of knowledge about Islamic positions on organ donation and that being unsure about Islamic views led participants to
withhold support for organ donation. For example, one participant noted “I’m from a Muslim religion and I didn’t get my research yet done and I didn’t find 100% that I’m allowed to do this,” not just demonstrating a knowledge gap, but also pointing towards the importance of acting in accord with religious guidelines. Another qualitative study, conducted among 100 South Asians in the UK, found that Muslim respondents were often unsure of their religion’s view on donation, and that, in addition to this religious knowledge gap, a general lack of knowledge about the process and need for organ donation pervaded the community (Ahmed, Harris, & Brown, 1999). In line with this, a study of university students in the UK found that Indian and Muslim Pakistani students’ views on organ donation were shaped by a general lack of awareness of its importance and need (Gauher et al., 2013). Similarly, other surveys of Muslim groups in United Kingdom found that individuals who were aware of the gap between organ need and supply, or knew individuals with kidney disease, had higher odds of supporting organ donation (Karim et al., 2013; Sharif et al., 2011). Given that a significant proportion of diasporic Muslims are unaware of the importance of organ donation and are uncertain of Islamic stances regarding donation, there is a need to increase knowledge about the religious and biomedical aspects of donation.

Mosque settings represent important and largely untapped partners for health behavioral interventions. Outside the US, mosques have been partners in health promotion campaigns around cardiovascular and reproductive health, as well as infectious disease control (Bader, Musshauer, Sahin, Bezirkan, & Hochleitner, 2006; Mason, 2010; Rao, 2006; Rifat et al., 2008; Zaidi, 2006). American mosques, however, have rarely partnered in such work. Nonetheless, American mosques routinely host educational, social, and civic events in addition to worship services, and with 50% of American Muslims attending the mosque once a week, they are an ideal venue for health education (Dana, Barreto, & Öskooii, 2011; Pew Research Center, 2011b). Furthermore, biomedical issues involving complex ethical decision making and that have religious dimensions may be best addressed in venues such as mosques which provide safe spaces for open dialogue, are constituted around the idea of religious education, and allow for community’s concerns to be frankly voiced.

This study sought to test the effectiveness of a mosque-based, religiously-tailored health education program aimed at addressing biomedical and religious knowledge gaps regarding living organ donation amongst Muslim Americans.

1.2 Primary hypothesis

Religion-related and biomedical knowledge gaps impacting Muslim American living organ donation attitudes can be feasibly addressed by a tailored intervention within mosque communities.

1.3 Secondary hypotheses

Teaching about the pros and cons, as well as the religious arguments for and against organ donation in a mosque-setting will positively impact the donation-related behavioral, normative and control beliefs of Muslim Americans. Such education will also increase their preparedness and intention to make organ donation-related decisions.

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2. Study Design and Methods

2.1 Design
This study is a randomized, controlled, cross-over trial of religiously-tailored educational workshops held at four mosques. The study consists of two arms, with the early arm receiving the experimental workshop first, while the late arm starts with the control workshop (see figure 1).

Figure 1. Design of Randomized, Controlled, Cross-Over Trial.

<table>
<thead>
<tr>
<th>O1</th>
<th>Exp Tx</th>
<th>O2</th>
<th>Cont Tx</th>
<th>O3</th>
<th>Early Arm</th>
</tr>
</thead>
<tbody>
<tr>
<td>R</td>
<td></td>
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<tr>
<td>O1</td>
<td>Cont Tx</td>
<td>O2</td>
<td>Exp Tx</td>
<td>O3</td>
<td>Late Arm</td>
</tr>
</tbody>
</table>

Note. R = Randomization process after mosque sign-up
O1-O3 = Time of survey assessment
Exp Tx = Exposure to Experimental Workshop
Cont Tx = Exposure to Control Workshop

2.2 Theoretical foundation
The conceptual model that informs this project’s intervention and outcome measures is the Theory of Planned Behavior (TPB) (Ajzen, 1991). The TPB is an expectancy model of intentioned or planned behavior, in which attitudes toward a particular behavior, subjective norm, and perceived control influence one’s intention to perform that behavior. Attitudes, subjective norms, and perceived behavioral control are, in turn, a function of behavioral, normative, and control beliefs. Behavioral beliefs consist of the salient positive and negative outcomes expected to accrue from engaging in the target behavior. Normative beliefs consist of the expectations that important social referents, including religious ones, believe one should, or should not, engage in the target behavior. And, control beliefs consist of the expectations that one has the requisite skills and resources for successfully performing the target behavior. The TPB has shown to be helpful in understanding antecedent beliefs for a range of health behaviors, including posthumous organ donation intentions and living donation intentions (Bresnahan, 2007; Browne, 2008; Radecki, 1997; Siegel, 2008). Moreover, the identification of differential weightings among antecedent behavioral, normative, and control beliefs has been used to tailor effective behavioral interventions that target cultural beliefs and values (Ajzen, 2011a; Ajzen, 2011b; Yun, 2010).

2.3 Partnerships and community engagement
Adopting community-based participatory research (CBPR) principles leads to more effective collaboration between researchers and communities, enhances the quality and
relevance of the research conducted, engenders greater trust between the academy and the community, and improves the effectiveness of educational interventions (Horowitz, Robinson, & Seifer, 2009; Israel, Schulz, Parker, & Becker, 1998; Israel, 2005). Accordingly, this project adopts several CBPR principles and values to insure shared decision-making and effective communication with community stakeholders across all study phases (Israel et al., 2010; Metzler et al., 2003). Hence the project’s organizational structure comprises of a research team, comprised of organ donation professionals and University of Chicago-based researchers, and a community advisory board (CAB), consisting of local community leaders, mosque representatives, and imams. Lastly, the proposed mosque workshops will be supported by a group of peer educators recruited from the community, who will taught to lead group discussions regarding organ donation following the expert didactic sessions within the workshops. Peer-led group discussions will facilitate free-flowing conversation for this controversial topic, without participants experiencing fear of judgment from an authority (Morgan, 1997). Further, peer-led workshops have shown particular effectiveness in increasing knowledge about health topics, and in particular about organ donation (Quinn et al., 2010).

2.4 Setting

This study will take place in four mosques representing diverse Muslim communities in Washington D.C. and Chicagoland. No prior educational workshops have been conducted in any of the partnered sites. Before the start of the study, the leaders of the mosques were introduced to the project and provided letters of support. By incorporating mosques in two cities, we are testing transferability and replicability of the workshops as well as broadening their impact.

2.5 Participants and eligibility

Participants for the workshops are subject to the following inclusion criteria: self-reported Muslims, aged 18 years or older, and proficient in English. The study’s exclusion criteria include positive donor history, defined as having donated or received an organ or having a close family member (e.g., parent, sibling, child) who has done so, and not being available for the selected workshop dates.

2.6 Recruitment

The primary recruitment method will consist of manned recruitment tables during Friday prayers and other events at each mosque. Other recruitment strategies will include: public announcements by CAB members, mosque newsletter advertisements, emails on listservs, flyers on community boards, social media and word-of-mouth. After individuals indicate their interest in the study, they will receive a follow-up call by a research assistant to complete the oral consent protocol and screen for eligibility. If criteria are met and the oral consent protocol is completed, the candidate is officially registered for the workshops (see figure 2). Participants will receive $60 total in gift cards for attending the 2-session workshop.

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2.7 Matching and randomization
The mosque sites selected for participation are matched prior to randomization by predominant ethnic/racial composition of congregations to help control for the potential confounding effect of mosque racial/ethnic composition. Randomization will subsequently occur via coin-toss.

2.8 Blinding
Participants, peer educators and guest speakers will be blinded as to the fact that one workshop composes the intervention and the other the control. The research team and CAB will not be blinded.

2.9 Design of the intervention
Each workshop will last approximately 5 hours, be held on a weekend morning, and includes a light breakfast and lunch to facilitate attendance. To address varied adult learning styles, the workshops incorporate didactic teaching, moderated panel presentations, and facilitated small group discussions led by trained peer educators. Each workshop also involves one or two self-administered surveys.

Figure 2. Study flowchart
2.9.1 Experimental workshop

This workshop will fill in known (e.g., identified educational needs from the literature and from our focus groups in the community) religious and biomedical knowledge gaps within the Muslim community regarding organ donation. The workshop will commence with a short welcome and participants taking a pre-survey. After taking the survey, didactic sessions by a living donor advocate physician and an organ donation professional will address societal context of organ donation, disparities in organ donation, the biomedical risks, benefits, types and processes of living donation, and community resources for donation. These sessions will be followed by a didactic session by an Islamic bioethics expert who will survey the various Islamic ethico-legal positions on organ donation, drawing upon existing rulings, scriptural source-texts and ethical concepts. The final segment of the workshop will entail a facilitated small group discussion over scripted cases that evoke concepts from the didactic sessions and allow for attendees to apply their learning. A post-survey will be self-administered at the conclusion of the session. All speakers and presentations will remain the same to ensure consistency across mosque-sites.

2.9.2 Control workshop

This workshop will focus on the religious dimensions of end-of-life care. The workshop will commence with a talk by a local imam or religious leader on the theological concepts underlying perspectives on sickness and health, followed by a didactic session delivered by an Islamic bioethics expert on the multiple Islamic ethico-legal perspectives on brain death and withdrawal of life support. An invited panel with local experts will address a topic relevant to end-of-life care or deceased organ donation and allow for ample time for attendee questions. Similar to the intervention workshop, the session will end with a facilitated group-based discussion. In the early arm participants will complete the survey at the start of the workshop and in the late arm at the end. Local speakers will be engaged to solidify mosque partnerships and connect the community to potential resources. Agendas for the workshops are noted in Table 1 below.

Table 1. Workshop agendas

<table>
<thead>
<tr>
<th>Time</th>
<th>Organ Donation Workshop</th>
<th>End-of-Life Care Workshop</th>
</tr>
</thead>
<tbody>
<tr>
<td>8.15 – 8.30</td>
<td>Registration</td>
<td>Critical Theological Concepts about Sickness &amp; Health in Islam [local speaker]</td>
</tr>
<tr>
<td>8.30 – 9.00</td>
<td>Welcome, Breakfast</td>
<td>Islamic Rulings about Brain Death &amp; Withdrawing/Withholding Life Support [Islamic bioethics expert]</td>
</tr>
<tr>
<td>9.00 – 9.30</td>
<td>Pre-Survey Assessment</td>
<td></td>
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<tr>
<td>9.30 – 10.10</td>
<td>Biomedical Aspects of Living Organ Donation [physician]</td>
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</tr>
<tr>
<td>10.10 – 10.40</td>
<td>Organ Transplant in the U.S. [organ donor professional]</td>
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<tr>
<td>10.40 – 10.55</td>
<td>Coffee/Tea</td>
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<tr>
<td>10.55 – 11.50</td>
<td>Islamic Perspectives on Living Organ Donation [Islamic bioethics expert]</td>
<td>Moderated Panel discussion [local speakers]</td>
</tr>
</tbody>
</table>
2.10 Outcome measures

The three survey measurements will allow for assessing the change in knowledge based on the experimental workshop in each of the two arms, provide a control comparator (represented by scores post-control workshop in the late arm), and allow for assessing time-stability of knowledge gained (represented by the post-workshop 2 knowledge scores when compared to post-workshop 1 scores in the early arm). The survey instrument will comprise both of conventional items, scales found in the literature, and measures developed de-novo. The instrument will be developed and refined through expert panel review and pilot-testing.

2.10.1 Primary outcome measures

The primary study outcomes are change in biomedical and religious knowledge of living organ donation. Biomedical knowledge will be assessed through the living donation subscale of the Rotterdam renal replacement knowledge test (R3K-T). The R3K-T has been used in educational intervention trials, and was developed in part for use in Arab and Turkish populations in the Netherlands. The living donation subscale consists of 10 items rated true/false/don’t know; with higher scores indicate greater knowledge. In a validation study within American populations, a mean score of 4.11 was reported (Ismail et al., 2013) while in an intervention study living donors scored near 7 (Ismail et al., 2014; Ismail et al., 2013). To assess knowledge about the religious arguments for and against living organ donation, several items have been constructed that ask participants to relate the Islamic ethico-legal ruling on organ donation with the grounds for that ruling. Such items have been used to study Muslim views on the permissibility of organ donation in Malaysia and will be adapted for living organ donation (López et al., 2012; Tumin et al., 2013). We have generated a several-item measure that draws upon our in-depth studies of the Islamic ethico-legal rulings on organ donation (Padela & Duivenbode, 2018). We have performed cognitive pre-testing and expert panel review of this de novo measure, and pilot-tested items during a mock workshop to assess the measure’s psychometric properties and its utility in measuring knowledge gain (Padela & Duivenbode, 2018).

2.10.2 Secondary outcome measures

Secondary outcome measures have been developed de novo and will assess (i) procedural knowledge about the process and types of living organ donation, (ii) belief structures regarding organ donation, and (iii) change in religious ethics knowledge regarding end-of-life care. Procedural knowledge will be assessed through a combination of 4 items not covered by the R3K-T. Three of these items were taken from the living donation knowledge (LDK) test and one from the kidney donor transplant knowledge questions developed by Waterman et al., (Rodrique, 2008; Waterman, Robbins, Paiva, & Hyland, 2010). We created a tool to assess participant belief structures based on the findings from our prior focus group data which, through a team-based framework method,
identified Muslim Americans’: (1) commonly perceived behavioral beliefs regarding living organ donation, including procedural knowledge, anticipated benefits, and anticipated risks; (2) commonly reported important people, groups, or religious figures who would approve or disapprove of living organ donation; (3) commonly reported perceived barriers and/or facilitators to living organ donation (Gale, Heath, Cameron, Rashid, & Redwood, 2013). This new tool will offer a representative and malleable set of beliefs, as well group norm and perceived control, and will allow for assessing whether our intervention changed the way in which American Muslims conceive of living organ donation. Lastly, the change in religious ethics knowledge regarding end-of-life care items were, similar to the organ donation religious knowledge scale, formulated based upon our in-depth studies of the Islamic ethico-legal rulings on the topic and reviewed for accuracy by religious leaders in the CAB (Padela & Qureshi, 2016; Padela, Shanawani, & Arozullah, 2011; Padela, Arozullah, & Moosa, 2011).

2.10.3 Independent measures

Independent measures comprise of conventional sociodemographic characteristics including those known to associate with organ donation attitude (age, sex, race/ethnicity, etc.) and a health status measure (short form-1) (Idler & Kasl, 1991; Ware, 2008). Given that our intervention is focused on religious dimensions of living organ donation, and that we expect differential response based on participant religiosity, surveys incorporate a modified religiosity measures that we have found to predict Muslim health behaviors and attitudes. The Duke University Religion Index (DUREL) modifications entailed i) an adaptation of the answer categories for congregational religious services attendance to accurately capture Muslim experiences (organizational religious activity), and ii) replacing the wording of some questions to make them more relatable to Muslim populations, i.e. “God” with “Allah,” “religious” with “Islamic” and “my religion” with “Islam” (intrinsic religiosity) (Koenig & Bussing, 2010). To measure Islamic religiosity we included two subscales of the Psychological Measure of Islamic Religiousness (PMIR) which measure positive and negative religious coping (Raiya, Pargament, Mahoney, & Stein, 2008). The 7-item PMIR-Positive Religious Coping and Identification subscale measures the extent to which Muslims use religious coping methods (e.g., reading Qur’an, seeking forgiveness, cultivating reliance upon God) to deal with life stressors. The 3-item PMIR-Punishing Allah Reappraisal subscale assesses whether people interpret events in their life as punishment from God (negative religious coping). This subscale was shown to correlate negatively with organ donation attitudes in our previous study of Muslim Americans (Padela & Zaganjor, 2014). In that study, the Islamic Positive Religious Coping and Identification Subscale had a Cronbach’s α of .9, and the Punishing Allah Reappraisal of .79. Both scales were slightly adapted as we changed the answer options from the original the 4-point Likert scale ranging from 1 “I do not do this at all” to 4 “I do this a lot” to a 4-point Likert agreement scale, ranging from 1 “completely disagree” to 4 “completely agree.”

Finally we also included discrimination measures to capture potential negative social and healthcare experiences that might impact on organ donation attitudes. A short (5-item) version of the Everyday Discrimination Scale was included (Cronbach α=.77) and the question wording was modified by replacing “other people” with “non-Muslims” (Sternthal, Slopen, & Williams, 2011; Williams, 1997). We also included an already

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existing healthcare oriented adaptation of the original Everyday Discrimination Scale consisting of 7-items (Peek, 2011). This scale was further modified by replacing “other people” with “non-Muslims” on three items, as we have done for in previous research (Cronbach α= .93) (Vu, Azmat, Radejk, & Padela, 2016).

2.11 Data collection and management

Data is collected via the three questionnaires completed by workshop participants during the allocated workshop time. The questionnaires are anonymous and a personal identifier, only known to the individual participants, is used to linked survey 1, 2 and 3 to each participant. Study data will be entered and managed using REDCap electronic data capture tools hosted at the University of Chicago (Harris et al., 2009). To ensure accuracy, we will perform double-data entry by two or more independent research assistants.

2.12 Statistical methods

2.12.1 Power calculation

Sample size determination was based on the primary study outcome of change in knowledge of living donation. Estimates of knowledge change attributable to an educational intervention are derived from the work of Rodrigue et al., in which family and friends of patients on the waiting list for cadaveric kidney transplant were invited to a home-based educational program on living kidney donation (Rodrigue, 2007). This study showed an increase in knowledge of 0.8 SD units, a large effect size (Cohen, 1992; Rodrigue, 2007). Setting power at 0.80 and a two-tailed alpha set at 0.05, a sample size of 52 (26 per group) would be required to reliably detect a difference of this magnitude between an educational intervention group and an untreated control group. Using a more conservative, medium effect size of 0.60 SD units, and with power set at 0.80 and a two-tailed alpha at 0.05, a sample size of 90 (45 per group) would be required. Assuming a 20% attrition rate per group, we plan to recruit for a total sample size of 114, or 57 for each of two groups.

2.12.2 Data analysis

Chi-square and independent sample t-tests will be used to compare baseline characteristics of both study arms on sociodemographic characteristics, (Islamic) religiosity measures, and discrimination measures. Internal consistency reliability (Cronbach’s α) will be computed for all summed scales. Primary and secondary outcomes will be assessed at three time points (see Fig. 1): O₁ will serve as the baseline for both the experimental group and the control group; O₂ will serve as post-intervention and post-control observation for the experimental group untreated control group respectively; O₃ will serve as follow-up for the now “treated” control group, along with a sustainability metric for the previously treated experimental arm. A two (group) by three (time) Mixed Methods repeated Measures Analysis of Variance (ANOVA) will be used to test for effects of group and time of measurement on each of the two primary outcomes and the three secondary outcomes, with post-hoc within-group and between group ANOVAs computed. In the event that randomization does not equally distribute potentially confounding baseline variables, these variables will be treated as covariates in an ANOVA model.
3. Discussion

This study’s design involves several innovations and contains multiple strengths. With respect to innovations, this study takes a balanced approach to education regarding organ donation ethics. To date nearly all educational interventions focused on organ donation within Muslim communities have sought to portray organ donation in a positive ethical light and present religious support for organ donation and transplant. Our approach acknowledges the ethical plurality amongst religious scholars, as well as the fact that organ donation carries some risks and costs. Consequently our tailored educational workshops teach about the religious arguments for and against organ donation (both living and deceased), and incorporate discussions about the health risks and financial costs of living donation. This balanced approach capitalizes on leading persuasion models to facilitate central processing of information (Petty & Cacioppo, 1986), and prioritizes informed-choice over changing negative views towards organ donation. This contrasts with more conventional organ donation-related interventions that aim at improving organ donation rates by increasing awareness of the societal need for organ donation and dispelling myths. Within Muslim communities, interventions frequently incorporate only the existing permissible rulings on organ transplantation. Accordingly, outreach is almost always unidirectional in nature (i.e., encouraging organ donation) and runs the risk of fostering mistrust in the community when the intervention fails to address valid concerns and the plurality of religious rulings. To our knowledge, unidirectional religiously-oriented interventions in Muslim communities have proven ineffective (Bilgel et al., 1991; Bilgel, Sadikoglu, Goktas, & Bilgel, 2004; Hafzalah et al., 2014; Rasheed & Padela, 2013). The study also innovates in the terms of religious ethics education as it seeks not to have a new, local, and positive religious edict (fatwa) issued to impact Muslim attitudes, but rather focuses on group discussions.

There are several strengths to the proposed research. The first strength is the randomized design, which controls for unmeasured confounders between the two study arms and thereby facilitates generating strong evidence for religiously-tailored, two-sided health education interventions in mosques. Indeed one aspect of capacity-building within our project involves recruiting, training and employing peer (health) educators. The benefits of community-capacity building are manifold and include minimizing community dependency on outside health and bioethics experts, generating a sense of ownership over the health attitudes, behaviors, and data of the community, and fostering the continuation of both formal and informal health education within community institutions once research collaborations end.

At the same time the study is limited in its generalizability. Specifically, although we aim to select a representative sample of American Muslims from the Washington DC and Chicagoland areas, our findings might not be applicable to diasporic Muslim communities elsewhere. Major differences might exist in migration background, socio-economic and political circumstances, religiosity, healthcare systems and acculturation. Another limitation is that the intervention itself consists of both the curricular content and the people who deliver it. While the content will be made available through the creation of a dissemination guide, the effect of the speakers on the results will remain unknown, thus leaving the effectiveness of future implementations somewhat uncertain.
4. Ethics and funding

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