I AM a LD

Community-Engaged Educational Research Workshops On Organ Donation in Mosques

Peer Educator Training Manual

AUTHORS:

Aasim Padela, Initiative on Islam and Medicine, University of Chicago
Michael Quinn, Department of Medicine, University of Chicago
Rosie Duivenbode, Initiative on Islam and Medicine, University of Chicago
Shaheen Nageeb, Initiative on Islam and Medicine, University of Chicago
Milda Saunders, Department of Medicine, University of Chicago

Initiative on Islam and Medicine
The University of Chicago

National Kidney Foundation® of Illinois

giftofhope®
Organ & Tissue Donor Network

Acknowledgements

This project is funded by the Health Resources and Services Administration (Grant Number R39OT31104), and represents a collaboration between the University of Chicago (primarily through its Initiative on Islam and Medicine) and the National Kidney Foundation Illinois and Gift of Hope. We thank the International Institute of Islamic Thought, the Islamic Society of North America, and the Islamic Medical Association of North America for convening educational forums that seeded this collaboration. This project's success will result from the many efforts of the community advisory board members (noted below), mosque leaders, community volunteers, and peer educators, we are grateful for their commitment, support and perseverance.

To the Community Peer Educator

The Initiative on Islam and Medicine (II&M), the National Kidney Foundation Illinois, Gift of Hope and the Chicago Muslim community, thank you for your participation in this workshop.

Our gathering seeks *to live out the Qur'anic imperatives to gain knowledge and petition God to increase us in knowledge, and to live out the Prophetic directive to seek knowledge that benefits ourselves and others*. Our aim in this project is to improve knowledge about organ donation within the Muslim community. By filling in knowledge gaps and dispelling myths, we will empower individuals to make informed decisions, ones that align with their values and ideals. *As a peer educator, you will be integral to this process and instrumental in helping generate such knowledge within our mosque communities.*

During this 1-day training, *you will acquire the skills necessary to facilitate group discussions on organ donation*. You will gain insight into the design and aims of the project, come to understand key ethical constructs and concepts of Islam, acquire knowledge on the biomedical and religious aspects of organ donation, and learn about the peer educator role and its responsibilities.

We thank you again for being a part of this training. If you have any questions or concerns, please contact name at email@gmail.com or call 555-555-5555.

Table of Contents

Agenda for Today's Peer Educator Training

9.00 – 9.30 AM	Registration and Consent Form
9.30 – 9.45	Group Introductions *Steering Committee and attendees*
9.45 – 10.00	What is I AM a LD? A Brief Overview *Aasim Padela*
10.00 – 10.10	Peer Educators: Role, Responsibilities and Benefits *Michael Quinn*
10.10 – 10.30	Organ Donation in the United States *Megan Craig*
10.30 – 11.00	An Introduction to Living Organ Donation *Milda Saunders*
11.00 – 11.15	**Break**
11.15 – 12.00	Islamic Perspectives on Living Organ Donation *Aasim Padela*
12.00 – 12.30	**Dhuhr Prayer + Boxed Lunch**
12.30 – 1.30	Group Facilitation Training: Theory & Practice *Michael Quinn*
1.30 – 1.50	**Asr Prayer**
1.50 – 2.30	Teach it Back: Topic of Choice *Group*
2.30 – 2.50	Closing Remarks *Steering Committee* Pre-Post-Training Confidence Evaluation, Attitudes Survey

The Project

WHO? The project is a partnership between The University of Chicago's Initiative on Islam and Medicine (II&M), the National Kidney Foundation Illinois, Gift of Hope, and Muslim Community leaders in the Chicagoland- and DMV-area, and four local mosques.

WHAT? Together we will conduct ½-day long educational workshops in mosques, which involve expert lectures and peer educator-led group discussions. The objective of the workshops is to address medical and religious information gaps about living organ donation.

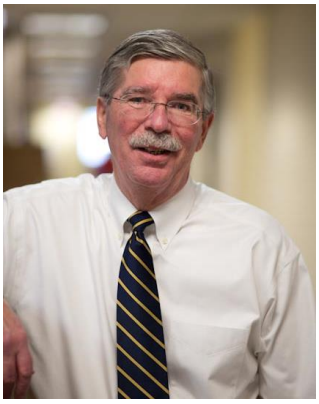
WHY? The research conducted will provide an evidence-based model for faith-based health education that helps individuals make informed decisions about organ donation.

The Steering Committee:

Dr. Aasim I. Padela

Project role: Principal Investigator and Expert Lecturer

Dr. Padela is the director of the Initiative on Islam and Medicine, associate professor of medicine at the University of Chicago and faculty at the MacLean Center for Clinical Medical Ethics and Divinity School. He is dually-trained in medicine and in Islam. His scholarship focuses on the intersection of community health and religion, and he has extensive experience in community-based, health education research and in conducting Islamic bioethics workshops.



Dr. Michael Quinn

Project role: Principal Researcher

Dr. Quinn is a senior research scientist in the Department of Medicine at the University of Chicago. He is a social psychologist with extensive experience in program evaluation and behavior change interventions.

Dr. Milda Saunders

Project role: Co-Investigator and Expert Lecturer

Dr. Saunders is an assistant professor of medicine at the University of Chicago, and faculty at the MacLean Center for Clinical Medical Ethics. She serves as the living donor advocate physician for the University's Transplant Center and has carried out extensive research and teaching related to organ donation and transplant ethics.

Megan Craig

Project role: Organ Donation Professional

Megan Craig has been with the National Kidney Foundation of Illinois since 2015. She became involved with the foundation after donating a kidney in 2011, and left her former career as journalist to run patient and professional programs for NKFI.

Susan Cochran

Project role: Organ Donation Professional

Susan Cochran has worked with the Gift of Hope Organ and Tissue Donor Network since 2003. Susan's work at Gift of Hope has been focused primarily on the Donor Family. Susan also leads Interfaith Outreach, managing an Interfaith Council that guides Gift of Hope on sensitivity issues surrounding donation for diverse populations.

Jennifer Aquilar

Project role: Organ Donation Professional

Jennifer Aguilar is a Community Outreach Specialist at Gift of Hope Organ & Tissue Network. Jennifer serves as Chair of the Latino Workgroup in the Association of Multicultural Affairs in Transplantation and is a member of Gift of Hope's Interfaith Council.

Participating Mosques:

All Dulles Area Muslim Society (ADAMS) Center Sterling	46903 Sugarland Road Sterling, VA 20164	https://www.adamscenter.org
Islamic Foundation North	1751 O'Plaine Rd, Libertyville, IL 60048	https://ifnonline.com
Muslim Education Center	8601 Menard Ave. Morton Grove, IL 60053	http://mccchicago.org/mec
All Dulles Area Muslim Society (ADAMS) Center Sully	4431 Brookfield Corporate Dr Suite F, Chantilly, VA 20151	https://www.adamscenter.org

1. Background

Muslim Americans are a diverse and growing population numbering between 3 and 7 million persons in the United States. Generally mistaken for a small homogenous group, American Muslims are many and diverse. Most are African Americans (35%), Arab Americans (25-30%), or South Asian Americans (20-25%).

Muslim Americans and Religious Influences on Health

National health databases and national health surveys do not collect data by religious affiliation, thereby making it difficult to accurately assess aggregate health outcomes amongst Muslim Americans and to make comparisons between Muslims and other populations. Despite this gap in knowledge community-based studies suggest that various groups of Muslims suffer from health disparities, and that mosque communities often neglect the religion and health interface.

However we know that religious identity impacts the health of Muslim Americans in at least three significant ways: (i) Muslims utilize a *God-centered framework*, an explanatory model for illness, to understand health, ill- ness, and treatment options, (ii) Muslims look to Islamic ethico-legal guidelines when deciding upon the permissibility of medical treatments, and (iii) Muslim religiosity conveys a socially marginalized identity to American Muslims, which may elicit Islam-directed discrimination both outside and inside the healthcare system.

The Organ Donation Challenge

In the past decade the number of individuals with organ failure and the amount of patients on the waiting list for organ transplant has increased, while the number of organ donors has remained relatively constant. The gap between the need for life-saving and/or sustaining organs and organ supply leads to over 150 people on the waiting list dying per week. The situation for ethnic and racial minorities is even more dire, as not only do biological factors make finding appropriately matches more rare, organ donation rates among racial and ethnic minority backgrounds are also less common (see table 1).

Table 1: Waiting list and donation rates among White, African Americans, and Asian Americans. Note: there is no specific data on Muslims overall, nor on South Asians and Arabs (Arabs are classified as white in most organ donation research).[i]

	Currently on waiting list	Living donors 2017	Deceased donors 2017
White	47,560	4,448	6,790
African Americans	33,069	526	1,603
Asians	9,206	272	258

Muslim American Health Problems Predisposing to Organ Failure

As noted above, national health care surveys and databases typically do not collect religious affiliation data, there is therefore limited data on aggregate American Muslim health outcomes; what is known is based on racial/ethnic group data and community surveys. These data show that Arabs, African Americans and South Asians suffer from disproportionately higher rates of diabetes than their White counterparts and that hypertension is more prevalent among African Americans than Whites. These conditions contribute to the higher likelihood of kidney failure and a greater need for kidney transplantation among African, South Asian and Arab Americans.

Thus, Muslim Americans (who are mostly comprised of African, South Asian, and Arab Americans) appear to have greater rates of the predisposing diseases that lead to kidney failure. As a result, one may hypothesize that Muslim Americans have organ donation and transplantation needs similar to, if not greater in proportional rate, than the general US population.

Muslim Attitudes Towards Organ Donation

Muslims tend to hold more negative attitudes towards organ donation than the general US population. While over 95% of the American population supports organ donation, reported support among Muslims Americans is much lower. Survey data among American Muslims suggest only 15-51% supports organ donation and/or is willing to donate their organs. For example, our (Padela and colleagues) representative population-based study of 1,016 Arab Americans living in Southeast Michigan found that only 35% of respondents held deceased organ donation to always be justified, with 20% considering it never justified. Muslim Arabs were approximately 1.5 times less likely to support organ donation than Christians This general lack of acceptability of organ donation among Muslims is also found in other Muslim

[i] To view national data reports on transplantation, donation and waiting lists visit https://optn.transplant.hrsa.gov/data/view-data-reports/national-data/

diasporic communities, such as in the United Kingdom and Australia.

Religious and Biomedical Knowledge Gaps Challenge Muslims in making Informed Decisions about Organ Donation

Empirical research finds that ambivalence within the Muslim community toward organ donation is fueled by a lack of awareness of religious rulings on the practice, and that greater awareness of organ donation need is associated with positive attitudes towards organ donation. Given that a significant proportion of 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 and religious leaders represent important and largely untapped partners for health education interventions

Outside the US, mosques have been partners in health promotion campaigns around cardiovascular and reproductive health, as well as infectious disease control. American mosques, however, have rarely partnered in health intervention work. Nonetheless, American mosques routinely host educational, social, and civic events in addition to worship services, and since 50% of American Muslims attend mosques once a week, mosques are an ideal venue for health education programs. Our prior work has demonstrated that local imams play significant health-related roles from providing religious guidance on bioethical challenges to helping congregants see health behaviors as part of their religious responsibilities. Indeed, we recently leveraged the role of the imam and of the mosque to implement a religiously tailored, educational intervention aimed at enhancing Muslim women's intention for mammography.

2. Project Goals

This project aims to deliver a tailored, mosque-based educational workshop that discuss the biomedical and religious aspects of living organ donation.

Workshop	To enhance attendee knowledge of the *benefits and risks*, understanding of *religious arguments for and against*, and biomedical knowledge about the process and types of living organ donation.

3. Activities

Develop	Religiously- and culturally-tailored lectures, survey measures, and workshops
Implement	Mosque partnerships, peer educator recruitment and training, workshop participant recruitment and workshop delivery
Evaluate	Assess implementation fidelity, biomedical and religious knowledge gained, and change in attitudes and beliefs regarding organ donation

Organ Donation Workshop

Objectives

- To enhance attendee knowledge of the *benefits and risks* of living organ donation
- Create an understanding of *religious arguments for and against* organ donation
- Gain knowledge on the process and types of living organ donation.

Preliminary Workshop Agenda

Time	**Organ Donation**
8.15 – 8.45	Registration, Breakfast and Pre-Survey Assessment
8.45 – 9.00	Welcome
9.00 – 9.30	Biomedical Aspects of Living Organ Donation [Dr. Saunders]
9.30 – 10.00	Organ Transplant in the U.S. [Megan Craig]
10.10 – 11.00	Islamic Perspectives on Living Organ Donation [Dr. Padela]
11.00 – 11.15	Coffee / Tea
11.15 – 12.20	Facilitated Group Discussions [peer educators]
12.20 – 12.35	Post-Survey Assessment

Peer Educators

1. Role and Benefits

What is a Peer Educator?

A peer educator is a community member who carries out educational activities that promote healthy behaviors and reduce health risks among their social peers and community networks. Peer educators often come from similar social backgrounds or have similar experiences to those who they are trying to teach. Peer educators engage their peers in conversations about the health issue of concern, seeking to promote health-enhancing knowledge and skills.

Why should someone train to be a Peer Educator?

Peer-led workshops have shown particular effectiveness in increasing knowledge about health guidelines, and in particular about sensitive and controversial topics.

Successful peer educators are people who:

- Understand the culture, needs, and values of community members. They are passionate about improving the health of their community members.
- Are able to bridge the gap between the community and health agencies or services and can help community members understand or connect to medical and care resources.
- Are good communicators who can effectively deliver health information, listen to concerns from community members, and answer health-related questions with a supportive and positive attitude.

What will peer educators in our project gain?

Group moderation and facilitation skills	○ Learn to create a respectful environment where participants feel safe to express themselves ○ Master critical techniques to steer conversations: open-ended questions, reflective listening, empathic statements, and probing to gain group views ○ Learn how to redirect a conversation and provide encouragement to discuss ideas
Research Skills	○ Training in the ethical considerations of conducting community-based research
Knowledge on organ donation (biomedical and religious)	○ Peer educators will be presented with background knowledge on end-stage organ disease and organ donation, including: advances in transplantation, shortage of organs available for transplantation and the benefits and risks of living donation ○ Peer educators will acquire fundamental knowledge on the Islamic view of living organ donation, including: relevant theological and legal constructs such as human dignity (*karāma* and *ḥurmah*), dire necessity (*ḍarūra*) and public

Interest (*maṣlaḥa*), and different Islamic legal rulings on living organ donation

2. Responsibilities

During each workshop peer educators will facilitate group discussions (1 hour). Details of these activities can be found in the workshop script below. Each workshop needs approximately five peer educators to enable the participants to work in discussion groups.

3. Peer Educator Training Overview

How is a peer educator trained?

Peer educators are trained through a one-day intensive peer educator training

Training Day	○ Didactic sessions on biomedical and religious aspects of Organ Donation ○ Skills training for group moderation

Training Day

The training day consists of a didactic morning with interactive lectures and life knowledge evaluations, and a skills-based afternoon. The afternoon will include two activities for peer educators to familiarize themselves with the materials and group moderation:

Mock group facilitation with feedback	Peer educators will each lead a brief, 5-minute small group discussion on organ-donation relevant topics in which they elicit group members' views on topics such as stewardship for others, responsibility to family, and prevention of harm to one self and others. Trainers will give feedback and elicit feedback from the group.
Teach-it-Back	Participants will be asked to pick a "main topic" (i.e., how to lead an ice-breaker, importance of human subjects research guidelines, components of human subjects research guidelines, how to create a respectful environment, techniques for leading group interactions, techniques to ensure theme saturation, ethical considerations in group discussions) and teach it back to the group. This will facilitate learning by helping the instructors to clarify and correct misunderstandings, acts as a rehearsal and ensures deeper grasp of the material and provides reinforcement for both the participant presenting and the participants listening.

Workshop Script

Important things that should happen at every workshop:

1. Ensure a warm, relaxed and friendly atmosphere.
2. Encourage question-asking. If you do not know the answers, obtain them from the steering committee members.
3. Monitor individual participation to prevent individual monopoly.
4. Keep discussions directed toward the subject.
5. Encourage group participants to examine their own experiences and to share these with the group.
6. Reinforce verbally or nonverbally (with nods of head, eye contact, etc.) every person, every session
7. Using non-judgmental, non-directive discussion (O-A-R-S): open ended questions, affirmations, reflections, summaries [See tip sheet below]
8. Keep to the time limits for each part of the workshop.
9. Do not add anything to the course.

1. Short Workshop Description

The workshop will begin with short welcomes and an overview provided by Dr. Padela and a local mosque representative. As participants sign in at the registration table they will be given a granola bar of a certain type which will help sort them into 5 groups and direct them to specific roundtables where peer educators will be sitting. Dr. Padela and the research team will discuss the ethics of confidentiality and ethos of not judging one another that encompass the workshop.

Each peer educator will be facilitating discussions amongst the individuals at their table. The ice-breaker below will involve "local" discussion at tables and then a report back to the group.

2. Peer Educator-Led Group Discussion Organ Donation Workshop (55 minutes)

Materials:
- Lunch (50x)
- Hand-out decisional balance sheet (50x)

Methods:
- Discussion

Learning Objectives:
- To be able to articulate and weigh the benefits and risks of living organ donation

1. The **peer educators** say
   Before we depart for the day, we have an opportunity to share and compare our learning with each other. I imagine that we may discuss what we learned today with

others outside of this room. Hence let's prepare for that by thinking about the topics discussed today a bit more.

2. The **peer educator** says to his/her discussion group
To help us in this discussion each of you received a decisional balance sheet hand-out. We will use this to explore all pros and cons of living organ donation. Please take a moment to fill out and then let's discuss with one another.

Living Organ Donation Balance Sheet

Outcomes	
Pros	**Cons**
Self	
For Others (note whom on the line)	
Religious Benefits (if any)	**Religious Harms (if any)**

Additional Reading

1. Branden, SVD. and Broeckaert, B. The Ongoing Charity of Organ Donation. Contemporary English Sunni Fatwas on Organ Donation and Blood Transfusion. Bioethics. 2011; 25(3): 167-175
2. Butt, Zubahir (2019) Organ Donation and Transplantation in Islam Fatwa from the Institute of Islamic Jurisprudence
3. Ghaly, M. (2012). Religio-ethical discussions on organ donation among Muslims in Europe: an example of transnational Islamic bioethics
4. Hamdy, S. (2008). Rethinking Islamic Legal Ethics in Egypt's Organ Transplant Debate. Muslim Medical Ethics, from Theory to Practice
5. Hussaini, MO. (2012) Organ Transplantation: Classical Hanafite Perspectives.
6. Mohammed, AM. (2017). Harvesting the Human: Tradition Sunni Islamic Perspectives
7. Organ Transplantation from the Islamic Perspective. Published by the Ministry of Health Malaysia.
8. Padela, AI. July 2016. Fairfax VA. Fiqh Forum on Organ Donation. International Institute of Islamic Thought (IIT)
9. Padela AI, Arozullah A, Moosa E. Brain death in Islamic ethico-legal deliberation: challenges for applied Islamic bioethics. Bioethics. 2013;27(3):132-139. doi:10.1111/j.1467-8519.2011.01935.x.
10. Padela AI, Duivenbode R. The ethics of organ donation, donation after circulatory determination of death, and xenotransplantation from an Islamic perspective. Xenotransplantation. 2018 May;25(3):1-2.
11. Rady, MY., Verheijde, JL., and Ali, MS. Islam and End-of-Life Practices in Organ Donation for Transplantation: New Questions and Serious Sociocultural Consequences. HEC Forum. 2009; 21(2): 175-205.
12. Shoaib AR. and Padela, AI. (2013). The interplay between religious leaders and organ donation among muslims. _Zygon_ 48 (3):635-654.

Additional Resources

1. Strategies for Motivational Interviewing – OARS
2. Peer Educator Group Facilitation Observation Rating

Strategies of Motivational Interviewing – OARS

Strategies	Description	Examples
Open-Ended Questions	• Elicits descriptive information • Requires more of a response than a simple yes or no • Encourages participants to do most of the talking • Helps us avoid premature judgments • Keeps communication moving forward	• Often start with words like "how" or "what" or "tell me about" or "describe." • Avoid "why" questions, which can elicit defensiveness • Tell me about your understanding of organ donation. • How would you like things to be different? • What have you tried before?
Affirmations	• Must be done sincerely • Supports and promote self-efficacy • Acknowledges difficulties the participant has experienced • Validates experience and feelings • Emphasizes past experiences that demonstrate strength and success	• I appreciate how hard it must have been for you to decide to come here. You took a big step. • I've enjoyed talking with you today. • I appreciate your honesty. • That's a good suggestion. • You've accomplished a lot in a short time.
Reflective Listening	• A way of checking rather than assuming that you *know* what is meant • Shows that you have an interest in and respect for what the participant has to say • Demonstrates that you have accurately heard and understood participants • Encourages further exploration of problems and feelings	• It sounds like you… • You're wondering if… • So you feel… • Please say more… • Reflections are statements. Statements ending with downward inflection (as opposed to questions) tend to work better because participants find it helpful to have some words to start a response • Avoid "Do you mean…" and "What I hear you saying is…." (can appear patronizing).

Summarize	• Reinforces what has been said • Shows that you have been listening carefully • Prepares the participants for transition • Can help promote deeper exploration of Pros and Cons	• So, let me see if I got this right… • So, you've been saying… is that correct? • Let me see if I understand so far… • Here's what I've heard. Tell me if I've missed anything. • Let me make sure I understand exactly what you've been saying…