



Session 8: Islamic Bioethics of Organ Donation and Transplantation Summary & Closing Lecture

 @aasim_padela

Research Approach



Muslim Behavior



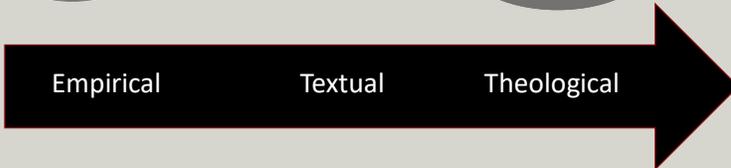
Islamic Bioethics



Empirical

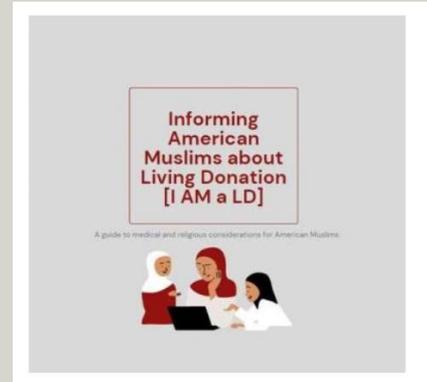
Textual

Theological



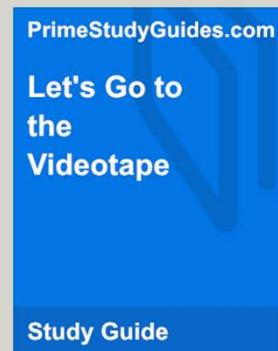
Insights into the Materials: All were Part of an Islamic Bioethics Intervention

- 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
- 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
- Butt, MZ. 2023 *Organ Donation and Transplantation in Islam: An Opinion* In: Abdul-Hussein, M., Padela, AI, and Randhawa G. (editors). *Organ Donation in Islam: The Interplay of Jurisprudence, Ethics, and Society*. Lexington Books
- 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.
- Padela, A.I., Titu, M., Keval, A., and Abdelrahim, M. *Muslims, Islam & Organ Donation: Righting Social Narratives & Designing Ethical Educational Interventions*. Experimental and Clinical Transplantation
- *Organ Donation: A guide to medical and religious considerations for American Muslims*. Initiative on Islam and Medicine
- Padela, AI. *Fiqh Forum on Organ Donation*. International Institute of Islamic Thought, Herndon, VA. 2017



Focus Questions

- What are the Islamic arguments for & against organ donation?
- What is the “Muslim” problem with organ donation?



The Mosque Context for Muslim Health Outcomes Research

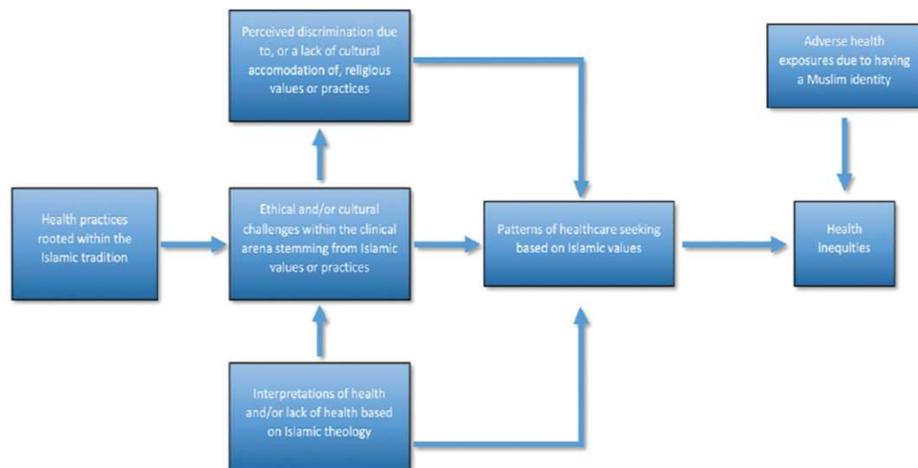


- **Central to Muslim life**
 - Nearly 50% of community attends mosque weekly
 - Hosts educational, social, health as well as religious functions
 - **Site of identity formation**
 - Islamic beliefs & values reinforced and taught → As a Muslim what should I do?
 - **A connected community**
 - An established social network centered around a physical site (mosque) with ancillary institutions
- **Testing ground for assessing religious influences on health across sociodemographic characteristics**
- African American, Arab American, S. Asian predominant mosques
 - Suburban and urban
 - Sunni and Shia

ORIGINAL ARTICLE

The Islamic tradition and health inequities: A preliminary conceptual model based on a systematic literature review of Muslim health-care disparities

Aasim I. Padela, Danish Zaidi¹
Department of Medicine, The University of Chicago, Chicago, IL





Muslims most opposed to organ donation: Survey

BY PAMELA FAYERMAN, POSTMEDIA NEWS AUGUST 18, 2010

Organ Donation Disquiets Wales Muslims
(2 votes, average 1.00 out of 5)

OnIslam & News Agencies
Monday, 05 November 2012 00:00

Dutch Muslims Happy to Take Organs But Not Give

4 March 2005

AMSTERDAM — Health Minister Hoogervorst wants to give priority on transplantation waiting lists to people who are registered as donors, but MPs slammed the proposal on claims it will introduce discrimination in healthcare.

The Liberal VVD minister defended his proposal by pointing out that Muslims often refuse to donate organs based on religious beliefs. This is despite the fact they are willing to receive an organ if they are ill. "That creates a bad feeling," he said.

"If you say: 'I refuse to donate an organ because of my religion, but I don't want to receive one either', than I will respect it. But I won't respect a one-sided attitude of receiving and not giving. I find that problematic," Hoogervorst said.

Muslim Attitudes Towards Organ Donation

- Arab Americans (N=1,016) (Padela et al, 2011)
 - 35% held *deceased* donation to always be justified
 - Muslims 1.5 times less likely to support donation
- Arab, S. Asian and African American Muslims (N=97) (Padela et al, 2014)
 - 39% supported *deceased* donation
 - 55% believe it is not ethically justified
- “Western” Muslims (N=891) (Sharif et al, 2011)
 - 39% held organ donation to be compatible with Islam
 - ‘Higher’ religiosity → less likely to hold positive views

General American population:
 > 95% support
 > 57% willing

Diaspora

The Logic Train & Interventions



1995 - Fatwa of The Muslim Law (Shariah) Council

The basic position of this fatwa was that organ donation
 — BBC COVERS THE IMPORTANT NEW FATWA ON ORGAN DONATION —



Clin Transplant 2014; 28: 263-267 DOI: 10.1111/ctr.12286
© 2013 John Wiley & Sons, Ltd. Published by John Wiley & Sons Ltd
Clinical Transplantation

Improving the potential for organ donation in an inner city Muslim American community: the impact of a religious educational intervention

Hafizah M. Azam R, Taha G, Hoehn KS. Improving the potential for organ donation in an inner city Muslim American community: the impact of a religious educational intervention. *Clinical Transplantation* 2014; 28: 263-267. DOI: 10.1111/ctr.12286

Mina Harizah¹, Ruba Azzam², Giuliano Testa³ and K. Sarah Hoehn⁴



Identifying and Addressing Organ Donation-Related Attitudes

Community Partnership Building

- Mosques
- Religious Think-tanks & Councils
- Organ Procurement Organizations

2011-2021

Evidence Gathering & Synthesis

-Phase 1- Community-Based Surveys

-Phase 2- Mosque-based Focus Groups

- Phase 3- Analyses of Religious Discourse

-Phase 4- Design of Measurement Tools & Curriculum

Feasibility & Efficacy Trial

-Cross-over RCT in 4 mosques in 2 cities

Goal: **Increase knowledge and behavioral intent**
Desired Outcome: **Informed decision-making**



Organ Donation: One Size Does Not Fit All

Benefits are not the same for all organs

- Life quality enhancing, e.g. cornea
- Life 'giving', e.g. heart

Decisions are of different significance

- Friend/family or unknown recipient
- Kidney vs. cornea

Nuance

The ethics of organ donation, donation after circulatory determination of death, and xenotransplantation from an Islamic perspective

Aasim I. Padela^{1,2,3} | Rosie Duivenbode¹

The “Islam” Factor: Plurality is Inherent

- ◆ Organ donation is impermissible, because it violates human dignity (*ḥurma* and *karāma*)
- ◆ Organ donation is impermissible in principle, but is conditionally permitted on the basis of dire necessity (*ḍarūra*)
- ◆ Organ donation is permissible with several stipulations, because it serves general public interest (*maṣlaḥa*)

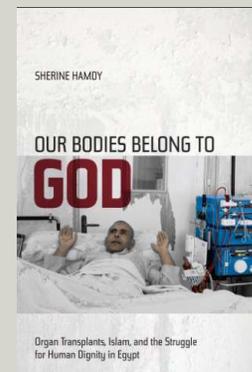


Religious Permissibility is Not the Only “Muslim” Concern

- Personal Concerns:
 - Treatment of the body → Will religious modesty requirements be met?
 - Moral culpability for deeds of the recipient → Can I choose/designate?
 - Health consequences in the future: Increased risk of kidney failure
- Societal Concerns:
 - Organ donation promotes into organ barter and illicit trade
 - Lack of prioritization of other solutions: Prevention, Xenotransplantation, Synthetic Organs
- Knowledge gaps:
 - Processes involved for living vs. deceased
 - “Brain Death”: Is it legal death or dying state in Islam

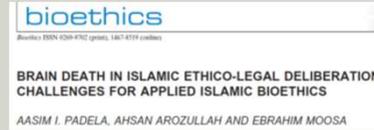
A Mosque-Based Qualitative Study on American Muslim Women’s Organ Donation Beliefs

Rosie Duivenbode, MD, MSc¹, Stephen Hall, MPH^{1,2}, and Aasim I. Padela, MD, MSc^{1,2}



Community
Voices

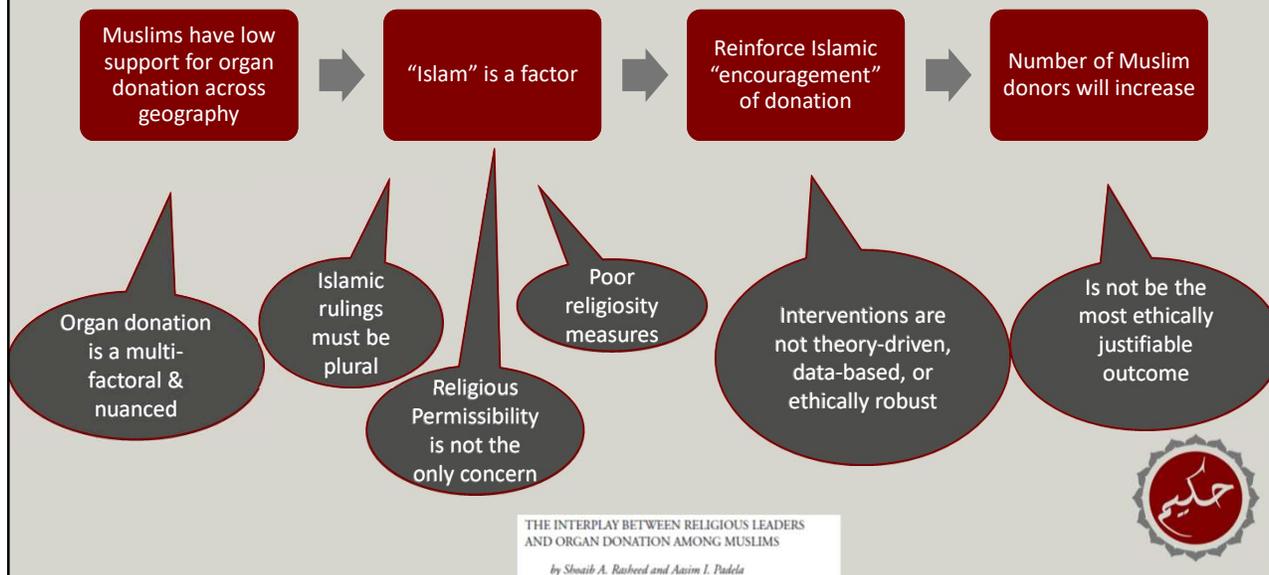
Unaddressed Terminology & Ethical Dimension



Differentiation between living and deceased donation is based on acceptance of neurological criteria for death as human death

Year	Juridical Body	Endorsed Brain Death as • Legal Death (LD) • Unstable Life (UL)
1981	Religious Rulings Committee of Kuwait	Brain death is NOT legal death
1982	Senior Religious Scholars Commission in Saudi Arabia	Yes, LD
1985	IOMS	Yes, UL
1987	Council of Islamic Jurisprudence of Muslim World League	Yes, UL
1988	OIC-IFA	Yes, LD
1994	Majlis al-Shura al-Islami, South Africa	Yes, LD
1994	Majlis al-Ulama, South Africa	BD person is alive
1995	United Kingdom Muslim Law Council	Yes, LD
1996	Indonesian Council of Ulama	Yes but unclear

Critical Appraisal of the Logic Train



Professionals: Workshop Intensives

Dissecting the Ethics of Organ Donation: One-Day Intensive

8:00 – 8:30
Registration and Continental Breakfast

8:30 – 8:45
Welcome

8:45 – 9:15
An Introduction to Islamic Bioethical Discourse: Key Concepts and Actors
Dr. Aasim Padela

Living Organ Donation

9:30 – 10:00
Biomedical Aspects of Living Organ Donation: Terminology, Procedures and Data
Dr. Milda Saunders

10:10 – 10:40
Ethical issues in Living Liver Donation
Dr. Talia Baker



Organ Procurement Process



Biomedical Aspects of Living Organ Donation



Islamic Juridical Views on the Ethics of Organ Donation

Muslim Debates on Organ Donation

11:45 – 1:00
Controversies, Concepts, and Questions in the Organ Donation Debate amongst Islamic Scholars
Moderated Panel: Shaykh Amin Kholwadia, Shaykh Zulfikar Ali Shah
Moderator: Dr. Rosie Duivenbode

- LUNCH & PRAYER -

2:00 – 2:20
Kidney Transplantation in Iran and the Moral Economy of Paid Living Unrelated Donation
Dr. Ehsan Mirshahi

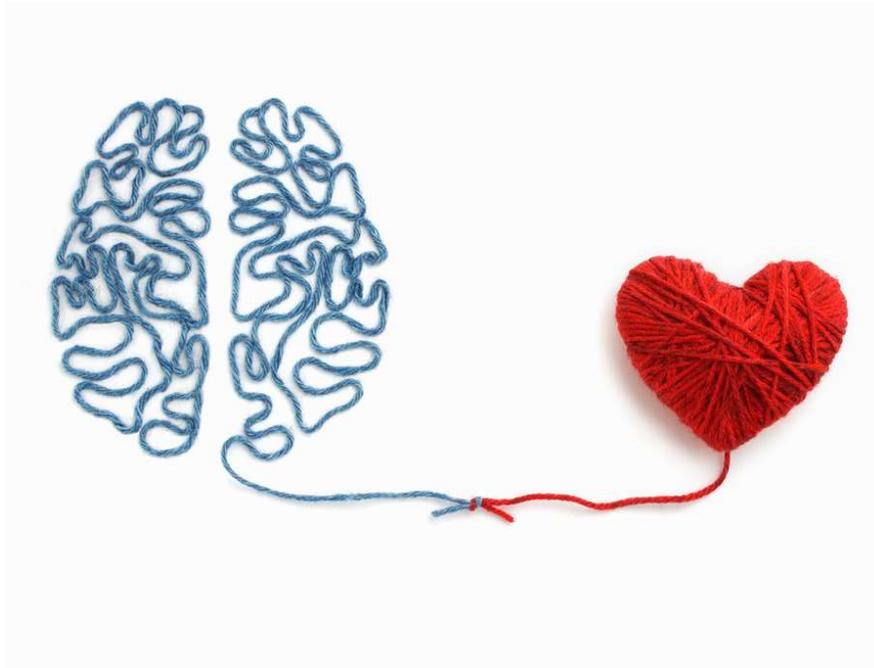
2:30 – 2:45
Research Project: Informing American Muslims on Organ Donation
Dr. Rosie Duivenbode

Deceased Organ Donation

3:00 – 3:30
Human Dignity in the Organ Donation Debate
Dr. Rifaqat Rashid

3:45 – 4:15
Probing the Boundaries of Death: Juridical Rulings on "Brain Death" and Liminal States
Dr. Aasim Padela

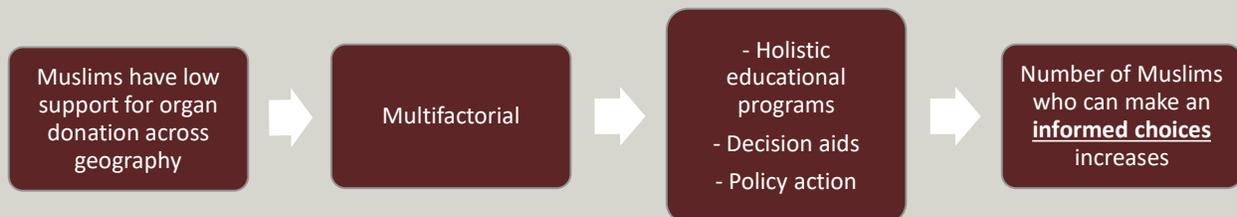
Organ donation

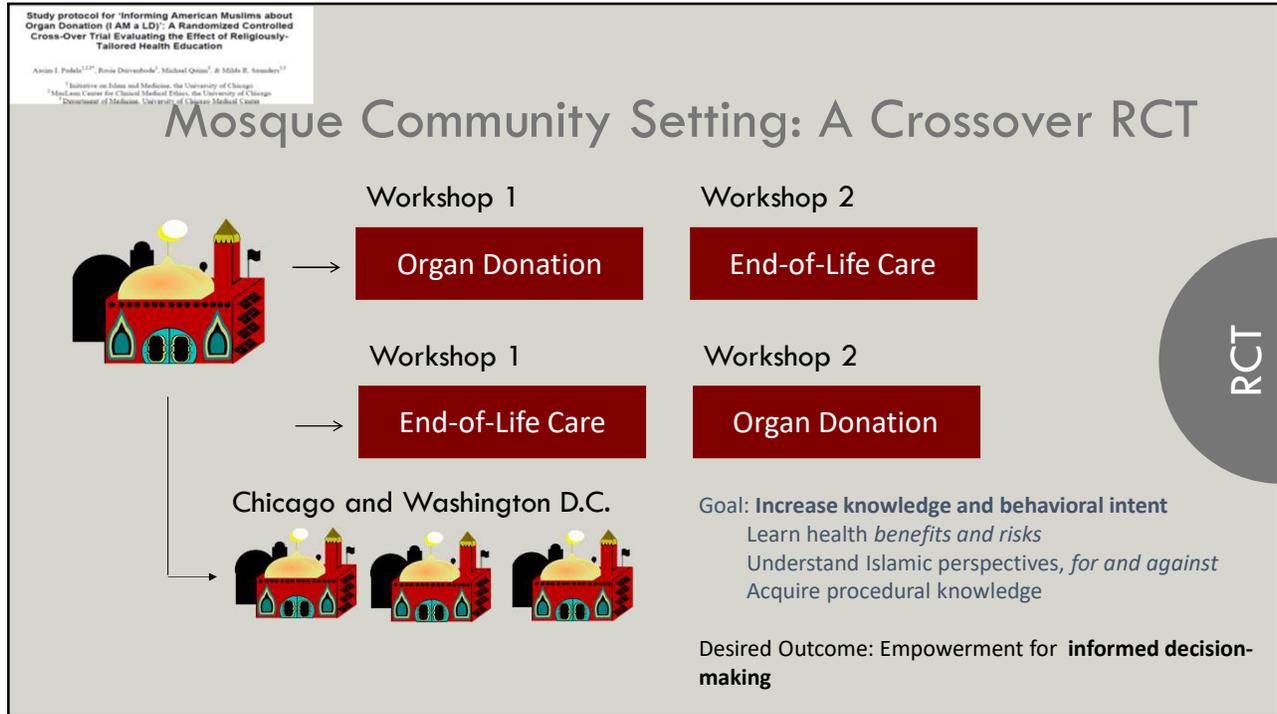


Religiously-Tailored & Ethically-Balanced Workshops on Organ Donation



Adjusted logic train for intervention design





The Intervention

- ❖ +/- Sermon "Advert"
 - ❖ Importance of religious bioethical knowledge
 - ❖ Communities are caretakers for one another
- ❖ Didactic lectures
 - ❖ Biomedical Knowledge Gaps
 - ❖ Religious Knowledge Gaps
 - ❖ Procedural Knowledge Gaps
 - ❖ Address myths & misconceptions
- ❖ Peer educator-led group discussions
 - ❖ Share & Compare views
 - ❖ Discuss uncertainties

COURSE BOOK

ORGAN DONATION WORKSHOP

JULY 27, 2019
8.30 AM - 2 PM

END-OF-LIFE CARE WORKSHOP

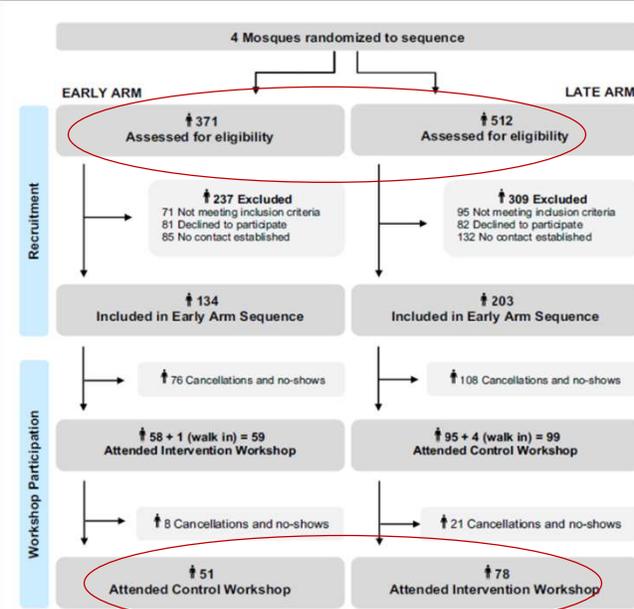
AUGUST 3, 2019

<p>9.30 – 10.10 Biomedical Aspects of Living Organ Donation <i>Dr. Saunders</i></p> <p>10.10 – 10.40 Organ Transplant in the U.S. <i>Megan Craig</i></p> <p>10.40 – 10.55 Coffee/Tea</p> <p>10.55 – 11.50 Islamic Perspectives on Living Organ Donation <i>Dr. Padela</i></p> <p>11.50 – 12.45 Facilitated Group Discussions <i>Peer Educators</i></p>	<p>9.00 – 9.30 Critical Theological Concepts about Sickness & Health in Islam <i>Imam Azfar</i></p> <p>9.30 – 10.15 Islamic Rulings about Brain Death & Withdrawing/Withholding Life Support <i>Dr. Padela</i></p> <p>10.15 – 10.30 Coffee/Tea</p> <p>10.30 – 11.25 Panel Discussion: Processes and Considerations Surrounding Deceased Organ & Tissue Donation <i>Dr. Azam, Kara Cameron</i></p> <p>11.25 – 12.20 Facilitated Group Discussions <i>Peer Educators</i></p>	<table border="1"> <thead> <tr> <th>pros</th> <th>cons</th> </tr> </thead> <tbody> <tr> <td> <ul style="list-style-type: none"> * prolonged the life of someone who can change their life for the better * good intentions * ^{deceased organ donation:} chance to do good, to serve Allah (opportunity and blessing to give) </td> <td> <ul style="list-style-type: none"> * benefit someone you don't like (i.e islamaphobe) * person doesn't take care of the "gift" * painful to go through operation deceased organ donation — donation for research or teaching, issue of → modesty </td> </tr> <tr> <td colspan="2"> <p>once donated, are we accountable for how it is used?</p> </td> </tr> </tbody> </table>	pros	cons	<ul style="list-style-type: none"> * prolonged the life of someone who can change their life for the better * good intentions * ^{deceased organ donation:} chance to do good, to serve Allah (opportunity and blessing to give) 	<ul style="list-style-type: none"> * benefit someone you don't like (i.e islamaphobe) * person doesn't take care of the "gift" * painful to go through operation deceased organ donation — donation for research or teaching, issue of → modesty 	<p>once donated, are we accountable for how it is used?</p>	
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<p>once donated, are we accountable for how it is used?</p>								



Participant Flow

- Inclusion/Exclusion
 - Adult, self-identified Muslim
 - English proficient
 - No personal or immediate family history of donation or transplantation



	EARLY ARM	LATE ARM
Recruitment	<ul style="list-style-type: none"> Assessed for eligibility: 371 Excluded: 237 (71 Not meeting inclusion criteria, 81 Declined to participate, 85 No contact established) Included in Early Arm Sequence: 134 	<ul style="list-style-type: none"> Assessed for eligibility: 512 Excluded: 309 (95 Not meeting inclusion criteria, 82 Declined to participate, 132 No contact established) Included in Early Arm Sequence: 203
Workshop Participation	<ul style="list-style-type: none"> 76 Cancellations and no-shows Attended Intervention Workshop: 58 + 1 (walk in) = 59 8 Cancellations and no-shows Attended Control Workshop: 51 	<ul style="list-style-type: none"> 108 Cancellations and no-shows Attended Control Workshop: 95 + 4 (walk in) = 99 21 Cancellations and no-shows Attended Intervention Workshop: 78

TABLE 1 Participant characteristics by study arm (n = 158)

Characteristics	Overall No. (%)	Early arm (N = 59)	Late arm, (N = 99)	P value
Socio-demographics				
Sex (n = 152)				
Female	83 (54.61)	34 (58.62)	49 (52.13)	0.435
Racial/ethnic background (n = 151)				0.653
South Asian	125 (82.78)	47 (81.03)	78 (83.67)	
Other	26 (17.22)	11 (18.97)	15 (16.13)	
Age, mean (range) (n = 151)	47 (18, 85)			0.000
18-30 years old	29 (19.21)	20	9	
31-40 years old	30 (19.87)	12	18	
41-50 years old	32 (21.19)	12	20	
51-60 years old	23 (15.23)	9	14	
61-70 years old	21 (13.91)	2	19	
71-85 years old	6 (10.60)	2	14	
Country of origin (n = 151)				0.042
United States	36 (23.84)	19 (32.76)	17 (18.28)	
Other	115 (76.16)	39 (67.24)	76 (81.72)	
Residency in the US (n = 117)				<0.001
20 years or less	42 (35.90)	23 (57.50)	19 (24.68)	
More than 20 years	75 (64.10)	17 (42.50)	58 (75.32)	
Primary language (n = 151)				0.033
English	67 (44.37)	30 (51.72)	37 (39.78)	
Urdu	61 (40.40)	16 (27.59)	45 (48.39)	
Other	23 (15.23)	12 (20.69)	11 (11.83)	
Religiosity				
Positive religious coping, mean (range) (n = 145)	26.34 (7, 28)	26.07 (19, 28)	26.52 (7, 28)	0.383
Negative religious coping, mean (range) (n = 149)	6.47 (3, 12)	6.14 (3, 12)	6.67 (3, 12)	0.297
DUREL, mean (range) (n = 148)	23.14 (6, 27)	23.38 (16, 27)	22.98 (6, 27)	0.419
Organ donation experience				
Organ donor registrant (n = 150)				
Yes	27 (18.00)	11	16	0.746
Relative or close friend who needed, received, or donated an organ (n = 152)				
Yes	43 (28.29)	18 (31.03)	25 (26.60)	0.555
Health (short form 1)				
Very poor/poor	0 (0.00)	0 (0.00)	0 (0.00)	0.906
Fair	21 (13.82)	7 (11.84)	14 (15.05)	
Good	46 (30.26)	17 (28.81)	29 (31.18)	
Very good	47 (30.92)	19 (32.20)	28 (30.11)	
Excellent	38 (25.00)	16 (27.12)	22 (23.66)	

Rotterdam Renal Replacement Knowledge Test (R3KT)

Biomedical Knowledge of Living Donation

Please indicate whether the following statements are true, false or that you don't know.

	True	False	I do not know
1. Surgical complications after donation are common in living kidney donors	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
2. Donating a kidney increases the risk of developing a kidney disease	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
3. Most living kidney donors remain in the hospital for 2 weeks after surgery	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
4. Very few living kidney donors have long-term health problems after donation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
5. Kidney donation may affect a woman's chance of getting pregnant	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
6. Most living kidney donors can participate in sports and work within 4-6 weeks after donation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
7. When the kidney of a living donor does not match the recipient, living donation is no longer an option with this donor	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
8. A living kidney donor has to be younger than 50 years old	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
9. Only direct family members (brothers, sisters, parents or children) can donate a living kidney	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
10. All the hospital costs of a living kidney donation are paid for by the recipient's health insurance and not by the donor's insurance	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Outcome

Islamic Knowledge of Living Organ Donation (IK-LOD)

The Development and Validation of the Islamic Knowledge of Living Organ Donation Knowledge Scale for Measuring Organ Donation Knowledge Among Muslim Communities

Aasim I. Padela, MD, MSc^{1,2}, Rosie Duivenbode, MD, MSc¹, and Michael Quinn, PhD²

PROGRESS IN TRANSPLANTATION
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DOI: 10.1177/1544201922111919
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Religious Perspectives on Living Donation
Please indicate whether the following statements are true, false or that you don't know.

	True	False	I do not know
11. Some Islamic jurists see violating human dignity (<i>karāma</i> or <i>hurma</i>) as grounds for a prohibition on living organ donation	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
12. According to Sunni scholars, the sale of human organs is permissible when a dire necessity (<i>darūra</i>) exists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
13. Because scholars differ about whether Islamic law prohibits, permits or encourages organ donation one is free to make whatever choice he/she deems justified	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
14. The majority of Islamic jurists deem living organ donation impermissible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
15. Those Islamic jurists who permit living organ donation consider the consent of the donor an essential requirement	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
16. The donation of sperm and eggs is generally considered to be permissible by Sunni Islamic jurists	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
17. On the basis of dire necessity (<i>darūra</i>) some Islamic jurists have deemed living organ donation permissible	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
18. When there is substantial harm to the donor, the permissibility of living organ donation can be overturned	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
19. Living donation of an organ that will cause your death (e.g. heart) is permissible according to Islamic Jurists in case of dire necessity (<i>darūra</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>
20. Sunni Islamic jurists deem receiving money for organs to violate human dignity (<i>karāma</i> or <i>hurma</i>)	<input type="radio"/>	<input type="radio"/>	<input type="radio"/>

Outcome

Increased Biomedical Knowledge

TABLE 3 Change in biomedical knowledge (R3KT)^a over the intervention period

	Intervention period (2 weeks)			Within-subjects difference
	Time 1 (baseline)	Time 2 (postintervention, preintervention)	Time 3 (postcontrol, postintervention)	
Early arm				
Mean (SD)	4.52 (2.41) →	7.65 (1.65)	7.35 (1.54)	
Sample size				46
Late arm				
Mean (SD)	4.00 (2.46)	4.90 (2.28) →	6.81 (1.82)	
Sample size				63
Treatment effect				
Sample size				109
Between group t test comparison	P = .273	P = .015 [*]	P = .274	
ANCOVA Time				0.000 [*]
ANCOVA Time x Arm				0.000 [*]

Note: Paired t tests:
 Early Arm: T1-T2: $t_{45} = -8.21, P = .000$; T2-T3: $t_{25} = 1.66, P = .104$; T1-T3: $t_{45} = -7.32, P = .000$.
 Late Arm: T1-T2: $t_{62} = -3.34, P = .001$; T2-T3: $t_{62} = -6.90, P = .000$; T1-T3: $t_{62} = -8.39, P = .000$.
^aCronbach's α R3KT: 0.682.
^{*}Significant at level of $P < .05$.

ORIGINAL ARTICLE

AJL

Informing American Muslims about living donation through tailored health education: A randomized controlled crossover trial evaluating increase in biomedical and religious knowledge

Aasim I. Padela^{1,2,3} | Rosie Duivenbode¹ | Michael Quinn³ | Milda R. Saunders^{2,3}

Knowledge

Increased Islamic Knowledge

TABLE 2 Change in Islamic knowledge (IK-LOD)^a over the intervention period

	Intervention period (2 weeks)			Within-subjects difference
	Time 1 (baseline)	Time 2 (postintervention; preintervention)	Time 3 (postcontrol, postintervention)	
Early arm				
Mean (SD)	4.02 (1.95)	7.11 (0.99)	7.09 (1.07)	
Sample size				46
Late arm				
Mean (SD)	4.53 (2.48)	5.19 (2.09)	7.16 (1.39)	
Sample size				70
Treatment effect				
Sample size				116
Between group t test comparison	P = .065	P = .000 [*]	P = .304	
ANCOVA Time				0.000 [*]
ANCOVA Time x Arm				0.000 [*]

Note: Paired t tests:
 Early arm: T1-T2: $t_{25} = -9.9, P = .000$; T2-T3: $t_{25} = 0.14, P = .888$; T1-T3: $t_{25} = -10.55, P = .000$.
 Late arm: T1-T2: $t_{69} = -2.7, P = .008$; T2-T3: $t_{69} = -8.34, P = .000$; T1-T3: $t_{69} = -7.95, P = .000$.
^aCronbach's α IK-LOD: 0.728.
^{*}Significant at level of $P < .05$.

Knowledge

Changed Belief Structures

TABLE 2. CHANGES IN ATTITUDE TOWARDS ORGAN DONATION

	Baseline		Post	Δ	p-value	Chronbach's α
	Mean (SD)					
Behavioral Beliefs, n = 131	28.26 (4.82)	→	29.13 (4.49)	0.88	0.007	0.8219
Normative Beliefs (w/MTC),* n=123	17.46 (5.15)	→	19.0 (5.60)	1.55	0.0002	0.7855
Control Beliefs, n = 126	16.18 (3.09)	→	17.44 (2.65)	1.26	< 0.0001	0.7074

*Normative Belief and Motivation to Comply (MTC) scores were multiplied and divided by 32 for appropriate scale.

TPB

Increased Behavioral Intention

Outcome	Baseline	Post	Overall group mean Δ	
	N (%)		Mean \pm SD (95% CI)	p-value
<i>Stage of change</i>				
Thinking about where you are today, which of the following best describes your thoughts on living organ donation? (n = 124)				
I have never thought about it	16 (12.0)	10 (7.9)	0.59 \pm 1.07 (0.40; 0.78)	<0.0001
It has crossed my mind, but I do not know what I think	26 (19.6)	13 (10.2)		
I have thought about it, but I would like to know more	65 (48.9)	36 (28.4)		
I have thought about it frequently and I know the benefits and risks	16 (12.0)	46 (36.2)		
I have thought about it a lot, and I am ready to make a decision if needed	10 (7.2)	22 (17.3)		

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ORIGINAL ARTICLE

Clinical TRANSPLANTATION WILEY

The impact of religiously tailored and ethically balanced education on intention for living organ donation among Muslim Americans

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TTM

Increased Behavioral Intention

Preparedness

How prepared would you feel to make a decision whether or not to donate your kidney to Ahmed? (n = 126)

Not prepared at all	21 (15.9)	7 (5.5)	0.55 \pm 0.86 (0.40; 0.70)	<0.0001
Not prepared	65 (49.2)	34 (26.6)		
Prepared	32 (24.2)	59 (46.1)		
Very prepared	14 (10.6)	28 (21.9)		

Likelihood to perform donation-related behaviors

[How likely are you to] donate your kidney? (n = 127)

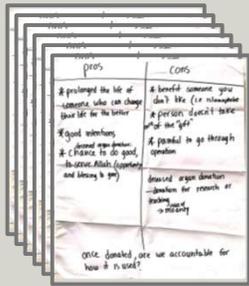
Extremely unlikely	25 (18.8)	5 (3.9)	0.39 \pm 0.85 (0.24; 0.53)	<0.0001
Somewhat unlikely	39 (29.3)	30 (23.3)		
Somewhat likely	58 (43.6)	76 (58.9)		
Extremely likely	11 (8.3)	18 (14.0)		

[How likely are you to] encourage a loved one with end-stage renal disease (ESRD) to seek out a donor? (n = 126)

Extremely unlikely	8 (6.0)	0 (0.0)	0.22 \pm 0.84 (0.07; 0.37)	0.0035
Somewhat unlikely	10 (7.5)	7 (5.5)		
Somewhat likely	56 (41.8)	48 (37.5)		
Extremely likely	60 (44.8)	73 (57.0)		

Behaviors

A Religiously-Tailored & Ethically-Balanced Pamphlet



Expert-written content that addresses data-driven community concerns and questions

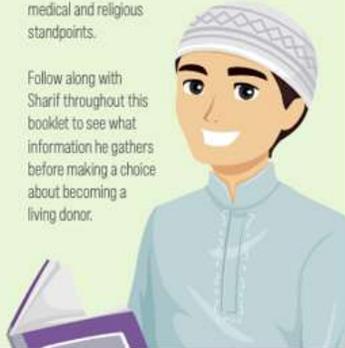


Follow Sharif's Story

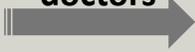
Meet Sharif. He is a very healthy 30-year-old Muslim man living in the United States.

Recently, Sharif's sister, Suhaila, found out she needs a kidney transplant. She went on dialysis and is waiting for Sharif to decide if living donation is right for him from medical and religious standpoints.

Follow along with Sharif throughout this booklet to see what information he gathers before making a choice about becoming a living donor.



Speaks to his doctors



Speaks to his Religious leaders



MEDICAL CONSIDERATIONS

DO WE REALLY NEED PEOPLE TO DONATE ORGANS? ARET THERE OTHER OPTIONS?
There are several options for people in kidney failure, but transplantation is often considered the best. Your loved one may be able to continue on dialysis, but that has significant physical and time burdens attached.

HOW MUCH WILL THIS COST? ARET THERE THINGS I DON'T WANT TO DO AFTER SURGERY?
The surgery itself will be completely free of cost for you, but you may incur some costs in the form of travel expenses for medical testing and lab services from work in the weeks after your surgery. The cost of the operation is the responsibility of the recipient's insurance.

HOW LONG WILL IT TAKE MY LOVED ONE TO GET AN ORGAN IF I DON'T DONATE?
If you don't donate to your loved one, she could be on the national transplant waiting list for 5.5 years or more, depending on her health and other factors. While dialysis is generally an option during this time, it can cause significant strain on the body. Sharp people do not survive the waiting time. If you do decide to donate, the process generally moves very quickly, and the surgery will be scheduled within a matter of months.

Sharif has learned a lot, and his worst fears about the medical aspects of organ donation have been soothed. Now, he needs to find out whether donation is permitted by his religion.

RELIGIOUS CONSIDERATIONS

MY SISTER NEEDS AN ORGAN TRANSPLANT TO LIVE. AM I ALLOWED TO DONATE MY KIDNEY TO HER?
This is a complicated question. Islamic jurists hold diverse views on whether it is permissible to donate an organ. Because scholars differ about whether Islamic law prohibits, permits, or encourages organ donation you can choose to make your own informed decision.

IF ORGAN DONATION VIOLATES HUMAN DIGNITY, WHY DO OTHER SCHOLARS SAY IT IS PERMISSIBLE TO DONATE OUR ORGANS?
There is a legal maxim that says that in times of dire necessity (dharuriyyah), things that are normally considered haram may become conditionally permissible (mubah) or even wajib (obligatory) in other words, a life-saving treatment can override the concerns about the dignity of the human body. The basis for this legal maxim can be found in the Quran:

Sharif understands that while there are concerns about organ donation, some scholars have offered it on the basis of dire necessity. He now has some additional questions for his religious scholar.

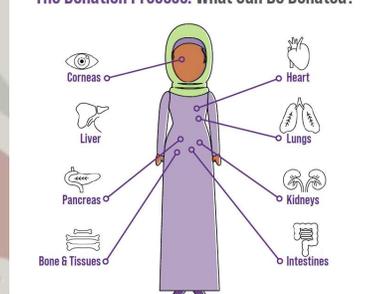
Pamphlet



Next, Follow Sophia's story

Sophia's brother, Karim, passed away a few months ago. Her brother never registered as an organ donor and did not discuss his wishes with anyone. As a result, there was a lot of uncertainty and discussion within the family when the organ procurement team asked if they would like to donate Karim's organs. As a result of this difficult

The Donation Process: What Can Be Donated?



DONATION MYTHS & MISCONCEPTIONS

Don't let false information get in the way of making the right decision for you.

MYTH	FACT
If doctors see that I'm registered to be an organ donor, the hospital staff won't try to save my life.	The only priority of the hospital staff is to save your life. Donation is impossible until all lifesaving measures have failed.
If I donate, burial rituals may be interrupted or negatively affected because my body will be disfigured.	Throughout the entire donation process, the body is treated with care, respect and dignity. Burial rituals are largely unaffected by donation.
If I'm in a coma, they could take my organs.	Comas and critical loss of brain function (sometimes called brain death) are not the same. People can recover from comas, but not from brain death. Determination of brain death is required before deceased donation can be considered.
My family will have to pay for the donation.	There is no cost to donors or their families for deceased organ or tissue donation. Costs are assumed by the recipient or the recipient's health insurance.
Somebody could sell my organs in an illegal market.	Federal law prohibits buying and selling organs in the U.S. Violators are punished with prison sentences and large fines.

What's Right For You?

The decision to donate one's organs should not be taken lightly.

The act of donation involves medical, social, and religious considerations on both sides – for the donor and the recipient. Donating an organ requires the weighing of many factors, including Islamic, social, and biomedical considerations. If you decide to register as an organ donor, research what is included in that decision. It is important to share your decision with your family and your legal next of kin. If you consider to register as an organ donor, make sure to do your research as to what is included in that decision.

Donor Perspective

From the perspective of the donor, the major benefits are:

- The knowledge that the altruistic gift of an organ is saving one or more lives.
- That gift can have a profound impact on the quality and length of life of those who receive the donation.
- If, at some time in the future you will need to receive an organ, as a living donor you will be given special priority and moved to the front of the waiting list.
- In the case of deceased donation, family members might find solace due to the donation.

From the perspective of the living donor, the major risks are:

- Organ donation involves surgery, and surgery can involve some pain, infection, and complications.

Recipient Perspective

From the perspective of the recipient, the major benefits are:

- Receiving a donated organ can significantly extend and improve the quality of one's life.
- Once a person is found to be in need of an organ, he/she may be put on a waiting list for an organ donation. But that wait time for an appropriate match may be several years, during which time health may be further deteriorating and some patients die before an organ becomes available. A benefit to having a living donor (only for donation of a kidney and a section of liver) is that the recipient can receive the transplant without having to wait in line, which eliminates much of the wait time and further deteriorating health.
- Organ recipients can return to work and other activities after a few weeks.

From the perspective of the recipient the major risks are:

- The transplanted organ may be rejected.
- Transplantation involves major surgery, for which recovery is likely to be painful, and can involve complications, and in rare cases even death.
- Recipients will have to take medications for the rest of their lives, which can lead to their own complications.
- Some transplant recipients report feeling guilty, angry, or indebted to the donor. However, some recipients also report that the risk is well worth the longer and improved quality of life.

Living Donation: It's Your Decision

Are you healthy enough to be a living donor?

No → Unfortunately, organ donation is not an option for you

Yes → Many scholars say yes, if some conditions are met

Is living donation permitted by Islam?

No → Some scholars say no, as they believe donating an organ would violate the dignity of your body

Yes → I would like to follow this juridical opinion

Would the donation endanger your own life?

As a living donor, you can't donate a vital organ, such as your heart. You also are not permitted to donate if you are not healthy enough to do so or if the surgery poses unacceptable risks.

No → Will the donation surgery be done by a trained medical team who will take great care to minimize harm?

Any transplant center in the United States consists of trained medical professionals who will take great care of you.

Yes → Will you receive monetary compensation or social benefit for donating your organ?

Direct or indirect payments by the recipient for the organ you are donating is forbidden according to Islamic scholars.

No → Have you taken the decision to donate freely?

This means you make the decision to donate to yourself, and that you do not feel pressure by others to do so (the recipient, your family, the medical team or anyone else).

Yes → **It is not Islamically permissible for you to donate.**

No → **If you feel this decision is right for you, organ donation is a laudable option for you and is Islamically permissible**

Ethics

OPEN

The Moral Status of Organ Donation and Transplantation Within Islamic Law: The Fiqh Council of North America's Position

Aasim I. Padela, MD, MSc^{1,2,3,4} and Jasser Auda, PhD^{5,6}



Letter to the Editor

OPEN

Islamic Bioethical Positions on Organ Donation and Transplantation: Stressing Rigor and Caution in Fatwa Reviews

Aasim I. Padela, MD, MSc^{1,2,3}



The Moral Status of Organ Donation & Transplantation within Islamic Law: The Fiqh Council of North America (FCNA)'s Position



There is a **difference** of Islamic legal opinions on the **permissibility of organ donation** which contributes to **community ambivalence** on the matter.

Using multidisciplinary methods, FCNA **deliberated** over organ donation and transplantation to issue an Islamic ethico-legal verdict (*fatwa*).



FCNA's *Fatwa* on the Permissibility of Organ Donation:

- One must be **living** or be **declared dead** by **circulatory** criteria 
-  • **Harm to donor** is minimized
- An **individual** must **make the final decision** 



This *fatwa* suggests the **need for further societal dialogue** on the ethics and practices of organ donation...

... and **provides nuanced guidance** for assisting Muslims in making **informed choices** on organ donation and transplantation.



Padela et al. *Transplantation Direct*. March 2020



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Public Articles for Muslim Audiences

MEDICAL ETHICS

Helping Those You Know

The possibilities of deceased directed donation

BY ABU FAHAD ABBASI AND AASIM I. PADELA

NEAR OR AT THE TIME OF OUR DEATH, many families will be asked to consider donating "our" organs. As we learn about organ donation, sometimes we wonder if there is a way to identify those who we feel should receive them.

Few of us have resolved our views on this subject, and even fewer have made them known by signing up for a donor registry or outlining our choice in our wills or advance healthcare directives. The diversity of religious opinions, societal pressures and acute need impacting one's choices; the multiple procedures and forms that can be involved; and one's health status and values make any

donation. With general organ donation, the donor is unable to choose a recipient: that decision is dictated by a complex algorithm based on geographic location and the medical status of individuals on the transplant list. DDD, however, enables donors to choose a specific person who will preferentially receive the donated organ should they have a medical need for it.

For Muslims, charity continues even after the deed (*salaqa jariya*). If we enable another Muslim to continue worshipping God, we may also benefit from this perceived altruistic choice. Simply enabling donors by giving them a choice restores autonomy to

is obtained. At this point it usually been identified; if not, ask if anyone within the family. Once a recipient has been identified and consent has been run and consent transplant team facilitates transfer. The recipient will be registered with the OPO will support the throughout the completion of the process.

The practice of DDD is legal in the U.S. under the Uniform Gift Act (UGA), which is a state's anatomical gift statute; effect after the donor's death

MEDICAL ETHICS

Perspectives on Organ Donation and Transplantation

Practical steps to moving forward in light of the latest legal opinion

BY ZAYD AHMED AND AASIM I. PADELA

THE ISSUE OF ORGAN DONATION AND transplantation raises many ethical and religious concerns for Muslims, whether it's signing up for a deceased donor registry or transplanting a kidney to one in need. Such things are relatively new, especially since this necessary medical technology didn't exist during the Prophet's (*salla Allahu alayhi wa sallam*) time.

Thus, given the absence of a direct related statement in the earliest *fiqh* books, we must consult the *usul al-fiqh* (principles of Islamic jurisprudence) and/or the *maqasid al-shari'a*

2,000 children under 18 and almost 70,000 ethnic minorities. Due to organ shortages, the number of transplantations actually performed is far less (Organ Procurement and Transplantation Network, 2019).

The oft-quoted "Whoever saves one life, it is as if he has saved all of humanity" (5:32) signifies the emphasis on saving lives, which may be realized through living or deceased organ donations. But how can this and other divine statements be applied toward relevant modern ethical issues in medicine? The best approach is to turn to those qualified

completing their deliberations, they can issue a fatwa, more specifically defined as a nonbinding opinion on which to base one's action, based upon two essential aspects: 1) It is created upon the shari'a's principles and juridical sources and 2) considers the context in which the question was asked (Padela, 2007, *Islamic Medical Ethics: A Primer*. Bioethics 21:169-78).

The challenge here is that the biomedical science and societal contexts framing the question may be unfamiliar to or beyond a single mufti's expertise. Thus, contemporary fatwa committees commonly convene a meeting of Islamic scholars, along with medical and social scientists, to offer a collective fatwa or position statement.

Over the past several decades, many fatwa committees abroad have discussed organ donation and transplantation. But no leading American *fiqh* council ever addressed this issue until a few months ago. In December 2018, the Fiqh Council of North America (FCNA; <http://fiqhoun>

Insights into the Materials: Parting Thoughts

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