

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

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Abstract

Introduction: Studies around the world demonstrate that Muslim attitudes toward organ donation are closely tied to religion, but also that Muslim publics suffer from a lack of detailed knowledge about the Islamic perspectives on organ donation. Consequently, organ donation professionals and stakeholders are increasingly addressing knowledge gaps in the Muslim community through educational interventions. Yet, a measurement of Islamic knowledge of organ donation, and thereby the efficacy of such education, is not available. **Research Question:** To present the development and psychometric evaluation of the Islamic Knowledge of Living Organ Donation scale, designed to measure knowledge of the Islamic ethicolegal stances, and their underlying rationale, regarding living organ donation. **Methods:** Items were developed based on a review of Islamic juridical perspectives on organ donation, addressed knowledge gaps pervading Muslim communities, and pilot tested. The scale was statistically validated and psychometrically analyzed with a sample of 158 mosque-going Muslims in the United States. **Results:** The 9-item Islamic Knowledge of Living Organ Donation scale was found to be reliable (Cronbach α : 0.86), unidimensional, independent of religiosity, and predictive of social attitudes toward organ donation. **Discussion:** The survey can be used to validly assess Islamic knowledge of living organ donation among Muslim communities in research, educational, and clinical settings.

Keywords

scale development, psychometrics, organ transplantation, Islamic bioethics, religion

Introduction

Across markers of ethnicity, race, and geography, Muslim attitudes toward organ donation, both positive and negative, are closely tied to religious values and beliefs.^{1,2} For example, interviews with 105 Pakistani Muslims found support for organ donation to be rooted in the religious value of preserving human life. At the same time, reluctance was couched in religious notions of human dignity and inviolability.³ These and other empirical and ethnographic data lead researchers to remark that “religion [is] often superseding (sic) all other factors affecting [Muslim] attitudes toward organ donation.”^{4(p362)}

Given the importance of religion, Muslims desire detailed religious guidance on organ donation.⁵ A qualitative study of 141 Muslims in the United Kingdom found participants deferring to the organ donation views of religious leaders in the community,⁶ and data from mosques around Chicago similarly revealed participants desiring knowledge of scholarly rulings on the issue, as well as a high motivation to comply with these.¹

Given these links between religion and organ donation, educational interventions are commonly employed to increase knowledge about Islamic perspectives and thereby influence attitudes and behaviors. For example, in Turkey, Oman, and the United Kingdom, local religious edicts that permit organ donation are popularized through public media campaigns and community events.⁷⁻⁹ Within the United States, organ procurement organizations have held community fora and disseminated informational pamphlets, aiming to increase awareness about permissive edicts and the societal benefits of organ donation.¹⁰ The impact of such interventions is understudied, with

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some scholars suggesting that these efforts may be ineffectual due to theoretical oversights, ethical misgivings, and poor implementation.¹¹⁻¹³ Critically, a measurement instrument assessing Islamic knowledge of organ donation, and thereby the efficacy of such educational interventions and campaigns, is not yet available.

We filled in this critical gap by developing and validating a scale for Islamic knowledge regarding living organ donation. Given the pluralism within Islamic law, well-informed decision-making requires knowledge of both permissive and prohibitive juridical rulings as well as an understanding of their underlying rationale. Additionally, because religiosity can have complex relationships with organ donation attitudes, it can be a force to motivate donation or to detract from it, we designed an instrument that attended to ethico-legal pluralism, and this dual impact. In addition to measuring knowledge among a population, the scale can be used to assess the prevalence of normative beliefs about organ donation and to assist informed decision-making in clinical settings. In what follows, we present the development and psychometric evaluation of the Islamic Knowledge of Living Organ Donation (IK-LOD).

Methods

Phase 1: Development of the IK-LOD Scale

We set the latent construct IK-LOD to be primarily ethico-legal in nature for several reasons. Conceptually, the foundation for Islamic norms inhere within the scriptural sources of Islam, namely the Qur'an and the Sunnah (the statements, actions, and tacit approvals of the Prophet Muhammad). The science most associated with the derivation of such moral norms is Islamic law, thus Islamic ethics and law are closely related.¹⁴ Accordingly, when inquiring about Islamic knowledge about an action, one implicitly refers to the morality of an action as judged by the tradition, its ethico-legal status. This notion bears out empirically, as research demonstrates that Muslim communities are concerned with the religious ethico-legal permissibility of organ donation when making donation decisions.^{1,4,6} Various Muslim publics realize that there is diversity of opinion among Islamic scholars on the permissibility of organ donation.^{1,3} The IK-LOD was constructed to encompass the principal religious arguments for and against donation as well as the underlying rationale and conditions surrounding these views from within the Islamic legal tradition.

The initial item pool was deductively generated from an extensive analysis of Islamic rulings on organ donation.^{15,16} These ethico-legal judgments can be grouped into 3 broad positions: organ donation is either a meritorious or permissible act based on it serving a general public interest (*maṣlaḥa*) in preserving life; organ donation is prohibited because it violates human dignity (*ḥurma* and *karāma*); and organ donation is impermissible in principle but contingently permitted because of a dire need without alternative recourses (*darūra*). Each view is supported by scriptural and legal evidences and is subject to a host of conditions. Items were designed de novo to

cover these different views, rationale, and stipulating conditions. Both factual and counterfactual statements were included. For example, 1 item assessed whether participants could identify the basis for judging organ donation to be permissible in Islamic law, and another inquired about whether selling organs was permitted by Sunni jurists. We concurrently mined the health literature for existing questions and scales assessing the underlying construct, but upon review most available items assessed personal attitudes rather than knowledge of religious perspectives. Ultimately, no extant items were added to our pool.^{2,17} A provisional scale of 10 items was pilot tested at a scheduled event.

Phase 2: Pilot Testing and Refining IK-LOD Items

Field pretesting of the scale under realistic conditions was performed via pen and paper by attendees of an educational workshop on organ donation at the University of Chicago.¹⁸ The attendees (N = 25) were Muslims of diverse ethnic, racial, sex, and professional backgrounds. Each participant completed the scale before and after the event, allowing us to evaluate individual items and as well as change in knowledge after a directed educational activity. While each item consisted of statements that were factually correct or incorrect, 2 different response categories were evaluated: true/false/do not know and a 5-point Likert-type agreement scale. The true/false/do not know version was modeled after the Rotterdam Renal Replacement Knowledge Test (R3KT) and included a "do not know" option in order to limit participants guessing and/or not answering the question.¹⁹ An agreement scale was tested in order to assess participant's perception of certainty along with their knowledge.

Respondents were asked to comment (both written and verbally) on question stems focusing on the clarity of the items in terms of wording and the precision of terms employed. Based on these data and feedback from a panel of survey and health research experts in the Department of Medicine, Center for Health and Social Sciences and the Program on Medicine and Religion at the University of Chicago, several items were rephrased for precision and accuracy. Particular attention was paid to items that were frequently left unanswered, disproportionately answered incorrectly, and were difficult to comprehend. Statistical analyses using paired *t* tests of pre-post scores revealed no added benefit to using the Likert-type response categories (pretest mean 35.09, posttest mean 35.73, $P = .038$) over the yes/no/do not know categories (pretest mean 7.70, posttest mean 8.00, $P = .0240$), hence the yes/no/do not know version was carried forth into the next phase.

Phase 3: Reliability, Validity, and Psychometric Property Testing of the IK-LOD

Our pilot-tested 10-item scale was self-administered in paper form by individuals at 4 mosques in Metropolitan Chicago and Washington DC between January and August 2019. Participants were recruited and underwent informed consent procedures as part of a randomized, controlled, cross-over trial of

religiously tailored and ethically balanced education on organ donation and thus had interest in the topic of the survey.²⁰ Participants had to be 18 years or older, English-speaking, and identify as Muslim. The only exclusion criterion was personal, or immediate family member, history of organ donation or transplantation. Ethical oversight and approval was obtained from the Institutional Review Board of the Biological Sciences Division at the University of Chicago (IRB#s 18-1378 and 19-1909). STATA SE Versions 15 and 16 (StataCorp LLC) were used to perform statistical analyses.

First, we performed an item reduction analysis for which we assessed the Item Difficulty Index (IDI), evaluated the relationships between items and the overall scale (Pearson-, item test, and item rest correlations), and computed the internal consistency reliability using Cronbach α statistics. In this analysis, we retained the notion that an awareness of not knowing the answer to a question is different from having inaccurate knowledge, hence we scored the “don’t know” answer category separately from false answers. These data enabled us to include items that were internally consistent and enhanced scale reliability.²¹ Second, we conducted an exploratory factor analysis using the principal component method to assess the dimensionality of the scale, which was hypothesized to be a unidimensional.

Finally, we assessed the discriminant and predictive validity of the scale using Spearman correlations and regressions to assess relationships with various religiosity and behavioral variables. Given that the IK-LOD relates to Islamic knowledge, we desired to assess its ability to discriminate among respondents in ways different from extant religiosity measures. The (Islamic) religiosity scales used were a modified version of the Duke University Religion Index (DUREL),²² and 2 subscales of the Psychological Measure of Islamic Religiosity (PMIR)²³: the Punishing Allah Reappraisal subscale and the PMIR-Positive Religious Coping and Identification subscale.

The DUREL assesses performance of organizational and nonorganizational activities, as well as intrinsic views on religion. The PMIR-Positive Religious Coping and Identification subscale measures the extent to which Muslims use religious coping methods to deal with life stressors, and the PMIR-Punishing Allah Reappraisal subscale assesses whether people interpret events in their life as punishment from God (negative religious coping). Slight modifications of item phraseology and answer categories of these measures are described elsewhere in detail.²⁰ Given that the IK-LOD measures knowledge of living organ donation, we also included the living organ donation subscale from the R3KT in discriminant validity analyses. This subscale measures knowledge of the benefits, risks, and procedural aspects of living organ donation. For behavioral prediction, we included 4 likelihood items inquiring how likely participants were to (1) donate a kidney, to encourage (2) a loved one, (3) a coworker, or (4) someone at their mosque with end-stage renal disease (ESRD) to find a living donor.

Table 1. Characteristics of Participants in Phase 3 Validation Testing^a

Characteristic	N (%)
Sociodemographic profile	
Sex (n = 152)	
Female	83 (54.6)
Racial/ethnic background (n = 151)	
South Asian	125 (82.8)
Age (n = 151)	
<46 years old	75 (49.67)
≥46 years old	76 (50.33)
Country of origin (n = 151)	
United States	36 (23.8)
Years of US residency (n = 117)	
Less than 20 years	39 (33.3)
More than 20 years	75 (66.7)
Primary language (n = 151)	
English	67 (44.4)
Islamic affiliation (n = 152)	
Sunni	147 (96.71)
Organ donation intent	
Designated donor (n = 150)	
Yes	27 (18.00)
Religiosity	Mean (standard deviation)
Duke University Religion Index (DUREL), scored 7-27 (n = 148)	23.1 (2.94)
Psychological Measure of Islamic Religiosity (PMIR)-Punishing Allah Reappraisal subscale, scored 3-12 (n = 145)	6.5 (2.97)
Psychological Measure of Islamic Religiosity (PMIR)-Positive Religious Coping subscale, scored 7-28 (n = 149)	26.3 (3.04)
Living Organ Donation Knowledge	
Rotterdam Renal Replacement Knowledge Test (R3KT), scored 0-10 (n = 146)	4.23 (2.35)
Islamic Knowledge of Living Organ Donation (IK-LOD), scored 0-10 (n = 148)	4.30 (2.34)

^aN = 158.

Results: Psychometric Analyses and Validity Testing

Characteristics of the Validation Sample

Of 158 participants (see Table 1), there was near equal representation of both biological sexes (female 55%) and a wide age distribution (range 18-85; mean 46). They were primarily of South Asian ethnicity (83%), and the majority was born outside of the United States (76%). Nearly half the sample primarily spoke English at home (44%) and a large proportion spoke Urdu (40%). Almost all participants were Sunni Muslims (98%) and highly religious (mean DUREL score of 23.1 out of 27). Compared to 42% of the general American population,²⁴ only 18% of participants were designated deceased donors, meaning they had registered as a donor on their driver’s license and/or indicated their wish to donate in their living will. With respect to biomedical knowledge of living organ donation, our sample scored similar to the norm reference of the

Table 2. Item Difficulty Index and Exploratory Factor Analysis (Factor Loadings) From Validation Sample.

Question	IDI		EFA	
	Proportion correct	Correct n (N)	Factor 1	Factor 2
1. Some Islamic jurists see violating human dignity (<i>karāma</i> or <i>ḥurma</i>) as grounds for a prohibition on living organ donation (TRUE)	0.55	84 (153)	0.66	0.30
2. According to Sunni scholars, the sale of human organs is permissible when a dire necessity (<i>ḍarūra</i>) exists (FALSE)	0.29	44 (152)	0.71	0.45
3. Because scholars differ about whether Islamic law prohibits, permits, or encourages organ donation, one is free to make whatever choice he/she deems justified (TRUE) ^a	0.41	62 (153)	–	–
4. The majority of Islamic jurists deem living organ donation impermissible (TRUE)	0.24	37 (153)	0.65	0.09
5. Those Islamic jurists who permit living organ donation consider the consent of the donor an essential requirement (TRUE)	0.67	102 (152)	0.72	-0.40
6. The donation of sperm and eggs is generally considered to be permissible by Sunni Islamic jurists (FALSE)	0.49	74 (152)	0.69	0.20
7. On the basis of dire necessity (<i>ḍarūra</i>), some Islamic jurists have deemed living organ donation permissible (TRUE)	0.64	98 (152)	0.70	-0.41
8. When there is substantial harm to the donor, the permissibility of living organ donation can be overturned (TRUE)	0.67	101 (150)	0.70	-0.41
9. Living donation of an organ that will cause your death (eg, heart) is permissible according to Islamic Jurists in case of dire necessity (<i>ḍarūra</i>) (FALSE)	0.60	90 (150)	0.69	-0.19
10. Sunni Islamic jurists deem receiving money for organs to violate human dignity (<i>karāma</i> or <i>ḥurma</i>) (TRUE)	0.15	23 (150)	0.73	0.38

Abbreviations: IDI, item difficulty index; EFA, exploratory factor analysis.

^aThis item was stricken from the final 9-item measure based on the analyses conducted.

general American population on the R3KT living organ donation subscale (mean scores of 4.23 and 4.11, respectively).¹⁹ Participants' mean score was 4.30 (out of 9) on the IK-LOD scale.

Step 1: Item Reduction Analysis

Item difficulty index, internal consistency, and reliability. In our item reduction analysis, we first assessed the IDI, defined by the proportion of correct answers on a given item (see Table 2).²¹ The case/item ratio for each item on the scale was at least 15:1. In this particular group, the index difficulty for most items was moderate or difficult (range 0.15-0.67). While items that are too difficult might be nondiscriminating, we considered item 10 (IDI of 0.15) to be conceptually essential given the unanimous agreement among Sunni jurists that the commodification of organs is prohibited. Next, we evaluated whether all scale items were sufficiently correlated with each other and with the scale. The goal here was to strike items that are not sufficiently related to the proposed latent construct. A Pearson correlation matrix found each item to be either moderately (>0.30) or strongly correlated (>0.50), except for item 3. This item exhibited weak correlations (<0.30) with 6 of 9 items suggesting it be discarded.²¹ Furthermore upon re-examination of the items phraseology some ambiguity and a double-barreled nature appeared as the wording both tested knowledge (“scholars differ about whether Islamic law prohibits, permits, or encourages organ donation”) and inquired of the moral implications of this information (“one is free to make whatever choice he/she

deems justified”). Consequently, item 3 was excluded from the scale.

All the resulting items were highly correlated with the scale (item-test correlation between 0.67 and 0.74) and highly correlated with a scale of the other items only (item-rest correlation between 0.56 and 0.64). Furthermore, the internal consistency reliability was higher when the responses yes/no/don't know were scored as separate responses (Cronbach $\alpha = 0.87$) than when don't know was collapsed into the “no” responses (Cronbach $\alpha = 0.76$). In either case, internal consistency was satisfactory (acceptable or good) and would not improve if other items were discarded (data not shown).

STEP 2: Psychometric Properties of the IK-LOD

Exploratory and confirmatory factor analysis. Exploratory factor analysis using the principal-factor method was used to assess the dimensionality of the 9-item scale. We employed 4 different methods, the Kaiser criterion, percentage of variance, Cattell scree plot, and the ratio of the first and second eigenvalue, to evaluate underlying factor structures.²¹ The first factor had an eigenvalue of 4.36 and a relative weight of 48% in total variance, while the second factor had an eigenvalue of 1.01 and a relative weight of 11%. The Kaiser criterion suggests including any factor that has an eigenvalue of 1.0 but has been criticized for its ambiguity when eigenvalues are close to 1.²⁵ While also somewhat arbitrary, the most conservative estimate of the percentage of variance (as explained by factor 1) needed for a scale to be considered unidimensional is 40%. Cattell scree plot, in which eigenvalues are plotted and the number

Table 3. Discriminant and Predictive Validity Testing for the IK-LOD in the Validation Sample.

	Spearman ρ	P value
Discriminant validity		
Duke University Religious Index (DUREL)	−0.09	.285
Psychological Measure of Islamic Religiousness (PMIR)-Punishing Allah Reappraisal subscale	0.02	.793
Psychological Measure of Islamic Religiousness (PMIR)-Positive Religious Coping subscale	0.10	.224
Rotterdam Renal Replacement Knowledge Test (R3KT)-Living Organ Donation subscale	0.51	.000
Predictive validity		
How likely are you to donate your kidney?	OR (CI)	
How likely are you to encourage . . . with ESRD to seek out a donor?	1.02 (0.89-1.15)	.780
A loved one	1.21 (1.05-1.40)	.007
A coworker	1.14 (1.00-1.31)	.057
Someone at your mosque	1.21 (1.05-1.39)	.008

Abbreviations: ESRD, end-stage renal disease; IK-LOD, Islamic Knowledge of Living Organ Donation; OR, odds ratio.

of values before the last substantial drop are said to fit the data, demonstrated strong support for a one-factor solution.²⁶ Lastly, the ratio between the first and second eigenvalue was 4.3, with ratios greater than 3 or 4 considered to be supportive of a unidimensional scale.²⁷

A one-factor solution was further supported by the loading of items upon the factors, as all items satisfactorily loaded onto factor 1 (see Table 2). Generally, factor loadings of items of a single scale should be above 0.5 and preferably above 0.6.²⁸ For factor 1, every item loaded with a magnitude >0.6 , while none of the items loaded above 0.5 for factor 2. Furthermore, a potential 2-factor solution based on the oblique factor rotation (correlated extracted factors) showed items 1, 2, 4, 6, and 10 to load (>0.5) onto factor 1 and items 5 and 7 to 9 to load (>0.5) onto factor 2. Dividing the items in this way to retain 2 factors reveals no distinguishing characteristics between the items nor presents coherent similarity within each group. Such a division threatens face validity and is conceptually uninterpretable. Taken together, these data supported the IK-LOD scale being unidimensional, having a single underlying latent construct.

STEP 3: Discriminant and Predictive Validity of the IK-LOD

Statistical validity testing was performed by assessing relationships between the IK-LOD and other items and scales included in the questionnaire. Spearman correlation coefficients relating the IK-LOD with the 3 measures of Islamic religiosity—the modified DUREL, the PMIR-Punishing Allah Reappraisal subscale (Cronbach $\alpha = 0.86$ in our data set), and the PMIR-Positive Religious Coping subscale (Cronbach $\alpha = 0.89$ in our dataset)—revealed no significant relationships indicating excellent discriminant validity.²¹ Since the IK-LOD assesses knowledge of living organ donation, we also tested correlations with the living organ donation subscale of the R3KT (Cronbach $\alpha = 0.83$). Here we found the IK-LOD to be significantly ($P = .00$) and moderately correlated (Spearman $\rho = 0.50$) with the living donation subscale of the R3KT (see Table 3).

The scale's predictive validity was evaluated by assessing its correlations with organ donation-related behaviors. The IK-

LOD was not significantly related to personal likelihood to donate a kidney but was significantly predictive of encouraging others afflicted with ESRD—loved ones, coworkers, and mosque community members—to find a donor ($P = .007$, $P = .057$, and $P = .008$, respectively; see Table 3).

Discussion

We report on the development and statistical validation of a novel tool that enables researchers, clinicians, and education specialists to gauge a Muslim population's knowledge of Islamic ethicolegal perspectives regarding living organ donation. Our process yielded a reliable, unidimensional 9-item scale, with a moderate to difficult IDI in our unexposed study population. The scale differentiates respondents' Islamic knowledge from biomedical knowledge regarding living organ donation and was independent of measurements of religiosity. Moreover, the scale predicted respondent social attitudes related to encouraging others within their social sphere to find a donor. While the scale predicted these social intentions, it did not associate with respondents' self-rated likelihood to donate a kidney. Ultimately, according to the theory of planned behavior, intention is shaped by multiple domains (behavioral, normative, and control beliefs), which could potentially explain this finding. In what follows we comment on the relative importance and potential uses of this scale, as well as limitations of the measure and our study.

Most directly, the IK-LOD scale can help organ donation specialists, researchers, and other stakeholders assess Islamic knowledge of organ donation in Muslim populations. The IK-LOD allows, for the first time, for assessing the efficacy of organ donation education directed toward Muslims. In addition, since religious knowledge is a determinant of attitude and behavior in this population, the IK-LOD enables researchers to design and evaluate behavior change interventions. As such, the scale is not just a knowledge test, it assists with designing ethically balanced educational programs because it provides the learning objectives needed to cover both sides of the religiously controversial topic.

In the context of organ donation education in general, and among Muslim communities in specific, the paradigm of ethically balanced education is novel. Given the overwhelming societal needs and benefits of organ donation and the fact that some Islamic authorities and Muslim nations have sanctioned organ donation and transplant, most educational endeavors focus on motivating donation. They do so by presenting one-sided religious arguments that support it. Yet these sorts of interventions have yielded uneven results.^{7,29} Our knowledge assessment instrument aims at informed decision-making from a religious perspective and thereby supports positive attitudinal and behavioral change. Knowledge is but one antecedent to behavior, and once individuals have unbiased knowledge about controversies, they are more likely to move from precontemplation to contemplation stages in their decision-making.³⁰

Beyond educational and behavioral research, the IK-LOD scale has several other teaching and research applications. In the context of religious bioethics classes, seminary and chaplaincy education, or even allied health care professional education, it can be used as a knowledge test. This measure can identify the knowledge gaps of individuals in advisory positions to Muslim patients. In the realm of ethics research, the IK-LOD allows for assessing and comparing the prevalence of normative beliefs among Muslim populations. In so doing, it can provide insight into how various religious constructs and edicts related to organ donation resonate with different Muslim communities.

In the clinical domain, transplant coordinators and clinicians caring for Muslim patients with ESRD could use the items to assess patient religious knowledge about, and readiness for, discussing living organ donation within their social circle. Similarly, living organ donor advocates and organ donation professionals can use the scale to gain insight into the religious knowledge, awareness, and preparedness of prospective Muslim living donors for whom religious perspectives are critically important. Identifying knowledge gaps is the first step in assisting such individuals in making informed decisions.

While the IK-LOD offers many benefits to researchers and educators, we must account for its limitations and need for refinement. The scale itself has several characteristics that must be recognized before it is used. Firstly, the items are in English and were validated among an English-literate population. Thus, the concepts as well as the language must be translated before it is used in non-English literate populations. Second, the validation sample was predominantly South Asian and highly religious. This selection bias calls for future validation in samples with greater racial/ethnic and religiosity diversity as the psychometric properties of the scale need to be further verified.

In addition, it may be worthwhile to assess how well the measure performs in populations with differing levels of education, as we did not require specific educational thresholds (nor measure such) for our validation sample. When adapting measure items to enhance generalizability, it is important to note that a religiously oriented Muslim population is most likely to attend programs focused on imparting religious knowledge on organ donation, thus item wording should be

cautiously adjusted, if at all, to enhance readability for non-religiously oriented Muslims. Another analytic limitation to our work is that we coded “do not know” responses as false when assessing discriminant and predictive validity. Conceptually, individuals who are aware that they do not have knowledge are different from those who have incorrect knowledge. When using the scale to setup curricula, educational specialists may find that not collapsing response categories might be more apropos.

Authors' Note

Aasim I. Padela and Rosie Duivenbode are co-first authors.

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