

“Let’s Talk about Organ Donation”; from a UK Muslim Perspective

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Keywords: *Organ donation, Transplantation, Education, Community, Muslim, Health promotion*

Abstract

There is a chronic shortage of transplant organs in the UK Muslim community. With the UK transition to an opt-out system, the British Islamic Medical Association held a nationwide series of educational meetings exploring barriers to organ donation. Eight public forum meetings were held between June 2019 and March 2020. A panel of experts and patients informed audiences about the process of organ donation and Islamic ethico-legal discourse. Attendees completed a self-administered questionnaire pre and post each meeting which captured demographic data along with opinions regarding permissibility and willingness to donate. Of 554 respondents, there were nearly equal numbers of men and women. The majority (78%) were South Asian. Only 45 (8%) respondents were already registered for organ donation before the event. the commonest reason was religious uncertainty. Before the educational meetings, half of the respondents (50%) were unsure of the permissibility of organ donation in Islam. Of those initially unsure or against the permissibility of organ donation and unwilling to register, 72% changed their opinion towards deeming it permissible and 60% towards a willingness to register indicating a significant change in opinion ($p < 0.001$). British Muslims are less likely than British non-Muslims to be organ donors, and religious concerns are a major, but not the only, perceived barrier. The effectiveness of our brief educational intervention suggests further education at the grassroots level may improve organ donation rates among the Muslim community.

Introduction

There is a significant shortage of organ donors amongst UK Muslim communities despite numerous public education campaigns. BAME groups represent 14% of the British population,(1) but only 7% of the opt-in NHS Organ Donation Register(2) and 31% of people on the transplant waiting list. Muslims represent 5% of the British population (3) and a significant proportion of BAME communities are Muslim. Many Muslims perceive the standpoint of their religion as a decisive factor in their behaviour towards organ donation (OD), and often await the official opinion of Muslim religious scholars on the issue.(4) Despite the release of a fatwa (a non-binding Islamic ethico-legal opinion) in 1995 by the UK Muslim Law (Shariah) Council and others around the world resolving the permissibility of live & deceased

OD,(5) other non-religious barriers, differences in opinion and lack of discussion within communities have meant the Muslim minority in the UK still contributes little to OD.

With the current law change in the UK and transition to an opt-out system, informing Muslim communities is of great importance. Ethnicity data suggests that those who opt-out of the donor register are more likely to be from BAME backgrounds, and 56% of these opt-outs were made by people of an Asian ethnicity. It is therefore important to ensure these communities can make a fully informed decision. The UK's OD Taskforce recognised an urgent need to identify and implement the most effective methods to promote OD and registration to the public generally and ethnic minority populations specifically.(6)

The primary aim of this study is to examine the effectiveness of an educational session, delivered by local physicians and religious leaders, in increasing awareness of OD and its Islamic ethico-legal discourse and rulings within various UK Muslim communities. The secondary aims of this study were to explore both the effect of these interventions in resolving the uncertainties among attendees who were previously unsure of Islam's position towards OD and the willingness of these communities to register for OD post-intervention.

Methods:

The British Islamic Medical Association (BIMA) organised a national campaign named "Let's Talk about Organ Donation" with the aim of determining British Muslim attitudes towards OD and increase awareness of the OD process. Between June 2019 and March 2020, eight open public forums were conducted in various parts of the country (Glasgow, Leeds, London, Manchester, Newcastle, Nottingham and twice in Bradford). These locations were selected due to their relatively generous British Muslim populations. The events were advertised via social media, mosque announcements, the distribution of posters & leaflets in mosques and Islamic study circles, GP surgeries, pharmacies and through word of mouth. The events were held in a mixture of settings including public spaces, mosques and universities.

During the event, attendees listened to a panel of experts consisting of various OD & transplantation healthcare professionals, specialist nurses in OD (SNOD), Islamic scholars, local Imams and Muslim recipients of an organ transplant. Healthcare professionals involved varied with location and included consultants in Critical Care, Nephrology, Transplant surgery and regional clinical leads for OD. The panel was succeeded by a live anonymous Q&A session. Each intervention lasted approximately 3 hours and involved the panel introducing the concept of OD and relevant statistics, patient experiences of being a recipient, the OD process and law change, a discussion on the attitudes of British Muslims towards OD and on organ transplantation from the perspective of the Shariah. The latter part involved familiarising the audience with the current available fatawa on OD, the ethical and moral discourse behind scholars' conclusions and addressing common misconceptions about OD.

Attendees were asked to complete a 9-item anonymised, confidential self-administered questionnaire in English comprising mostly closed-ended questions with specific answer categories in order to gather demographic data and respondents' opinions (see **Figure 1**). The questionnaire was composed of two sections. The first section was completed before the start of the panel discussion and included questions related to demographics (age, gender, and ethnicity) & current OD registration status, as well as an open field for describing the barriers to registering. The second section included two questions regarding opinion on (1) permissibility of OD and (2) willingness to register presupposing OD was Halal. This section was completed before and after the event.

Results on the categorical variables were presented as percentage values. Analysis was performed using version 26 of the SPSS software. Pearson's Chi-Squared statistical test was used to evaluate correlations between different variables. Values with $p < 0.050$ were deemed to be statistically significant.

Results:

Demographics:

The educational intervention was held in eight sittings across seven cities. A total of 554 attendees completed the questionnaire.

Respondents were subdivided into groups for age, sex, ethnic origin, location, and OD card possession. The divisions and characteristics acquired from the survey are highlighted in (Figure 2) and (Table 1) and (Figure 2) below. The male to female ratio was 1.1:1. The most prevalent ethnic groups within the cohort were Pakistani (57.4%), Indian (12.5%) and Arab (9.2%). Nottingham (18.2%) had the highest percentage of participants, followed by Bradford's 2020 run (16.4%) and Newcastle

Part A – BEFORE the session

Your Age: Your gender: ☐ Female ☐ Male

Your Ethnicity: ☐ Bangladesh ☐ Pakistani ☐ Indian ☐ Arab ☐ White ☐ Other

Are you on the registry for Organ Donation (Do you carry an Organ Donor card?) ☐ Yes ☐ No

If No, have you ever thought to register for Organ Donation? ☐ Yes ☐ No

If you haven't registered or thought to do so, why do you think you have not done so?

Do you think Organ Donation is: ☐ Halal (allowed) ☐ Haram (not allowed) ☐ Unsure

If you think it is Halal, would you consider registering for Organ Donation? ☐ Yes ☐ No ☐ Unsure

Part B – AFTER the session

Do you think Organ Donation is: ☐ Halal (allowed) ☐ Haram (not allowed) ☐ Unsure

If you think it is Halal, would you consider registering for Organ Donation? ☐ Yes ☐ No ☐ Unsure

Figure 1: Contents of the distributed questionnaire

(15.5%). Finally, 91.9% (n=509) of the study cohort did not possess an OD card, whereas 8.1% (n=45) did.

Organ Donation registration:

Only 45 (8.1%) respondents were already registered for OD before the event, and of those not registered, 138 (27.1%) indicated they had previously thought about registering. Those who highlighted their reasons for not registering (n=127) cited multiple reasons broadly classified as faith beliefs & views on religious permissibility (73%), lack of knowledge on OD (21%), family influence & reluctance to discuss OD (2%), death & burial concerns (2%) and moral considerations (2%).

Respondents from BAME backgrounds (Pakistani, Indian, Arab, Bangladeshi) were significantly less likely to be registered as organ donors than their White counterparts ($p<0.001$), with 10 out of 29 (34%) White ethnicity respondents already registered but only 33 out of 487 (0.07%) respondents of BAME background.

Question 1 – ‘Do you think OD is religiously permissible?’

Before the education session, when questioned on their perception of the permissibility of OD in Islam (Question 1), only a minority of the cohort considered OD to be permissible (27.6%) and half (50.4%) were unsure. After the education session, there was an overall increase of 51.8% of participants who perceived OD to be

permissible ($p < 0.001$), resulting in an overwhelming 79.4% of the study cohort to consider OD permissible post-intervention. There was also a corresponding 18.2% decrease of participants who believed OD to be impermissible ($p < 0.001$), coupled with a reduction of 33.6% of participants among the 'Unsure' population ($p = 0.006$).

| Demographics | Number of respondents (%) |
|------------------------------|---------------------------|
| Age (years) | |
| <20 | 98 (18) |
| 21-40 | 219 (40) |
| 41-60 | 182 (33) |
| 61-80 | 52 (9) |
| >80 | 3 (0.5) |
| Gender | |
| Male | 266 (48) |
| Female | 288 (52) |
| Ethnicity | |
| Pakistani | 318 (57) |
| Indian | 69 (12) |
| Arab | 51 (9) |
| Bangladeshi | 49 (9) |
| White | 29 (5) |
| Other (incl. Afro-Caribbean) | 38 (7) |

Table 1: Respondents' demographic data

No specific age group or gender group was most likely to select a particular response pre- or post-intervention, and generally most groups manifested a significant shift post-intervention towards permissibility (see Table 2). With regards to ethnicity, Pakistani individuals were most likely to respond 'Impermissible' pre-intervention, with

25.8% ($p = 0.013$) such responses, which became 4.4% post-intervention, demonstrating a statistically significant decrease of 21.4% ($p < .001$). All ethnic groups evaluated through the Chi-squared analysis showed a net increase in 'Permissible' responses and a net decrease in 'Impermissible' responses post-intervention, which was all deemed to be statistically significant ($p < .050$). Significant decreases in 'Unsure' answers were also observed in the Arab population ($p = 0.024$). The majority of those who did not possess an OD card were unsure about the religious permissibility of organ donation in Islam (52.5%) pre-intervention.#

Question 2 – 'If it is religiously permissible, would you consider registering for OD?'

When asked if they would consider registering as an organ donor under the condition that OD was religiously permissible (Question 2), 53.6% of participants answered 'Yes', whereas 46.4% answered 'No' or 'Unsure' before the intervention. When posed the same question after the session, there was an increase of 25.8% of participants who answered 'Yes' ($p < 0.001$). Indeed, there was also a decrease of 7.2% and 18.6% among those who objected to or were unsure, respectively ($p < 0.001$).

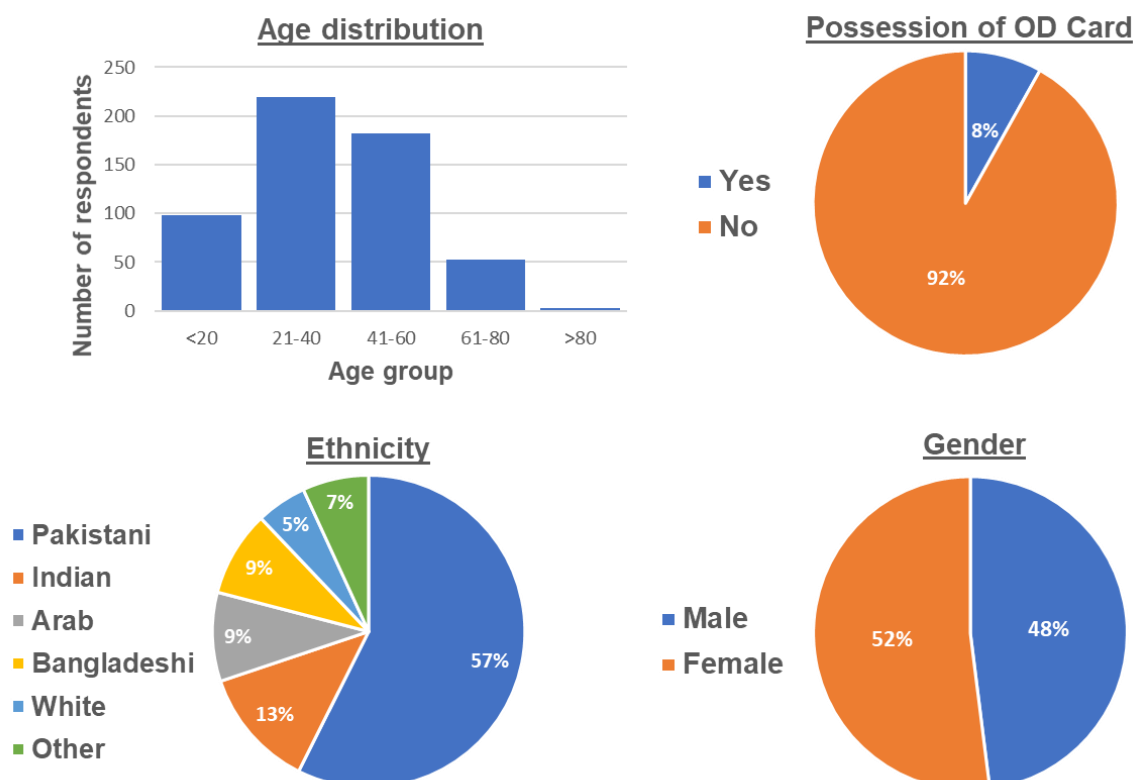


Figure 2: Respondent demographics

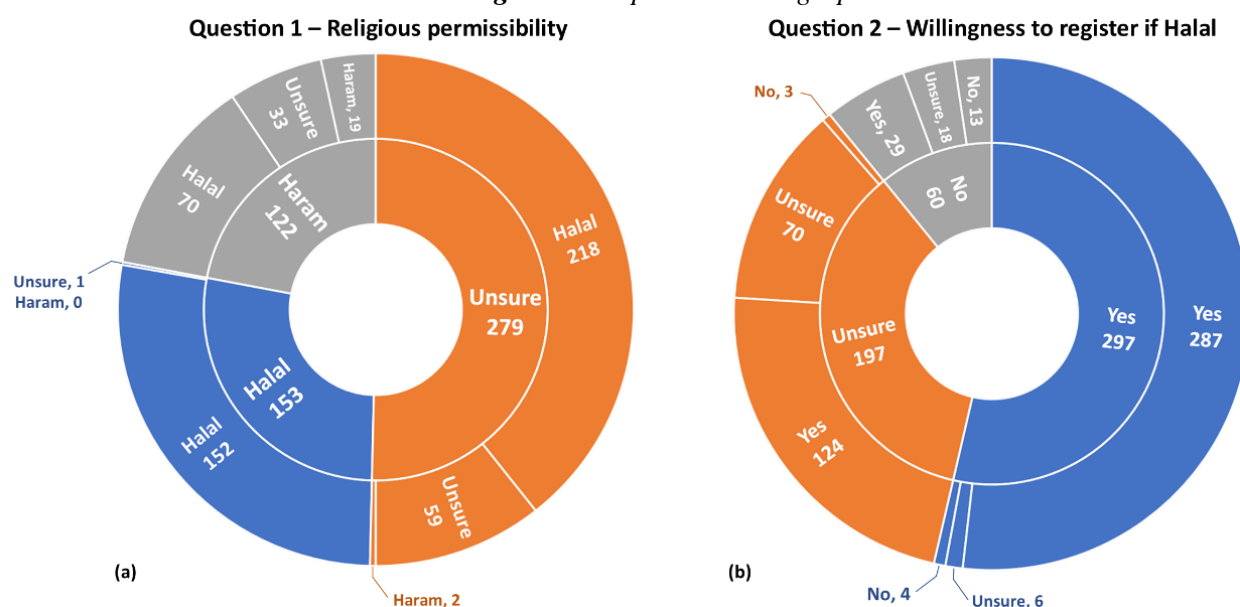


Figure 3: Pre- and post-intervention perceptions on (a) religious permissibility, (b) willingness to register if OD was considered Halal. Inner ring displays number of responses pre-intervention. Outer ring displays post-interventional responses, broken down according to pre-interventional response.

Net Change in Question 1 responses (OD permissibility)

Net Change in Question 2 responses (Willingness to register)

| Variables | Halal (%) | P | Haram (%) | P | Unsure (%) | P | Yes (%) | P | No (%) | P | Unsure (%) | P |
|--------------------|-----------|-------------|-----------|-------------|------------|-------------|---------|-------------|--------|-------------|------------|-------------|
| Age(y) | | | | | | | | | | | | |
| <18 [n=47] | 53.2 | .037 | -21.3 | .014 | -31.9 | .105 | 23.4 | .000 | -8.5 | .000 | -14.9 | .000 |
| 18-24 [n=99] | 53.5 | .003 | -27.3 | .026 | -26.3 | .076 | 16.2 | .000 | -10.1 | .000 | -6.1 | .008 |
| 25-34 [n=103] | 55.3 | .004 | -15.5 | .000 | -39.8 | .636 | 27.2 | .002 | -5.8 | .030 | -21.4 | .025 |
| 35-44 [n=114] | 45.6 | .000 | -16.7 | .000 | -28.9 | .068 | 30.7 | .000 | -3.5 | .000 | -27.2 | .000 |
| 45-54 [n=101] | 54.5 | .005 | -16.8 | .003 | -37.6 | .796 | 27.7 | .000 | -5.0 | .015 | -22.8 | .000 |
| 55-64 [n=50] | 48.0 | .080 | -10.0 | .006 | -38.0 | .287 | 32.0 | .004 | -6.0 | .054 | 26.0 | .011 |
| 65+ [n=40] | 52.5 | .051 | -17.5 | .339 | -35.0 | .893 | 22.5 | .001 | -20.0 | .060 | -2.5 | .037 |
| Sex | | | | | | | | | | | | |
| Female [n=266] | 54.9 | .000 | -19.9 | .000 | -35.0 | .128 | 26.3 | .000 | -6.4 | .000 | -19.9 | .000 |
| Male [n=288] | 49.0 | .000 | -16.7 | .000 | -32.3 | .018 | 25.3 | .000 | -8.0 | .000 | -17.4 | .000 |
| Ethnic Origin | | | | | | | | | | | | |
| Pakistani [n=318] | 51.3 | .000 | -21.4 | .000 | -29.9 | .083 | 27.4 | .000 | -8.2 | .000 | -19.2 | .000 |
| Indian [n=69] | 55.1 | .024 | -17.4 | .001 | -37.7 | .781 | 20.3 | .000 | -4.3 | .018 | -15.9 | .001 |
| Arab [n=51] | 47.1 | .018 | -11.8 | - | -35.3 | .024 | 19.6 | .000 | -2.0 | .091 | -17.6 | .003 |
| Bangladeshi [n=49] | 49.0 | .024 | -16.3 | .004 | -32.7 | .252 | 28.6 | .001 | -12.2 | - | -16.3 | .005 |
| White [n=29] | 75.9 | - | -6.9 | - | -69.0 | - | 37.9 | .120 | -6.9 | - | -31.0 | .046 |
| Other [n=38] | 42.1 | .013 | -13.2 | .002 | -28.9 | .057 | 18.4 | .001 | -5.3 | .004 | -13.2 | .000 |
| OD Card | | | | | | | | | | | | |
| Yes [n=45] | 22.2 | .445 | 0.0 | - | -22.2 | .445 | 17.8 | .007 | 0.0 | - | -17.8 | .007 |
| No [n=509] | 54.4 | .000 | -19.8 | .000 | -34.6 | .017 | 26.5 | .000 | -7.9 | .000 | -18.7 | .000 |
| Total [n=554] | 51.8 | .000 | -18.2 | .000 | -33.6 | .006 | 25.8 | .000 | -7.2 | .000 | -18.6 | .000 |

Table 2: Net percentage change in number of responses for Question 1 and 2 in relation to each demographic variable. Percentage values demonstrate percentage of row total for each question. Significant p-values highlighted in bold. Total net change in responses is seen in the final row.

All age groups displayed a significant net increase in “Yes” responses and net decrease in “Unsure” responses, with all groups under 55 years also showing a significant decrease in “No” responses. Across both sexes, all net shifts were statistically significant. There was a statistically significant increase in ‘Yes’ responses towards Question 2 for all ethnicities ($p < .050$), except for the white population. For the ethnic groups assessed via the Chi-Squared analysis, all but Arabs showed a statistically significant decrease, the largest of which were Pakistanis at 8.2% ($p < .001$). All ethnicities demonstrated a statistically significant fall in the ‘Unsure’ responses, with the white population having the largest decrease at 31.0% ($p = 0.046$). There appeared to be a general post-interventional decrease in ‘No’ and ‘Unsure’ answers regardless of possession of an OD card, except for those who possessed an OD card pre-intervention, which had 0.0% unwilling to register as a donor

Discussion:

This study aims to explore the effects of educational interventions aimed at Muslim communities around the UK on perceptions towards religious permissibility for OD and willingness to register as a donor.

Overall findings suggest a consistent net post-interventional increase in the number of attendees considering OD to be religiously permissible, across all variables. This trend presents in tandem with a post-interventional net decrease in participants who previously considered OD to be impermissible, were unwilling to register as a donor or were unsure of either across all variables.

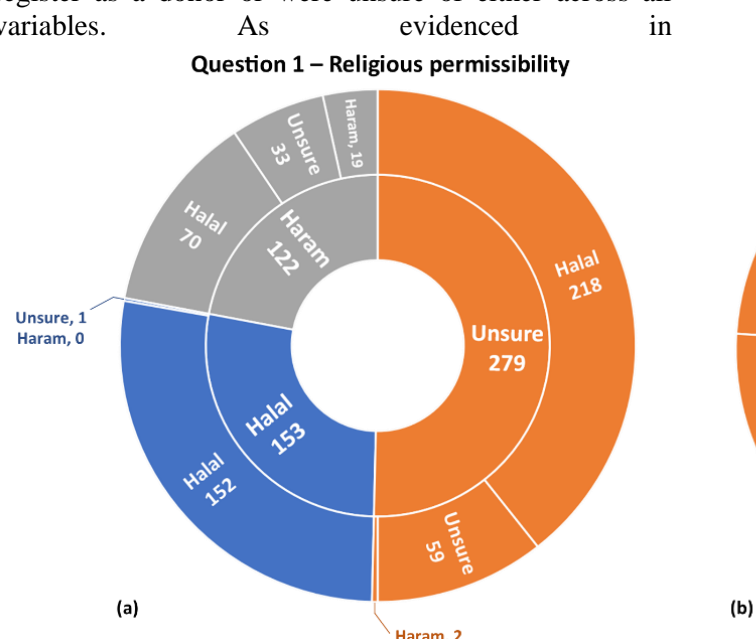


Figure 3, among the 122 participants who answered

'Impermissible'/'Haram' in Question 1, a majority changed their minds and answered 'Permissible'/'Halal' post-intervention. These findings are remarkable as they demonstrate the effectiveness of an educational programme in increasing awareness of the permissibility of OD among Muslim communities.

Another theme we wished to address throughout the study was participant uncertainty and doubts over OD. Irrespective of age, sex, or ethnic origin, there was a substantial shift from 'Unsure' responses towards 'Halal' and 'Yes' answers for Question 1 and Question 2, respectively. This change is emphasized in

Question 1 – Religious permissibility

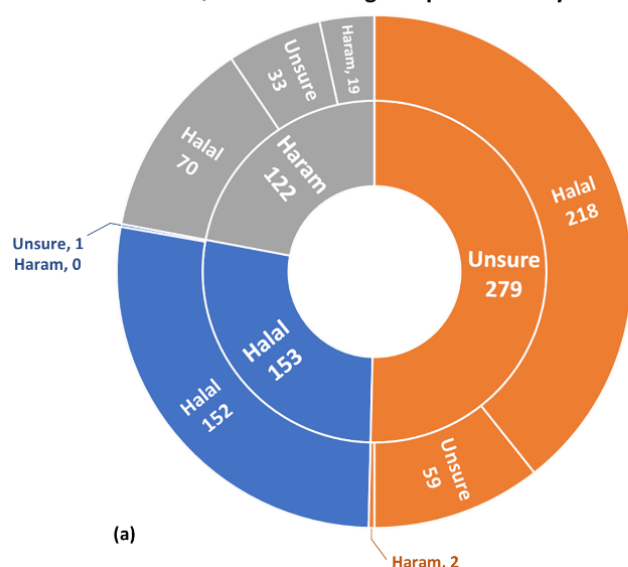


Figure 3, which shows that a large proportion of post-interventional 'Halal' responses originated from the population that had responded 'Unsure' pre-intervention. Furthermore, this shift was also present in Question 2, whereby a large percentage (62.9%) of those who answered 'Unsure' before the session, changed their minds to 'Yes' afterwards. Thus, we can postulate that the intervention was successful in shifting participants' perspectives regarding OD and donor registration from uncertainty towards a more positive stance.

The final aspect that we wanted to explore during this study was whether the intervention was effective in improving participants' willingness to register as organ donors. Before the study, most participants did not possess an OD card but stated that they were willing to register for OD under the condition that it was religiously permissible, a subject addressed previously. Furthermore, there was also a significant number of those who were still unsure or were against registration, despite the assumption that it was permissible in Islam. In the results for Question 2, there was a significant post-interventional

decrease in those unwilling to register or were unsure, which was especially pertinent as this group had responded as such despite the assumption of OD being religiously permissible. This emphasises that religious concerns are certainly not the only barriers to many Muslims, and that even after addressing them there remain other anxieties pertinent. Our educational interventions involved delivering considerable information on the technical processes and procedures of OD before delving into faith-based discussions. Our data suggests including such empirical and specialist information is essential in motivating a significant proportion of Muslims. Healthcare professionals should not lose sight of this when conversing with Muslim patients and families.

In our study, we did find that Muslims community members were less likely to be registered organ donors than White respondents and the general population. The organ donor rate of 8% of our sample roughly matches the population-wide BAME rate of 7.1% (2). We found most respondents were unaware of the religious position on the matter, and that for many, religious concerns were the foremost constraint to donation. A strong emphasis on understanding Islam's position has been found in multiple studies.(7, 8) Compared to 1% of White families, 30% of Asian families cite religious beliefs as their reasons for refusing to consent for OD.(2) A global survey found that 69% of Muslims living in the West agreed with OD in principle but only 39% deemed it compatible with their religion, and that higher self-rated religiosity correlated with less positive views.(4)

The Islamic ethico-legal discourse on OD is varied with scholars divided into three broad categories; (1) live and/or deceased OD is categorically impermissible as it violates human sanctity & dignity or due to repudiation of the notion of brain death, (2) OD is contingently permissible on the basis of dire necessity, and (3) OD is permissible or even praiseworthy as it serves the general human and public interest. The majority of individual scholars and juridical councils fall into the 3rd category and deem OD and transplantation to be ethico-legally permissible. It is worth noting, however, that these religious verdicts are non-binding, and individuals and institutions are free to select their appropriate fatwa based on the presented arguments and moral authority of the jursiconsult. In 1995, the Muslim Law (Shariah) Council of the UK issued a fatwa deeming OD permissible, in line with major global religious institutions such as the Islamic Fiqh Academy of the Organisation of Islam Conference, the Grand Ulama Council of Saudi Arabia and Al-Azhar Academy of

Egypt.(5) In 2000, the European Council for Fatwa & Research issued a similar statement.(9)

Despite the majority of religious scholars supporting OD, this favourable disposition has not been translated into acceptance rates amongst the UK Muslim community. In a 1998 survey in Luton, Rhandawa et al found that that despite Muslim respondents perceiving their religion's standpoint as a decisive factor in shaping their opinion of OD and awaiting a religious scholar's opinion, only a small minority of respondents had heard about the 1995 fatwa.(10) Fatwa-centred interventions have generally proven unsuccessful in reaching out to the general public and overcoming Muslim reticence towards OD. Rasheed & Padela posit the need for a shift away from focussing on advertising fatawa and official, academic legal verdicts to engaging with local trusted representatives and providers of spiritual guidance, such as the local imam or religious mentor, in transmitting and interpreting these fatawa and effecting real health behavioural change in the Muslim laity.(11)

Our data suggests that though most respondents were initially unsure of the religious permissibility of donation, information and clarification from scholars alongside local mosque Imams & community members on the religious bioethical discourse can produce a positive shift towards donation. This large positive change suggests this is not an issue widely discussed amongst Muslim communities and that many of these communities remain in the pre-contemplation stage. Only 27% of respondents not carrying a donor card identified they'd previously considered registering, and 53% indicated before the intervention that if OD was permissible they would be willing to register. The positive shift to 79% willing to register after the event, and the majority of the remaining respondents unsure rather than in opposition to registration, highlights the potential for OD amongst UK Muslims.

Strengths of this study include the large sample size and the use of a standard survey across multiple cities throughout the UK. The primary limitation of this study is regarding the sampling bias, due to Muslim and BAME communities being the targets of the educational sessions explored in this study. Thus, the participants may not reflect the general attitudes in society at large due to the lack of randomisation with the open nature of the educational session. Furthermore, the wording of the questionnaire was a limitation as a potential confounding factor in our methodology. For example, Question 2 in Part A seemed to ask whether the participant would register for organ donation under the condition that it is

religiously permissible. Whereas, in Part B, the answer to Question 2 is dependent on the response to Question 1. Finally, the presentation and questionnaire were both in English, which could have itself presented as a barrier to those for whom English is not their first language. Whilst the events were advertised and geared towards Muslims, there was no confirmation of respondents' religion or denomination (although there is little difference amongst Sunni & Shia scholars on the permissibility of OD).

Greater detail on perspectives is warranted such as willingness to accept an organ, views on live versus deceased donation and views on brain death. Our sample populations may not be representative since attendees would more likely be uncertain from the start over the topic of OD to have found it necessary to attend such events. Although there was positive movement post-intervention towards readiness to become an organ donor, and willingness to register matched views on permissibility, whether attendees later took action and signed a donor card (or did not opt out) is unclear and requires further follow-up. One study has previously shown only a small proportion of participants stating an intention to register actually do so at follow-up.(12)

Recommendations for future research include gathering more detailed demographic data to establish specific population groups amongst British Muslims in particular need of information or in influential positions in their social network to encourage discussion and affect change. Research on the opinions of Imams and local mosque leads is lacking – the only study on this issue included only three Muslim organisation leaders.(13) Reaching out to local imams and preachers and examining the barriers to their involvement in health promotion and the challenges they face with regards to OD is an important step. Appropriate follow-up studies are essential to assess whether these changes in behaviour are actualised. Furthermore, it may be interesting to explore the specific barriers encountered by those who remain resistant to OD post-intervention and improve the content or delivery of these sessions. As this OD education programme is ongoing, we will be able to address the limitations mentioned previously, improve on the methodology and ensure these sessions are delivered effectively to the targeted communities.

Conclusion:

In summary, we identified multiple barriers to OD amongst Muslim communities in the UK. Our focussed local educational interventions produced a significant positive shift in opinion of participants towards OD's

religious permissibility whilst reducing uncertainty and may be used to increase the willingness of Muslim groups to become organ donors. Further work & follow up is needed to evaluate the efficacy of this educational intervention. With the shortage of organs for transplantation, the growing Muslim, BAME & immigrant communities and the UK's transition to an opt-out system, such discussions are surfacing across households & places of worship, and there is a need for the input of local community leaders, healthcare professionals and faith leaders to provide the information & clarification necessary to deal with medical, ethical, religious & cultural concerns regarding OD and enable the formulation of an informed decision.

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