

Institution: Cardiff University		
Unit of Assessment: History (28)		
Title of case study: Advancing understanding of organ transplantation among British Muslims		
Period when the underpinning research was undertaken: 01/01/2016 – 31/07/2020		
Details of staff conducting the underpinning research from the submitting unit:		
Name(s): Dr Muhammad Mansur Ali	Role(s) (e.g. job title): Lecturer	Period(s) employed by submitting HEI: 01/11/2015 – present
Period when the claimed impact occurred: 01/01/2017 – 31/12/2020		
Is this case study continued from a case study submitted in 2014? No		
1. Summary of the impact (indicative maximum 100 words) <p>There is a shortage of registered organ donors from Black, Asian and Minority Ethnic (BAME) communities in the UK. This is often linked to ethical and theological concerns surrounding organ transplantation within Muslim communities and a lack of scriptural sources on organ donation in a modern context. Ali's research clarified the Islamic theological standpoint on organ donation and identified how Muslim communities understand the issue. This research underpinned a public health campaign by the National Health Service Blood and Transplant (NHSBT). By working with spiritual leaders of Muslim communities, as well as individuals at public engagement events, Ali changed the understanding of, and inspired a more positive attitude towards, organ donation.</p>		
2. Underpinning research (indicative maximum 500 words) <p>In the UK, a high proportion of people from BAME backgrounds develop high blood pressure, diabetes and certain forms of hepatitis, which increase their chances of needing a transplant. The best donor match is likely to come from a shared ethnic background, so the shortage of BAME organ donors in the UK reduces the chance of a successful match being found for BAME patients. According to NHSBT, in 2015/16, BAME people made up nearly 30% (1,836) of the waiting list, but only 5% (67) of deceased donors. This means BAME patients often end up waiting significantly longer for a transplant, leading to an increased risk of mortality.</p> <p>Legislation which assumes consent for organ donation unless individuals have opted out has been introduced in Wales (2015) and England (2020), with Scotland due to follow in 2021. Ali's research was inspired by these legislative changes, specifically addressing issues they would raise for Muslim communities.</p> <p>2.1 Theological justifications for and against organ donation</p> <p>A fatwa is a morally (but not legally) authoritative religious opinion from a person trained in Islamic law (mufti). Prior to Ali's research, three organ donation fatwas had been commissioned in the UK in 1995, 2000 and 2004. Although at first appearance all three seem to broadly subscribe to a permissive attitude towards organ donation, they either do not account for dissenting views (2000 fatwa), do not give clear theological and scriptural justification for their conclusions (1995 fatwa and 2000 fatwa), or do not give clear guidance (2004 fatwa) [3.1].</p> <p>In 2018-19, Ali extended his analysis of these fatwas (also called fatawa) to study all relevant fatwas (in English, Arabic and Urdu) outside the UK. He conducted interviews with Muslim scholars to interpret the fatwas in a modern British Islamic context whilst taking careful consideration of the theological and scriptural reasoning. He found that there are seven main - often contradictory - theological standpoints on organ donation [3.2, 3.3]. These range from forbidding organ reception and donation through to suspending judgement until further investigation. Two of these standpoints include that:</p>		

- organ reception and all forms of organ donation (living, circulatory-death, brain-death) are permissible with certain caveats (i.e. an agreement on the interpretation of death). It is an altruistic action, which is encouraged in the Islamic faith. Scholars who support this reading have argued that brain-stem death should be used as the closest criteria of death to the Islamic understanding (where the soul leaves the body) [3.2, 3.3];
- it is permissible to receive an organ but not to donate one. This opinion is popular amongst Muslims, but no scholarly references were found to support it [3.2, 3.3].

Ali's research concluded that there are theological justifications both for and against organ donation, and given that any of the seven positions are theologically justifiable for Muslims to adopt, British Muslims should be allowed to make a personal choice [3.2].

2.2 Understanding and communicating organ donation in the British Muslim community

Ali's cumulative body of research from 2016-2019 found that British Muslims were rarely fully informed of all interpretations around organ donation. In 2016, he documented for the first time the theological reasons behind Muslim reticence to post-mortem organ donation, and the ethical challenges raised by the legislation. His survey of 421 British Muslims found:

- half believed that organ donation was not permissible or were unsure of the situation and would not donate as a result [3.1];
- in the absence of clear scriptural evidence, respondents projected their experiences, understanding of what it means to be a human, and how death and dying is to be conceived, onto the issue [3.1];
- the Welsh and English legislation is deemed to be an infringement of religious sensibility and an affront on the dignity accorded to the deceased by Islam [3.4].

His research also uncovered key themes for discussion around organ donation within the British Muslim community, finding that:

- Muslims have the freedom to change their view in light of personal context or new information: given the absence of clear direction from scripture, people can change their mind or adopt any of the seven positions without theological guilt or moral culpability [3.3, 3.5, 3.6];
- there is a lack of clarity in the debate: proponents and opponents of organ transplantation often pick scriptural references and legal justification to support one particular viewpoint. This led to a lack of understanding around the possible different Islamic positions, and the spread of misinformation [3.2, 3.6];
- the debate is not accessible: simpler language should be used to make sure that individuals understand they can make a personal choice [3.2].

This body of research has provided the clarity and understanding necessary to support new approaches designed to help British Muslims make informed choices about organ donation.

3. References to the research (indicative maximum of six references)

[3.1] Ali, M. 2019. Three British Muftis Understanding of Organ Transplantation. *Journal of the British Islamic Medical Association* 2(1), pp. 42-50 <https://jbima.com/article/three-british-muftis-understanding-of-organ-transplantation/>

[3.2] Ali, M. 2019. Our Bodies Belong to God, So what? God's ownership vs. human rights in the Muslim organ transplantation debate. *Journal of Arabic and Islamic Studies* 19, pp. 57-80 DOI:10.5617/jais.7642

[3.3] Ali, M. and Maravia, U. 2020. Seven Faces of a Fatwa: Organ transplantation and Islam. *MDPI: Religions*, 11(2), 99 DOI:10.3390/REL11020099. Available in REF2.

[3.4] Ali, M. 2020. *Our bodies belong to God: The Human Transplantation and Cardiff Muslims' Response to it, Conference paper: Seminar on Death and Dying at the University of Bath*. Available from HEI on request.

[3.5] Chiramel, F. D., Kalavampara, V. S., Ali, M., Singh, B., and Mohamed, Z. U. 2020. The view of major religions of India on brain stem death and organ donation. *Amrita Journal of Medicine* 16 (2), pp. 82-86 DOI:10.4103/AMJM.AMJM_33_20

[3.6] Ali, M. 2019. Organ donation: 'Redressing the reality'. *Journal of the British Islamic Medical Association*, 2(1), pp. 8-10 <https://jbima.com/article/organ-donation-redressing-the-reality/>

4. Details of the impact (indicative maximum 750 words)

The impact of Ali's research changed understanding amongst British Muslims regarding the permissibility of organ donation. Ali achieved this through influencing the communication of public health campaigns including via the National Health Service Blood and Transplant (NHSBT) and British Islamic Medical Association (BIMA). Workshops across the UK, for example in Cardiff, London, Bolton and Birmingham, also led to an increase in the number of British Muslims pledging to donate their organs.

4.1 Influencing NHS Blood and Transplant's 'Transplantation in Islam' campaign

Since 2017, the research shaped the communication of the NHSBT's 'Transplantation in Islam' campaign. The campaign engages with Muslim faith leaders and community influencers to increase positive attitudes towards organ donation amongst the diverse Muslim communities in the UK. For example, the research supported communication of a new pro-donation fatwa commissioned by NHSBT and published in June 2019. The fatwa provides a religious justification for organ donation, by way of removing theological guilt and helping those who may be unsure to understand that donation is morally permissible.

Ali was asked to play an integral role in the campaign as there was a risk that people might feel the new fatwa was commissioned purely to support a specific government agenda. The NHSBT Project Lead for the campaign, explains that "*Dr Ali's academic work reviewing over 100 Fatawa (religious edicts) on organ donation in Islam are unrivalled in the UK*" and so he was approached "*as an independent academic scholar to demonstrate that the Fatwa was indeed free from any prescriptive directive by NHSBT*" [5.1].

Ali led the communication and public discussion around the new fatwa alongside the NHSBT Project Lead for the 'Transplantation in Islam' campaign [5.1, 5.2, 5.3]. Five videos of Ali interviewing the Muslim scholar, who was commissioned to write the fatwa, were released in June 2019 to explain that fatwa's place within theological and medical doctrine [5.4a]. These videos "*received positive feedback for their clarity and relevance to community concerns*" [5.1]. They are among the most popular on the NHSBT channel, having been watched over 19,494 times [5.4a]. In comparison, the other 11 general videos explaining the new 'opt-out' legislation have only been watched 2,576 times in the same period.

The NHSBT Project Lead confirmed Ali's impact on the success of the campaign: "*His [Ali] outreach has without doubt raised awareness and understanding of organ donation. The diverse Muslim communities have definitely moved from the position of not wanting to engage in the discussion to being more proactive and actively seeking out information as a result of our combined efforts*" [5.1]. NHSBT's Chief Executive and its Director of Organ Donation and Transplantation both thanked Ali for "*providing such extensive insight*" to "*help Muslims across the UK make their own donation decision*" [5.2].

4.2 Increasing understanding of organ donation within the British Muslim community

Ali engaged British Muslims via workshops and media interviews. He worked in particular with imams (religious leaders) as these trusted and well-respected figures have a great deal of influence within their respective communities. This resulted in a more positive view of organ donation among the community and increased the ability of British Muslims to make informed and personal choices about organ donation. This included:

- leading a series of seven workshops and roundtables (funded by NHSBT 'Transplantation in Islam' Community Investment Fund, £2,046). These were held in areas with significant Muslim populations (compared with the total 4.8% population of England and Wales, data from Muslim Council of Britain). For example, 195 imams,

scholars and members of the Muslim community attended events in London (12.4% of the city's population are Muslim), Cardiff (6.8%), and Newcastle (6.3%), with further workshops in Bradford (24.7%), Bristol (5.1%), Blackburn (27%) and Preston (11.2%) [5.1, 5.2, 5.5a];

- speaking at events run by the British Islamic Medical Association (BIMA) in Newcastle (120 attendees) and London (80 attendees). Ali – who spoke on the theological interpretations of organ donation in Islam – was the only academic on the panel with the other members either medical professionals or imams [5.6];
- taking part in media debates and discussions on the theological interpretations of organ donation, including interviews on Islamic TV channel 'Iqra TV' with a weekly average of 62,000 viewers, and live webinars on Facebook and YouTube (for example, an interview on Facebook Live in April 2020 with 515 views) [5.4b, 5.4c, 5.6].

4.3 Impact of this work on community leaders and influencers

Two of the workshops (in Preston and London, with 30 attendees at each) were delivered exclusively to imams. Imam Suliman Gani, from London, states the important role that imams hold as moral guides as *"the community members trust the imam and often rely on his knowledge and guidance...It is important for imams to have the knowledge of organ donation as the Muslim community will rely on him and listen to his views"* [5.7]. Attending the workshops helped change imams' understanding of organ donation, an important message to spread to their communities.

For example, Imam Mohammad Roziur Rahman notes that ahead of the BIMA event in Newcastle *"Imams...were reluctant to attend due to 'legitimising organ donation' by their presence"* [5.8]. However, he confirms that *"His [Ali's] clear explanation and theological examination of the matter proved to be a turning point for all of the attendees"* [5.8]. Imam Suliman Gani notes that *"Dr Ali's research has clarified the Islamic justifications for organ donation and has helped imams to be able to better communicate with the community"* [5.7].

4.4 Impact of this work on community members

National Health Service Blood and Transplant (NHSBT) stated that the workshops led by Ali *"empowered members of the Muslim community and helped them to make a decision regarding organ donation through theologically informed presentations"* [5.9]. Imam Mohammad Roziur Rahman, who hosted the BIMA event in Newcastle, highlighted that *"Dr Mansur Ali made the biggest impact on the audience"* and that his interpretation of Islamic law in an easily digestible and relatable way led to *"a massive achievement"* in communicating this complex area to Muslim communities [5.8].

Feedback from the workshops and sessions for NHSBT [5.5b] showed that:

- over 60% of participants who were either unsure or had viewed organ donation as forbidden, regarded it as permissible in certain contexts after the workshops;
- nearly 95% of participants reported learning new theological standpoints, and that their concerns were alleviated by learning about the multiple possible lines of interpretation;
- 100% of respondents to a post-webinar survey reported a change in understanding from their previous position [5.5b].

Participant feedback from Ali's workshops for NHSBT [5.5b] not only demonstrates this change in understanding, but additionally shows that participants would also now promote and encourage organ donation after the event:

- One workshop participant, who reported that they *"thought it was haram [forbidden by Islamic law]"* at the start of the session, stated afterwards that they now believed *"to donate is a valid position. And I am inclined to donate"*;
- [Before the session] *"That it was absolutely haram"*, but [after the session] that *"Islam is very easy on us, it's our personal understanding"*;

- “[I thought that donation was] Not permissible however after the presentation I understand the whole issue better and can lean to the permissibility of Organ Donation”;
- “I have a better understanding of the opinions of receiving and donating organs as well as the arguments for and against such opinions...I would make people aware of the different stances and inform them that it is not a simple yes or no topic”;
- “I would encourage people to think about organ donation and make an informed decision and then communicate this to their next of kin and families” [5.5b].

Surveys from the BIMA events show a similar change in participant understanding and intention to donate their organs. For example, at the Newcastle event, “most of the attendees were unsure if organ donation is permissible (halal) in Islam and only 16% had registered to be organ donors before the event. After the event 79% showed intention to register as organ donors as they felt it is permissible and a noble deed after they had their concerns and questions addressed” [5.6, 5.9]. BIMA’s Health Promotion Lead stated that “Dr Ali’s analysis of the Islamic jurisprudence and historical and current verdicts (Fatawa) was instrumental in increasing the knowledge and changing the opinion of a significant number of attendees” [5.6].

An NHS tracking code provided for attendees at two of these workshops showed that 25 participants also pledged to donate organs after death (despite the new laws on opt-out organ donation, the NHS still encourages the “pledging” of organs to remove any ambiguity around a person’s wishes after they are deceased) [5.5b]. This represents an important contribution for a group so significantly under-represented in organ donation, as evidenced by the fact that in 2019, there were only 121 BAME (or just 8% of the UK total) deceased organ donors in the UK [5.10].

5. Sources to corroborate the impact (indicative maximum of 10 references)

[5.1] Testimonial: Project Lead NHSBT ‘Transplantation in Islam’

[5.2] Testimonial: Director of NHS Blood and Transplant

[5.3] NHSBT release statement for commissioned fatwa

[5.4] Media sources **a.** NHSBT commissioned interviews discussing new doctrinal and NHS policy change **b.** Iqra TV interview; **c.** Facebook Live with Shoaib Malik

[5.5] Workshops and results **a.** NHSBT end of grant report (2019) **b.** ‘Our Bodies Belong to God: Islam and Organ Transplantation’: Impact Blog (2020)

[5.6] Testimonial: Arshad Latif, BIMA Health Promotion Team Lead

[5.7] Statement: Imam Suliman Gani (South London)

[5.8] Testimonial: Imam Mohammed Roziur Rahman, scholar and lead on BIMA workshops

[5.9] NHSBT Progress Report for BAME Community Investment Scheme Initiative (2020)

[5.10] NHS Blood and Transplant, ‘Organ donation and transplantation data for Black, Asian and Minority Ethnic (BAME) Communities 2018/19’