

Permissibility of organ donation in Islam -

The opinion of lay Muslims in Britain

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"NANA

my grandfather had an affinity for death all his life

death was not a shadow that hung over him but
the very light source he was drawn to

my mother says he talked about dying since she was a child
it's almost as if Allah is holding out especially or maybe my
childhood prayers paid off in the echo of Nana's voice
saying one day he'd go 'upstairs'
I'd plead, Allah let him and my Nani live forever

Nana would probably curse that prayer I
imagine he has prayed for death all his life
not in a sad way, but valiantly

and yet death has been perhaps the only thing life let him hold close tight onto he left
everything behind split the world in half worked the factory night shift in Bradford mills
where cotton was spun and eyesight lost

he never saw his mother pass couldn't
afford to go

now he can but he's
never been back

fifty-five years of dark winters and cold summers

I marvel at him wonder what fear prevents
him going how far inside himself he lives how
many traumas underpin his love of death

he is a tall man but smallness lurks in his
eyes nowadays and sometimes when I
hug his hard body
I wonder at what age brown men are allowed to cry

or is that why he's courting death? perhaps there are no tears left for
this life where the only language he could ever speak heartbreak in was
silence"

(Manzoor-Khan, 2019)

Abstract

This Masters thesis follows on from the 2019/20 undergraduate research dissertation by the same author which documented the interview responses of non-scholarly (lay) Muslims in relation to their opinions about the permissibility of organ donation in Islam. The undergraduate primary research study findings broadly concluded that Muslims in Britain are grappling with their positionality regarding the permissibility of posthumous organ donation because there is an absence of absolute divine decree from the Qur'an and Sunnah. There is however a spectrum of permissibility in Islam derived from the Qur'an and Sunnah based on methodological reasoning within the scholarly Sharia framework as expressed by numerous scholars. Thus, theological, social, and ethical debates amongst Muslims were commonplace with the advent of the Organ Donation (Deemed Consent) Act 2019, which came into effect in England in May 2020. The study found that at individual level, Muslims face multifaceted forums of theological discourse ranging from the opinions of known scholars, respected elders, their own interpretation of ancient scholarly text and a booming global online community of scholars and commentators, which is why lay Muslims were inclined to opt out of deemed consent. The discussion is pertinent because British Muslims are disproportionately represented through Black, Asian, and other Minority Ethnic (BME) people, who are under-represented organ donors. According to 2019 NHS statistics; 408 patients needing an organ transplant died while awaiting a suitable donor.

In this ethnographical research, volunteer participants from multi-generational households are interviewed about their views on posthumous organ donation in Islam. The study highlights intergenerational trends between three generations of mainly labour migrants owing to the demography of those participants who volunteered to take part in this study. This primary research demonstrates a paradigm of moral dilemmas; adherence to customary practice vis-à-vis making informed choices while achieving sharia (doctrinal legal) compliance. This deeply contextual analysis considers the esoteric through societal discourse to develop an understanding of the ethical deliberations for Muslims in Britain who are straddling between cultures and interpretations of religious text.

Background summary

The undergraduate final year project for any student is arguably an opportunity to expound on their cumulative studies, for a BA in Islamic Studies this means demonstrating the interdisciplinary nature of Islamic scholarship regarding theology, history, legislation, philosophy and particularly its relevance in the field of social sciences research. Given the final year undergraduate research is independent and continues over the whole academic year, it is important that the selected topic can sustain the student's interest. Therefore, it is prudent to consider several topics to understand the breadth and limitations for the scope of the topic.

The societal impact of Islamophobia in Britain was thought to be a prime candidate for the dissertation, but initial research indicated that the discussion was academically saturated. Any undergraduate efforts would be reduced to reiterating the recent works of academics such as Salman Sayyid, Khaled Baydoun, and Suhaimah Manzoor-Khan to mention a few. Even narrowing the scope to include primary research and to consider the many manifestations of Islamophobia at societal level such as the impact of physical or political aggression directed at the hijab is widely reported in academic journals and on social media platforms. After acknowledging that despite the merit of such research, personal bias may also come into play to hinder academic objectivity.

From 2018, the English Muslim community online and at societal level were discussing the permissibility of organ donation because of plans to introduce the Organ Donation (Deemed Consent) Act 2019 for posthumous organ donation in the NHS. As social media chat groups were a flurry with links to 'opt out' online, some Muslims were engaged in discussions about the permissibility of organ donation in Islam after death, notwithstanding one's own lack of knowledge on the topic. Where better to start a research project than by sitting on the fence in the midst of enquiry? Initial scoping phases revealed the depth of academic research opportunities while focussing on societal discourse to springboard the discussion as an important contribution for social sciences.

The undergraduate dissertation found that the Organ Donation (Deemed Consent) Act 2019 was planned to be rolled out in two phases; the initial 'soft launch' introduced in Wales in December 2015, followed by roll out across England, Scotland, and Northern Ireland. Within scope of the legislative changes, the heart, lungs, liver, kidneys, small bowel, pancreas, and corneas (part of eye that covers the iris), will be considered for donation (NHS, 2020). During the inception period, the next of kin will be consulted with for overriding consent to retrieve the vital organs of their deceased loved ones to then be transplanted to patients awaiting a

donor from the NHS waiting list, whether the patient had opted out of deemed consent or not (Ali, 2019). The Organ Donation Deemed Consent Act came into effect in England on 20th May 2020 (NHS, 2020), despite speculation that the impact of the coronavirus pandemic on the NHS would cause delays.

The 2019/20 undergraduate dissertation was comprised of academic research and medical journal reviews to demonstrate the spectrum of permissibility of organ donation in Islam. Qualitative primary research with interview participants was also conducted to reflect the viewpoints of lay-Muslims as to whether they believed post-humous organ donation is permissible in Islam. The crux of the undergraduate research for the theological and Islamic legal rationale was derived from Mufti Zubair Butt's research paper regarding the permissibility of organ donation in Islam. British Hanafi scholar Mufti Butt engaged the NHS task force team to develop an understanding for the legitimacy of organ donation in Islam by reviewing ancient scholarly manuals from all four major Sunni madhabs (schools of thought), medical journals, and modern scholarly fatwas (edicts) to derive his jurisprudential opinion; detailed in a 111-page document which is available to download via the NHS website.

In the initial stages, Mufti Butt was of the general opinion that organ donation after death is not permissible in Islam (Randhawa et al. 2012). However, after conducting his own research using jurisprudential methods and reviewing legal manuals while considering the views of other scholars and medics, Mufti Butt released a one-page fatwa which can also be downloaded from the NHS website stating that it is permissible to donate organs after death in Islam although not in the case of brain-stem death (2020). Despite this, in the undergraduate qualitative research, it is argued that a majority of lay-Muslims believe that donating organs after death is not permissible in Islam, admittedly, the sample is size comprised of merely thirteen interview participants. Nevertheless, it is argued that their qualitative responses are reflective of their cultural trends and therefore reflective of the opinions within their wider community. Listed below are the nine key findings from the undergraduate dissertation:

1. “*A majority of the participants believe that the body feels pain after death.
2. *A majority of the participants believe that the body must be buried in the condition it was in at the point of death [i.e., avoidance of post-mortem where possible and removal of organs are impermissible].
3. *A majority of the participants believe that organ donation is impermissible because it would delay the burial.
4. All the participants agree that living donations are permissible in Islam so long as consented and there is no detriment to the donor.

5. *A majority of those participants asked agreed that they would definitely consider donation while alive, albeit altruistic for a member of their family or a close friend.
6. Credence is given to the opinion of family elders and the views of the community.
7. Inherited traditions go unquestioned.
8. Of all nine Indian and Pakistani Muslims interviewed, none identified themselves as Deobandi or Barelwi.
9. Spheres of influence are shifting from local scholar to online scholars” (Fargin, p.28, 2020).

*A majority here means ten or more participants who took part in the study.

Moreover, in the concluding summary it is argued that “English lay-Muslims are undecided and consequently erring on the side of caution by opting out of posthumous organ donation altogether” (Fargin, p.41, 2020). From the lay perspective, this stems from casual readings of hadith scripture to determine an Islamic legal position but fails to understand the validity of hadith through the rigorous methodical framework of Islamic jurisprudence. Although the concluding summary of the undergraduate dissertation cast light on the positionality of lay Muslims regarding posthumous organ donation, it fell short of developing meaningful insights as to why, where, and how such ideas are informed. Thus, scope to continue the research to delve below the surface within this master’s research.

Introduction

This dissertation expounds upon the undergraduate thesis that Muslims in Britain are erring on the side of caution and opting out of posthumous organ donation altogether by broadening the discussion in an attempt to develop a meaningful understanding based on the personal and societal references of research participants. Moreover, the research findings contained in this study is set apart from the previous study for the lay person perception of organ donation in Islam because the period of study coincided with the Deemed Consent (Organ Donation) Act coming into effect, and therefore participants had already given some consideration to whether they want to donate their organs after death; all but one had already opted out. The views expressed by the participants in this research provide insights into their interactions with Islamic teachings for the purpose of establishing Islamic practices in Britain while being a minority community through intergenerational discourse, this does not suggest that all British Muslims share the same lived realities or refer to the same modes of Islamic teaching.

This study reviews the responses of 30 interview participants mainly from 1st, 2nd, and 3rd generation of South Asian (Bangladeshi, Indian and Pakistani) labour migrant communities, owing to the demography of those participants who volunteered. To attempt to map the genesis of Muslims in Britain within this research would gloss over the intricacies of a rich history that is woven into British society. Since the South Asian colonial context is dated over 3 centuries of British Imperialism resulting in mass bloodshed, political and economic destabilisation, civil and religious unrest (Daly Metcalf, 1989); leaving behind a legacy of decolonial unravelling arguably still felt at societal level. Lewis argued “colonialism compounded the difficulties facing Muslim thinkers, India during the British Raj sharply focussed on the discontinuity between theory and practice” (2002, p.50). The lived reality of colonialism had informed the South Asian Muslim mindset in Britain, straddling between being Muslim, being British and remaining somehow connected to their motherland. Incisively, Winter argues. “Britishness is certainly undefinable, and what we have traditionally taken to be its constituents are in any case subject to rapid erosion by the same globalisation that is disembedding Islam” (Winter, 2013, p.6). Although, many academics have written extensively on Muslims in Britain, Gilliat-Ray, Lewis, McLoughlin, Metcalf and Modood are amongst those studied, this study will draw mainly on the works of Lewis to provide an outline of labour migration in Britain to complement the research findings for this study; starting from Chapter 2 through to Chapter 4 to outline a trajectory against the societal narrative gleaned from interview transcripts.

Each chapter is supported with verbatim ethnographies, beginning with the thorny topic of brainstem death as complete death in Islam which is analysed through the lens of lay Muslims. Owing to a methodology that allows the primary research findings to determine the analysis, the definition of brainstem death as complete death in Islam is discussed extensively within a three-part discussion in Chapter 1 because research participants cited pain perception as their main objection to posthumous organ donation. In Chapter 1, emphasis is given to the 3rd generation participants preferred mode of theological research which is via online lectures and through Islamic question and answers web forums to describe how they reconcile Islamic theology with their own lived reality of Islam, this highlights some discrepancies between how the three generations understand and enact Islamic principles while maintaining the discussion of the permissibility of posthumous organ donation at the core. The following chapters analyse the decolonial context for South Asian labour migration, Chapter 2 highlights the lived reality of elderly research participants who migrated from India to West Yorkshire as mill labourers, again describing their mode of Islamic teaching which was mainly through books and the opinions of their local imams.

Chapter 3 follows the intergenerational trajectory of labour migrants as they became established as British citizens and considers their pedagogical influences for establishing an Islamic community, through the lens of their children; the second generation. Chapter 4 explores a prominent trend within the ethnographies of female participants by considering their lived realities associated with scholarly interpretations of religious text.

Albeit deeply contextual, it is argued that despite scholarly fatwa's highlighting the permissibility of posthumous organ donation in Islam, many lay Muslims are still erring on the side of caution and opting out of deemed consent; this is largely attributed to the notion that the deceased perceive pain in the period after death prior to their burial. This notion stems from literal interpretations of scripture and mistrust of the government to a certain extent. However, the analysis of the intergenerational trends demonstrates that new generations are more inclined towards the notion posthumous organ donation despite opting out of organ donation in adherence to their family traditions.

The academic research on organ donation and Islam within this dissertation is anchored in the journal by Ali and Maravia titled, 'Seven Faces of a Fatwa: Organ Transplantation and Islam' (2020), because it provides detailed analysis by seven thematic scholarly representations from around the Muslim world in modern history, thus placing the context within the period of organ donation as standard medical practise specifically. Additional core academic references are discussed within the Literature Review section. This study has taken inspiration from the work of Hamdy, who wrote about the very topic leading up to and during the Arab Spring in Egypt. She argues that "Anthropologists have shown that studying a contested debate in a given social setting can illuminate deeply held beliefs that are sharply articulated during times of crisis" (2012, p.2). This study is arguably underpinned with similar patterns of social unrest in Britain, post Brexit, amidst a global pandemic.

Caveats

This research complies with the University of Leeds ethics approval policy, no further ethics approvals were required on the condition that the title and research method remain the same as the undergraduate dissertation (De Souza, R. 2020). Although, the Director of Arabic, Islamic and Middle Eastern Studies at the University of Leeds, Dr Mustapha Sheikh authorised a title change more befitting to the overall discussion of the thesis (Sheikh, M 2021). A sample template of the ethics approval consent form is included within the appendix.

Participants were invited to partake in the research voluntarily through proxy social contacts via closed social network groups on WhatsApp. Consent forms were signed and dated in advance of the interviews. The interviews were held in accordance with government social distancing guidelines and were therefore conducted online or in person when permitted. Participant verbatim responses are documented in *italics*, squared brackets are used for editorial interjections, words in Arabic and Urdu have been transliterated and translated when they first appear in the text. All participants have been given pseudonyms for anonymity in accordance with the ethic approval policy.

Thirty participants volunteered to take part in the study, aged over 18 years old, all of whom are British citizens, residing in England, most were of either Indian or Pakistani ethnicity. Therefore, this study focuses on the lived realities of South Asian labour migrants because they made up nucleus participant demography. Notwithstanding, participant responses contained in this study by no means infers British Muslim South Asian homogeneity.

None of the participants had an Islamic scholarly background thus the term lay Muslim/s is used throughout. For comparative analysis, some participants are representative of different ethnic backgrounds, in which case, it is noted, although this line of inquiry has not been fully explored due to the time constraints.

Methodology

The principles of ethnography for social sciences are rooted in engaging participants by listening to their stories to develop meaningful insights of the societal context from their point of view. Ethnography provides the basis of effective research for the study of social patterns within cultures and people, and therefore this approach has been adopted for the primary research element of this study. According to Fetterman's principles of ethnography, one's own shared ethnicity with the participants is deemed advantageous. Fetterman argues that "the interview is the ethnographer's most important data gathering technique ...a structured or semi-structured interview is most valuable when the fieldworker comprehends the fundamentals of a community from the 'insider's' perspective" (2007, p.40), thus the term ethnography is applied throughout the study. Additionally, therefore, qualitative research interviews were conducted with open ended questions, starting with asking if the participant was aware of the Deemed Consent Act and then inviting them to discuss their views, i.e., "*what do you think about it?*" This meant the participants took control of the interview, revealed as much or as little they felt comfortable with which was important given the

potentially sensitive nature of the topic. It is argued that this approach yielded nuanced research findings beyond the perceived scope of study to develop insights into how participants over three generations have engaged Islamic pedagogy in Britain with specific references to books and websites used.

To investigate a contested topic from the emic perspective, it is important that the researcher has a methodological approach (Fetterman, 2010) to navigate the research phases and articulate the analytical findings. Ethnography begins with the problem or the topic, then the researcher can select the theory or model “to delineate and shape effort”. (Fetterman, 2010, p. 2). In theory, the researcher has the potential to develop a meaningful understanding of the issues and root causes for certain mindsets and behaviours based on qualitative analysis despite small sample sizes of data. Centred on the findings of the 2019 undergraduate dissertation, this research began with a hypothesis that some lay Muslims were opting out of posthumous organ donation owing to their pre-held beliefs.

According to Audi, epistemology is the theory of knowledge in respect to its methods, validity and scope and the distinction between perception and opinion (2011). Given we all have our own inherent bias, from an epistemological lens, ethnography offers the basis to develop well-meaning societal insights that would otherwise be overlooked insofar as providing multiple views, Fetterman elaborates on this notion as ‘who’s truth’ (2010). “People act on their own individual perceptions, and those actions have real consequences, thus the subjective reality each individual sees is no less real than objectively defined and measured reality” (Fetterman, 2010, p. 5). It was a chance encounter during an initial interview that proved to be the most valuable in terms of revealing not just intergenerational trends, but the intergenerational relationships. During an interview with a young student who was unsure of her madhab affiliation, she turned to her father who she lived with. After gaining his consent to be part of the interview, the pair discussed their views on organ donation as part of the research. Interestingly, the views that the participant had shared with me in favour of posthumous organ donation were completely countered by those of her father. Despite their close relationship and the shared current societal context; their positionality differed based on their pedagogical experiences, while he referred to a local Imam, she referred to online scholars. Despite the differences in opinions initially expressed, the young participant concluded with aligning her views to those of her father to oppose posthumous organ donation. In this regard, Fetterman argues “Ethnography is not always orderly, it involves serendipity, creativity, being in the right place at the right or wrong time, a lot of hard work and old-fashioned luck” (Fetterman, 2010, p. 2). Essentially, this interview itself tested the responses I was receiving in the realist sense.

Arguably, ethnography enables the researcher to develop empathy for the societal barriers that may exist in some cultures. Similarly, being able to observe the relationship between generations of the same family meant I could develop insight into why their viewpoints differ; factors such as educational and socio-economic play into these. The process of collating interview transcripts, then disaggregating the responses to identify thematic trends has informed the analysis in all the chapters of this research. Fetterman discusses theories within the context of ideational and materialistic as being 'prime movers', however he argues that this skims the surface (2010). Having the chance opportunity due to covid restrictions to interview participants from their own home albeit online provided nuanced insights to intergenerational relationships, which may otherwise have been inaccessible.

Ethnography provides a holistic view into culture and makes sense of data of the emic (insider's) to the etic (external) social sciences perspective (Fetterman, 2010). Fieldwork with participants provides a relevant vantage point from which to analyse academic material on the subject. Pre-covid, the participant research phase hoped to engage interview participants at local mosques, community centres and health clinics as the NHS delivered their awareness campaigns, the challenge therefore was to undertake fieldwork during the coronavirus lockdowns because restrictions meant that community events were cancelled and mosques either closed or had strict social distancing regulations in place.

Therefore, the methodological approach was central to help reorganise primary research according to the circumstances. Having an operational Project Management background also helped in this regard because careful planning is key to delivering results. Producing a baseline plan with timelines, deliverables, milestones, and a periodic tracking tool built in provided an analytical overview to ensure objectives were met according to the scope. Additionally, the supervision meetings served as vital checkpoints to ensure progress was being made and issues addressed. This pragmatic approach aided the research phase throughout the unprecedented climate of the global pandemic. Owing to the manoeuvrability of the methodological approach as opposed to a rigid framework; deliverables like the literature review could be switched between phases of research and analysis in response to the immediate societal impact of lockdown. Moreover, most academic journals were made available online by the university; thus, the pursuit of academic research was largely unhindered.

Early studies focussed on understanding the feasibility of conducting ethnography from distance and via online video conferencing apps such as MS Teams, WhatsApp video call and Zoom were prioritised. While in theory, transitioning to an online fieldwork model offered a practical solution, I was worried that the distance would somehow be disservice for

authentic research by yielding filtered participant responses. I therefore turned my attention to academic examples of ethnography from distance, Dr Shwaikh's ethnography of the female hunger striking Palestinian women in Israeli prisons demonstrates that by having that all important 'insiders' perspective, it is possible to conduct ethnography while being physically distant. "As a Palestinian scholar, the topic of political imprisonment has been central to my upbringing. At a young age, one family member served a short period in Israeli prison for his role in the first Intifada. ...My Palestinian nationality served as a common point of reference with the former political prisoners that I interviewed. I had worked with prisoners ...and this gave me familiarity with the culture and language of those I researched. This work experience also forms an important part of my methodology, awareness, and empathy with the interviewees' past ordeals. Having this experience facilitated my conversations with prisoners and it eliminated the tension that often occurs when researching such sensitive issues" (Shwaikh, 2020, p.2). As an outsider, I've always grappled with the notion of hunger strikes, and struggled to understand what motivates a person to protest with their bodies in such a harsh manner. Shwaikh successfully conveys a deeply contextual topic by describing the lived reality to demonstrate the extent of societal and personal challenges the women face, that an outsider can develop a much more meaningful understanding. Thus, inspiring confidence that online interviews are indeed appreciable if they are conducted sensitively with academic integrity. It is to my advantage that I chose to study the perceptions of South Asian Muslims in particular, from an access point of view but also benefiting from having 'insiders perspective' to deploy ethno-semantic techniques. When studying languages and cultures within a multicultural society one learns that some messages are inevitably 'lost in translation', and therefore primary research with the participants is crucial for gaining valuable insights and importantly to ensure the most appropriate tone is adopted when discussing potentially sensitive topics.

The initial plan was to interview thirty participants to understand if there is a difference of opinion between generations. Therefore, I'd envisaged interviewing ten participants from first, second and third generation of British Muslims each. While I could not foresee an issue with engaging younger participants online, I acknowledged that it would be very difficult to engage older participants online. Kelly argues that of the many social inequalities realised as part of the pandemic; digital poverty amongst the elderly is particularly stark (2020). Meaning some elderly people either do not have the means or I.T skills to be digitally proficient. Moreover, based on my previous studies, the notion that older generation participants would be willing to meet a stranger online to discuss a sensitive topic was inconceivable.

Therefore, pragmatic steps were taken to assess if the research could be transitioned online by starting with the third generation. The initial response was overwhelmingly positive after reaching out to established WhatsApp groups through friends, such as those associated with Muslim students by simply highlighting the research topic and requesting volunteers. The quota was fulfilled for the third-generation participants immediately, hence the first stage of fieldwork centred upon the youngest eligible demographic, aged between of 20 and 35. Despite their diversity in terms of ethnicity and madhab affiliation, their responses were markedly similar; all were 'open' to the notion of posthumous organ donation, although most had opted out already in respect of their parents or elders wishes.

Unlike with quantitative data analysis, ethnographic analysis is undertaken in parallel with the data collection process, drawing interim conclusions throughout the interview process mitigated the risk of outweighing the research findings in favour of one leaning. In doing so, analytical assessment of previous interviews facilitated self-evaluation too, was I as the interviewer asking the right questions? Did I need to probe further to explore ideas or frame the questions differently to encourage broader responses. This approach was adopted throughout the research.

Securing second generation participants proved to be slightly more difficult because less than half the potential participants responded, the scheduling of their interviews took considerably longer than planned because many had to prioritise home schooling of their children and working from home schedules. These participants were mainly women of either Indian or Pakistani ethnicity, therefore determined the defining criteria of lay Muslim analysis. Again, similar responses were reported, indicating inherent cultural trends within especially female societal experience. Additionally, this group, once engaged were more inclined to telling their stories and has therefore shaped the more nuanced outlook of this research. Given, some participants lived in multigenerational households and close-knit communities, one was able to recruit the quota for first generation participants through those who had already volunteered, thus overcoming any potential I.T. poverty issues.

One argues that a skilled ethnographer can yield significant output by working with a manoeuvrable methodology that allows the researcher to alternate between research phases accordingly. Therefore, the ethnographies are not all limited to simply one meeting, specifically two second generation participants were reinterviewed for longitudinal analysis. This was particularly useful to assess how ideas and behaviours evolve through relationships and varying generations as part of an important decision-making process.

During the scoping phase, I turned to the published works of Dehlwi in his book 'What Happens After Death', because 1st and 2nd generation participants had referenced the book as informative text, thus; included within the literature review section of this paper. Dehlwi's introductory gambit is pivotal to this primary research because it points to the impact of colonialism, thus demonstrating the epistemology of the colonised Indian Muslims scholars; arguably seeped into the consciousness of first-generation interview participants who were more inclined towards preservation of Islamic values. Additionally, critical analysis of the intergenerational relationships demonstrates positionality changes within an evolving timeframe between generations of Muslims in response to their changing socio-political context from labour migrants to citizens during a time of global mobility and in the digital age meaning they are straddling between preservation and modernist Islam. In trying to understand the lay Muslim perception of organ donation, this research has developed meaningful insight into the societal context over the last few decades to understand the ethical considerations that have shaped the mindset of Muslims living in Britain.

Literature Review

This literature review is comprised of synopses of the oft consulted academic works throughout this dissertation. Chosen because they specifically address the context from a social sciences perspective, the theological considerations of the participants and a selection of academic journals that have cast light on nuanced research areas. Given the broad scope of discussion, the literature review is subdivided by genre.

Social Sciences' Research

Matthews, B, and Ross, L 2010, *Research Methods: a practical guide for social sciences.*

To validate judgement on selecting the most appropriate research tool for this study, I chose to read 'Research methods: a practical guide for social sciences' by Matthews and Ross. Their work was easily accessed online as an eBook which was welcome during the prolonged periods of library closures during the Covid-19 lockdowns. The layout and ability to navigate between specific sections of the book is user friendly online, allowing the reader to choose the relevant sections with ease.

The content is broken down coherently to complement the lifecycle of planning and executing a research project. Emphasis is placed during the initial stages of defining a project for the researcher to first, take a step back and assess the objectives of their research through the lens of social sciences. Matthews and Ross introduce theories and gradually build upon them to demonstrate the breadth of research possibilities by introducing the concept of ontology and epistemology as foundational (2010). Each component is supported with hypothetical case studies to help the reader evaluate the concept and begin to visualize the research output, which can seem too far-fetched during the initial planning stages. However, the density of examples can seem somewhat excessive, in which case, with confidence, the researcher can easily skip to relevant sections.

The authors argue that all too often social sciences studies consider the collective narrative based on shared experience within society and therefore neglects the individual stories (Matthews and Ross, 2010). This played a vital role in shaping this research, rather than focusing solely on the answer, particular emphasis was placed on the 'why' through different experiences, resulting in nuanced findings. The interview questions were therefore framed as an open discussion around the topic of organ donation, arguably by allowing the

participant to tell their stories, the analytical depth is expanded. Furthermore, Matthews and Ross explain how society and how one views the world is not fixed (2010), therefore variations in intergenerational attitudes are regarded as a valuable contribution to the scope of this project. By interviewing multigenerational participants from within the same community, this study has developed insights into external factors that perhaps indirectly influenced a community of people and how they understand their place in society historically and the impact of that today.

Having dealt with the theory, the subsequent chapters adopt a pragmatic approach to assist preparing and planning the research tasks, beginning with design options, namely longitudinal, comparative and ethnography of course. This reinforced the view that ethnography is the preferred choice for this study while also introducing the notion of 'mixed methods' whereby qualitative analysis can be supported with quantitative data. However, some case studies are too broad and therefore are arguably limited to introductory learning or are more suited to classroom-based group discussion studies. Moreover, for the independent learner, Matthews and Ross provide examples of practical tools such as checklists that the researcher can adopt according to their own preference. This helps to track the progress of the project against milestones while ensuring objectives are met. The book is recommended for anyone about to embark on a social sciences research project, the combination of theory, practical tools and case studies make this advantageous for autonomous learning.

Social Sciences' Research – Ethnography

Fetterman D.M. 2010 *Ethnography. Step by Step. Applied social research methods series volume 17.*

Fetterman's work is referenced significantly in the methodology section of this thesis, therefore the literature review is comprised of a short summary to limit duplication.

According to Fetterman's applied social research model, to effectively carry out ethnography based on a contested topic, the researcher is reliant upon a hypothesis, a methodological approach, academic resources, the selection of appropriate analytical tools and most importantly primary research participants for fieldwork (2010). Not dissimilar to Matthews and Ross; Fetterman places emphasis on planning and organising. Thus, encouraging the researcher to identify the tasks required and apply realistic timescales; this invariably helps to facilitates time management, reduces duplication of effort, and allows for manoeuvrability

between research phases in response to external factors that may impact the schedule (Fetterman, 2010). This has proven to be invaluable during the pandemic, whereby the best laid plans had to be shuffled due to the constraints of lockdown.

As an experienced Anthropologist, Fetterman places great value on everyday lived realities from the perspective of those being studied, which has influenced the crux of this research. Fetterman argues that “Applying the values of respect and honesty to daily life is readily apparent. However, less obvious may be the power of culture, contextualisation, and triangulation to make sense of everyday life. Applying a cultural interpretation and soliciting emic, or insider’s, perspective have helped me to be sensitive to the needs, fears and aspirations of the people around me.” (Fetterman, 2010, p. xi). To support the theoretical approach, Fetterman offers case studies throughout the book, such as the example of conditions of fruit harvesting at a Kibbutz in Israel by being on-site and actively involved in the fieldwork, Fetterman describes the conditions and daily challenges faced during harvest season (2010). However, Fetterman neglects to mention the wider social, political, and ethical context for the plight of the indigenous people who have been uprooted and are consequently subject to impoverished socio-political conditions. Thus, it is argued that for objectivity, one also needs to consider the views of those on the periphery too to truly assess the wider context. Therefore, it is encouraged that the researcher acknowledges their inherent bias before commencing the data gathering phase.

Additionally, Fetterman argues that the culturally sensitive ethnographer listens, observes, and responds appropriately (2010); therefore, being familiar with the customs and language can be advantageous. In some cultures, emphasis is placed not with words but with gestures or silence. Although, intuition is still required when adopting the ‘insiders’ perspective’ i.e., softening the tone or pausing to allow the participant time to express their thoughts or enabling them to swiftly move on when they deem it necessary. Nevertheless, Fetterman argues that the researcher needs to keep “an open mind ...[to] explore rich, untapped sources of data not mapped out in the research design” (Fetterman, 2010, p. 1), as this study has shown. In summary, Fetterman’s approach to ethnography is commendable in terms of theory. However, one argues that the researcher must be cognizant that omitting ‘other people’s truths’ can undermine their own credibility.

Organ Donation and Islam

Hamdy S, 2012, *Our Bodies Belong to God, Organ transplants, Islam, and the Struggle for Human Dignity in Egypt.*

Professor Sherine Hamdy's 'our bodies belong to God' is arguably the baseline study text for this research. The book is a culmination of her academic dissertation undertaken between her student base in New York University and ethnography fieldwork at several organ transplant clinics in Cairo and neighbouring cities Tanta, and Mansoura (Hamdy, 2012). Within the scope of her work, Hamdy also attended Islamic conferences, jurisprudential classes, and interviewed Islamic scholars and medics (2012). This aptly titled book takes its name from the often-repeated phrase, 'our bodies belong to God' used as a counter argument against organ transplant and donation amongst lay Muslims in Egypt. The theological debate amongst scholars which filtered through to societal level features in the foreground throughout the study, thus Hamdy provides the political context at a time of "mounting dissent towards an unjust and brutal regime, the privatisation of health care, advances in science, and the growing gap between rich and poor, and the Islamic revival" (Hamdy, 2012, p.1). With this in mind, one argues the research is analogous to some extent with shared sentiments of British lay Muslims as expressed in the main body of research herein; thus, Hamdy's work has been a constant source of reference.

In the wider societal context, organ transplantation and donation is and has been a prominent topic of discussion within Egyptian mainstream media and within societal discourse due to the large-scale and long-term impact on the health of the locals with rising cases of kidney, liver, and eye disease, attributed to the toxic waste being dumped by "local and multinational corporations on agricultural land" (Hamdy, 2012, p.xxii). Meaning the locals are habitually subjected to ingesting the pollutants through their natural produce, the air, and the irrigation systems which they survive off, therefore for them; life inhibiting, and threatening disease is endemic (Hamdy, 2012). Over the last few decades, the conditions are exacerbated by the prevalence of covert organ procurement and transplant clinics available on the black market, consequently disenfranchised locals are systematically subject to making life critical decisions; since medical treatment for their health conditions is expensive, impractical, and only life sustaining (Hamdy, 2012). Therefore, this study expounds upon the binary medical science 'v' Islamic theology analysis by delving into personal ethnographies to discern the considerations of those directly affected by decades of societal issues that has widened the gap between rich and the poor. The rich being able to

afford private health care for organ transplants, when inevitably the organs were 'sold' or procured through unethical means that undoubtedly exploit the poor.

The focus of this study is to develop an understanding of "why transplant medicine surfaced as a topic of much social and ethical debate in Egypt from the early 1980's to the early 2010's, amidst dramatic political and economic change" (Hamdy, 2012, p.1). Hamdy's work is an important contribution to bioethics research, by unveiling the wider ethical considerations for people when medical intervention is the recommended treatment, regarding financial, logistical, emotional, a matter of life or death or the quality of life and how it can be sustained after treatment. Therefore, it is argued that the research findings of the ethnographies contained in this study, can in principle be applied to analyses of other medical prescriptions too.

This study is multifaced but has been vivified with the ethnographies of the study participants which Hamdy describes eloquently. Throughout her research, Hamdy spent time at transplant clinics and resided within the local community, in doing so she experiences the extent of social deprivation that the locals face first-hand, such as poor public transport links within already economically deprived conditions (Hamdy, 2012). Some of Hamdy's ethnography participants agreed to being photographed which accompany their stories. Ragia is pictured lying on a hospital bed during dialysis treatment while her husband is sat beside her, Ragia has diabetes from which she is blinded and suffers kidney failure (Hamdy, 2012). Hamdy writes, "Ragia told me with tears streaming down her face that more painful than the dialysis, was the fact that after years of living in blindness, she had forgotten the face of her seven-year-old daughter. Her husband, at her side consoled her, saying that he would give his kidney, and even his eyes to see her not suffer" (2012, p.26). Arguably bringing the seriousness of the debate to life and evoking empathy in the reader. Incidentally, although he offered, Ragia's husband was not a medical match to donate a kidney to his wife, demonstrating the complexity involved in the organ procurement process.

Hamdy's dissertation is underpinned by the fatwa's (Islamic scholarly edict) and scholarly opinions of prominent scholars in Egypt, primarily that of Muhammad Mitwalli al-Sha'rawi (d. 1998), who famously argued against posthumous organ donation initially (Hamdy, 2012). Hamdy argues, Sha'rawi opposed the unethical practice of illegal organ procurement and the commodification of organs (2012). Additionally, Hamdy contextualises the extent of Sha'rawi's widespread influence in that he was a prominent television scholarly personality who did not shy away from political debate, for this he was regarded 'champion of the people' because he spoke out against political injustice by being unaffiliated with state

sponsored policies (Hamdy, 2012). Thus, inferring Sha'rawi's popularity with the lower classes in the face of growing political elitism. The politically unstable backdrop from decoloniality, anti-west authoritarianism, and anti-west capitalism (Hamdy, 2012) has arguably meant that Islamic jurisprudence is often used as a political football upon which policies are apparently rooted and people are supposedly united. Mufti's (jurisprudential scholars) are part of the constitution in Egyptian modern state politics, they can be elected by the president and are employed by the state (Hamdy, 2012). It is therefore no surprise that despite the Grand Mufti of Egypt releasing a fatwa stating the permissibility of posthumous organ donation in Islam, lay Muslim discourse echoed Sha'rawi's arguments; that our bodies are the creation of God and thus belong to Him (Hamdy, 2012).

As the contentions raged over the last few decades, other Islamic scholars, medics, politicians, the media, and society at large waded into the debate, insofar as flaws in Sha'rawi's arguments were highlighted and refuted or endorsed as righteous and praised (Hamdy, 2012). As part of the ongoing debate, Sha'rawi addressed anti-Islamic trends seeping into Muslim minds, inferring that people were demonstrating discontent with God's will by 'playing God' and thus falling into *fa-hisha* (heedlessness) (Hamdy, 2012). Additionally, Sha'rawi makes the distinction between body parts and bodily functions introspectively, "there is divine wisdom behind disease and bodily incapacity" (Hamdy, 2012, p.122). Explicitly regarding the definition of brain-stem death, Sha'rawi makes the link between Qur'anic forbiddance of suicide and impermissibility of organ donation, conceding that blood donation is permissible because blood regenerates (Hamdy, 2012). Arguably, the same can be said of the liver which can regenerate and requires a live liver lobe donor. Although, Sha'rawi is considered as having "a particular sufi disposition" (Hamdy, 2012, p.124), whereas the prominent madhab in Egypt is Shafi'i, Hamdy's research shows that Sha'rawi's arguments resonate with lay Muslims until recent times, one asks is this because the people feel powerless ever since colonialism, and therefore their faith rests with eternal justice with Allah in the hereafter?

It is argued that Hamdy's work is a brilliant academic contribution to social sciences and bioethics that is not limited to modern Islamic thought, but applicable to ethical consideration for humankind. One argues, this book should be recommended reading for students of politics and medicine because of it provides the long-term substantiation of introducing modern scientific and technological solutions. The personal stories, like that of a mother having to choose which son she donates her kidney to or the young man who has to sell his kidney to set up a small roadside business to support his family (Hamdy, 2012) expose the root causes and the extent of local and global policies that reduces the integrity of those who

proclaim that their bodies belong to God as 'backward'; rather one argues they are hopeful of eternal justice.

Ali, M. 2019. Three British Muftis Understanding of Organ Transplantation. *Journal of the British Islamic Medical Association*. 2(1), pp.1-9.

Dr. Mansur Ali's journal on organ donation and Islam is arguably the benchmark to understand the wider medical and Islamically theological considerations for British Muslims regarding organ donation. This literature review consists of two journals by Ali, first and foremost is based on the qualitative research interviews with three British muftis conducted in 2016 (Ali, 2019). This journal is grounded in developing an understanding of the ethical and Islamic legal considerations of three Sunni muftis because it is argued that "the ulema are the first port of call for members of the Muslim community for bioethics related issues" (Ali, 2019, p.1). One argues, that while this may be the case for the older generation of South Asian British Muslims, the landscape has changed somewhat due to the prominence of online scholars and therefore 'Shaikh-Google' is often the first port of call; this is the case for most lay-Muslims of the latest generation as this study has found. Granted, the first and second generation of South Asian Muslims are still inclined towards the opinions of their local imam and community elders as opposed to referring to online unknown scholars, and there is an expectation for youngsters to take their lead; nevertheless, a shift in authoritative sources is variable and should not be disregarded. Notably, the reference material used to assert that the ulema are influential is dated between 2012 and 2013; given the acceleration of technological accessibility particularly during and post covid-19 outbreak, it is argued that a proportionate revision of who the main Islamic influencers are now would be advantageous in further studies, as these vary by generation and their preferred mode of inquiry. That aside, this research is incisive and provides vital insights into the scholarly thought process regarding organ donation and therefore lends itself well to a reconciliation analysis of scholarly vis-à-vis lay-Muslim thought.

Reflective of the majority British Muslim demographic, Ali interviewed British muftis with South Asian ethnicity, two of whom are affiliated with Deoband, while the other is associated with the Berelwi school of thought (Ali, 2019). Unsurprisingly, given the scope of discussion, all three muftis presented different opinions. However, for succinctness, the report provides a breakdown of the discussions, and therefore it is deduced that regarding live non-lifethreatening organ donation, all three muftis agree there is permissibility. Throughout the interview analysis, Ali applies shariah maxims based on the maqasid as-shariah to demonstrate that the principle of preservation of life is central to scholarly analysis, thus

showcasing his own expertise in Islamic jurisprudence and finding contradictions in the scholarly arguments. Additionally, the analysis demonstrates that there is legitimacy in the shariah for differences of opinions depending on time and place, particularly where there is no divine directive.

To provide background context, Ali highlights some noteworthy fatwas, for example an important fatwa derived in 1985, which was published after a prolonged scholarly conference “ijtihad jama’i (collective effort)” (Ali, 2019, p.2), held in Mecca, declaring permissibility for non-life threatening live and cadaveric organ donations (Ali, 2019). The heavily caveated fatwa is contrasted by that of Muhammad Mitwalli al-Sha’rawi, the famous Egyptian scholar called upon people to plough their faith in God and asserted that ‘our bodies belong to God’, although as described in Hamdy’s review, al-Sha’rawi was mainly speaking out against the exploitation of the poor amidst the rise of organ harvesting and endemic health conditions due to toxic waste (Ali, 2019). While this research has shown that South Asian lay-Muslims also echo the same words that ‘our bodies belong to God’, Ali argues that perhaps the most significant influence has been the inconclusive statements of Deobandi Mufti Al-Kawthari who neither endorsed nor rejected the permissibility of organ donation (2019). However, Ali argues that Al-Kawthari’s ambivalence can be inferred as bias towards the “prohibition by the Pakistani Mufti Muhammad Shafi”, who was the father of his teacher, mufti Mohammad Taqi Uthmani (2019, p.2). Moreover, Al-Kawthari went on to state that the layperson may choose any scholarly position, however in accepting permissibility, one must “seek forgiveness from Allah (istigfar) and donate something in charity” (Ali, 2019, p.3). There are many conclusions to be drawn by reconciling Ali’s analysis and the findings of this research as to how such scholarly discursive is discerned by the lay Muslim. On one hand, when thinking about organ donation hypothetically, the lay Muslim is inclined to err on the side of caution for fear of committing sin, as the comments of Al-Kawthari imply. On the other hand, when faced with a medical condition, the lay person would be inclined to accept the position of permissibility. Thus, it can be argued that the personal motivations resulting from individual circumstances are more influential than any scholarly opinion.

The topic of brain-stem death generates interesting discussion and has been valuable the analysis in Chapter 4, therefore is not discussed extensively here. Importantly, the disputation in scholarly discourse regarding what is known medically and understood of Islamic theology is an important contribution to understanding death. One mufti refused to accept brain-stem cessation as a true definition of death, certainly from an Islamic theological perspective. While another said death is metaphysical and that, “trying to pinpoint the exact moment of death is a red herring” (Ali, 2019, p.5). It is argued that in doing so the

mufti indicates his own naivety because death and the metaphysical realm are important constitutes in Islamic theology. Nevertheless, the broad spectrum of discussion and analysis render this article a valuable contribution to a step towards understanding organ donation and Islamic jurisprudential considerations.

Ali, M. and Maravia, U. 2020. Seven Faces of a Fatwa: Organ Transplantation and Islam. Religions Online. 11(2), pp.1-22.

This report is an in-depth analysis of seven differing yet well founded Islamic scholarly opinions on allotransplantation “gleaned from an exhaustive reading of fatwas and research papers in Arabic, Urdu, and English” (Ali, Maravia, 2020, p.2), from around the global Muslim population between 1925 to 2020. Moreover, the authors argue that all positions are valid, and therefore a lay person may choose any position on the spectrum of permissibility (Ali, Maravia, 2020). The salient opinions are based on scholarly arguments regarding, “God’s ownership of the human body, human dignity, necessity, altruism and charity, benefit and harm, and a watertight definition of death” (Ali, Maravia, 2020, p.4). The defining arguments are thematically arranged and then disaggregated through methodological analysis, which arguably allows for an unbiased interpretation of the permissible positions for organ transplantation and donation in Islam. Qur’anic based evidence is analysed using ArabiCorpus, a sophisticated online tool that enables lexical analysis of Qur’anic terms in various contexts within the text itself (Ali, Maravia, 2020). In doing so, Ali and Maravia test the basis of scholarly arguments through Qur’anic semantics within the context of revelation, as is the case with the verb ‘yamlic’ (to own), which is proven through their analysis as having interchangeable meaning (2020). Consequently, the arguments are explored through the legal lens and analysis of secondary scripture to assess their viability which invariably evaluates the weight of each argument based on the maqasid as sharia. In their assessment of the scholarly position for only permitting cadaver organ donations as endorsed by “Ahmad Fahmi Abu Sunna (d. 2003) from the Islamic Fiqh Council of Mecca ...and Muhammad Abd al-Rahman, former grand mufti of Cameroon (1988)” (Ali, Maravia, 2020, p.16); the authors demonstrate a level of subjectivity within the application of maqasid maxims such as ‘necessity’ and “‘in the presence of two harms the least harmful must be chosen’, as well as the maxim ‘a minor harm is tolerated for the sake of major gain’” (Ali, Maravia, 2020, p.16). In arriving at their conclusion, the scholars weigh up the rights and imposition of dignity for the deceased vis a vis the living (Ali, Maravia, 2020). This argument is then juxtaposed by Abu Sunna’s own argument regarding the right for living person to good health with the risk that a healthy donor will become susceptible to ill health in the future, meaning that the

benefit of a healthy person donating an organ to an already ill person negates the objective, twofold (Ali, Maravia, 2020). Ali and Maravia argue that Abu Sunna's "position is contingent upon a particular understanding of the state of transplant medicine in the Muslim world at the time of his writing the paper" (2020, p16). Thus, the authors demonstrate the validity of different opinions because circumstances vary with time, place, and personal experiences and provide justification that the sharia does not need to be prescriptive. On one end of the spectrum, Sha'rawi argued in principle against organ donation but within the long-sighted context of the Egyptian endemic health and social conditions that cannot be resolved through the blinkeredness of quick fix medical solutions. On the other, UK based Muslim scholar Dr Rashid however provides evidence that brain-stem death criteria can be considered as being complete death in accordance with the Islamic definition of death because his evaluation is based on his own medical knowledge and within the societal context of regulated organ donation (Ali, Maravia, 2020), where the risk of organ harvesting does not pose a direct societal threat. One argues therefore that for the Muslim ummah, the reverberations of both positions will have a profound impact dependent upon their own personal circumstances. Therein lies the eternal wisdom of the sharia, neither oppressive nor prescriptive.

This methodical analysis which is applied for all seven positions offers a balanced academic review of the scholarly deductions regarding organ donation in Islam and should be the basis of helping lay-Muslims exercise their own judgement. However, as the authors remark their analysis demonstrates the extent of organ donation jurisprudential discursive not being limited to binary position of halal or haram (Ali, Maravia, 2020). On one hand it can be argued that the limitations of this study are in part due to it not being easily accessible on popular online forums for lay Muslims. On the other hand, the findings of this dissertation have shown that although information is readily available regarding organ donation and Islam on the NHS webpage, lay people have defaulted to their pre-conceived positions and pro-actively opted out of consenting to organ donation. The limitation of one's own study is due to the relatively small sample size, however in the absence of statistical data provides a mere indication of the views of a sub-set of lay-Muslims. Nevertheless, Ali and Maravia have produced a comprehensive report which provides a synopsis of the various scholarly positions with succinct analysis to enable decision making, based on Islamic theological rationale reconciled with medical definitions.

Islamic theology regarding death

T.J. Winter, 2018. *Al-Ghazali. The remembrance of death and the afterlife. Kitab dhikr al maw twa ma ba'dahu. Book XL of the revival of the revival of the religious sciences. Ihya'ulum al-din. Translated with an introduction and notes by T.J. Winter. 2nd Edition. The Islamic Texts Society.*

This literature review does not assess the quality of translation, it is given that authenticity can be assured; Winter himself has the credentials to instil confidence in the reader that he is suitably qualified to authentically translate the classical work. Evidently, the work has also been peer reviewed for quality assurance, as noted within the preface. However, the lexical composition of this English translation cannot be overlooked from the readers perspective. One argues that the written style is both eloquent and immersive; written in such a way that the reader can imagine being in an Islamic seminary while reading the text. Often, the author addresses the reader directly by inviting the reader to 'contemplate' specific scenarios as is the case when al-Ghazali describes the pain at the moment of death or the first moments in the grave when faced with the two angels Munkar and Nakir (Winter, 2018). The philosophical nature of the text arguably has a profound effect on the reader because death is inevitable and therefore al-Ghazali distinguishes between three types of reader from the outset, the apathetic, irresolute and the one preparing for death (Winter, 2018).

Regarded as highly esteemed Sunni Muslim theologian, al-Ghazali's work is arguably a cornerstone for Islamic scholarship. In this, the final part of his "forty 'book' Revival of the Religious Sciences", the Imam addresses eschatology (Winter, 2018, p.xxiii). The first part of the book which this research is mainly concerned with pays particular emphasis on the remembrance of death, alerting Muslim consciousness to the inevitability of death and the transience life in this world, by drawing on Qur'an, hadith, exegesis, and tertiary scholarly works to describe the moments when the spirit is taken from the body at the time of death until the initial stages of burial. The second part deals exclusively with the events that take place after death, thus is demarked by the opening chapter with a discussion on 'the trumpet blast' which precedes the events of the day of 'arising' (Winter, 2018). This text is heavily referenced in chapter four of this dissertation because it deals specifically with how death was understood before the advent of modern medicine and technology. Therefore, provides a retrospective insight to the phenomenon of the moments prior to, during and after death but before burial; a truly esoteric and an important contribution for this study that is otherwise side-lined for other milestone eschatological events such as the questioning and punishment in the grave and what happens after death and the on the day of judgement. It is argued that

book is recommended reading for introspective reader, lay or scholar; although, one suspects that it will be met some scepticism from those who prefer daleel (proof) through hadith with authentic isnads (chains of transmission) because the text does refer to dreams and interpretations of scholars. Despite that, it is argued that the depth of esoteric discursive within this book cannot be disregarded as a bona fide contribution to the Islamic understanding of death.

Smith, J.I. and Haddad, Y.Y. 2002. *The Islamic understanding of death and resurrection*. Oxford University Press

By comparison to Winter's translation of al-Ghazali's work, Smith and Haddad's Islamic understanding of death offers a broader academic discussion regarding Islamic eschatology. Their first edition was published in 1981 and calls upon the work of al-Ghazali's aforementioned work and prominent Islamic scholars thereafter, namely Ibn Qayyim. Therefore, Smith and Haddad's academic research has proven to be a complimentary addition to the literature reviews of both Winter and Dehlwi's books for balance. Importantly, Smith and Haddad's research encompasses the breath of eschatological discursive in the Islamic scholarly tradition by delving into the debates of various schools of thought including the main Sunni madhabs and the Ash'ari viewpoint, while also providing analysis of the refutations and counter arguments offered by each discipline throughout the course of history.

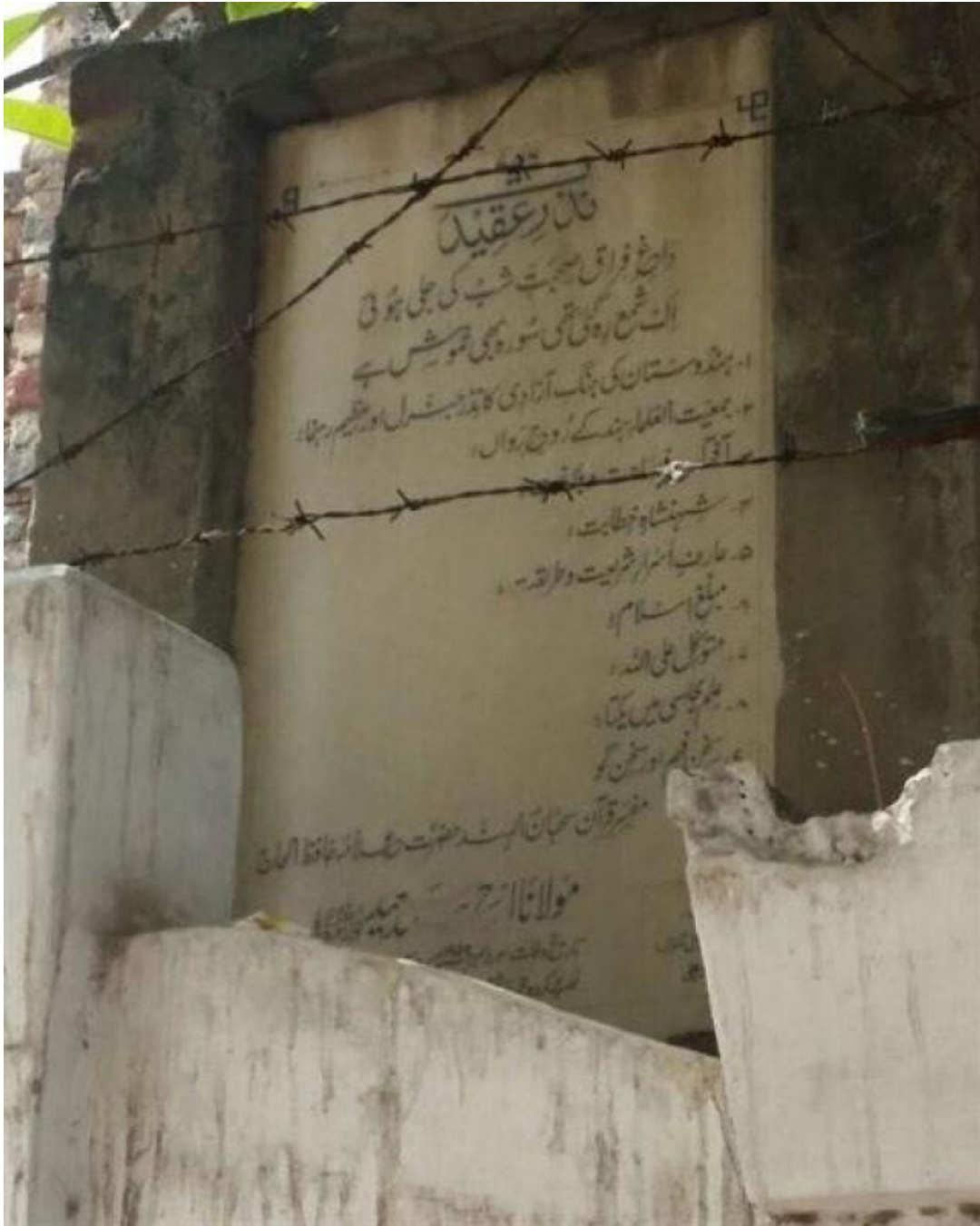
For the purposes of this research, there is considerably less emphasis on the moments leading to death, during and after death but prior to burial where the crux of this research rests. Although, from a social sciences research lens, one cannot neglect the holistic overview of eschatological events because they are interconnected. Invariably Muslims are interested in learning about eschatology as integral Islamic tenet, thus, within the timeframe between the first publication of their book in 1981 and 2002; Smith and Haddad argue that "For centuries Muslims have interpreted the social and moral ills of their societies as indications that the time of judgement is near. Now ...the signs are apparent and the end is imminent." (2002, p.vii). While at the time, they cited "continuation of injustice perpetrated on Muslim citizens in a growing number of countries" (2002. vii). It can be surmised that an interest in eschatology is even more compelling now with the amplification of such political injustice towards Muslims globally and with the growing concerns of the climate change crisis. Given the comprehensive scope of Smith and Haddad's work which include classic

and more contemporary scholarly works, this book lends itself to objectivity for academic research as demonstrated within chapter four of this dissertation.

Dehlwi, A.S. 1987. *Marne ke bad kia hoga – what happens after death*. Translated by A. Jalil Siddiqui / Mohammad Hanif Khan. Second Revised Edition. Dini book depot, Delhi, India.

Dehlwi's work is included within the scope of this literature review because it has been referred to by interview participants, many owned or recalled members of their wider community having a copy of the book in Urdu or Gujrati. This literature review is based upon the English translation, which was published as a second edition in 1987, although Dehlwi's original version is dated back to 1957. The authorship of the translation is unclear because on the sleeve of the hardback cover, the translation is ascribed to A. Jalil Siddiqui, while inside the same book, Mohd. Hanif Khan is noted as the translator. In the absence of translator's notes, the book begins with a foreword by Dehlwi who is also referred to as Sehbanul Hind (d.1959). Therefore, one assumes that there is a possibility that both Siddiqui and Khan contributed to the translation, perhaps at different times throughout the project, hence the discrepancy in the publication of their names.

While a biographical account would be helpful to understand the motivations for Ahmad Saeed Dehlwi to write about what happens after death, this research has shown that very little information is available about the author in English and online. Although a Wikipedia search generated a brief biography, his name spelt on the website as Dehlavi; is believed to have been a founding member of the Deoband affiliated Islamic seminary Jamiat Ulama-eHind (2021). Born in India in 1888, Dehlwi is believed to have a strong background in Islamic education from Deoband seminaries in Delhi and having studied the Qur'an and authored other works including 'Fear of Hell' and 'Key to the Garden of Bliss' (Wikipedia, 2021). Significantly, Dehlwi is regarded as a key figure in the revolutionary Indian freedom struggle against British colonial rule, for which he was imprisoned periodically (Wikipedia 2021). A further online search generated a link to a short blog with a photograph of Dehlwi's place of burial.



(Safvi, R. 2015).

Although the inscription on the tombstone is illegible from the online photograph, the blogger wrote that a security guard indicated that the tombstone marked the resting place of an important figure in the Freedom struggle (Safvi, 2015). The precise location is believed to be outside the neglected ruins of Zafar Mahal in South Delhi where poet Mogul Bahadur Shah (d.1712) is also buried with an apt Urdu stanza inscribed on his tombstone that he had written in earlier life, echoing the imposition of colonial rule in India.

“Kitna hai badnaseeb Zafar! Dafn

ke liye

Do gaz zameen bhi

Mil na saki kuye yaar mein

English translation:

How unlucky is Zafar! For burial, even two yards of land were not to be had in the land of his beloved”.

(2021, Wikipedia).

Therefore, first-hand insight is gleaned from the authors foreword which casts light on the wider socio-political context of Islam in India during British colonialism, and thus the positionality of Islamic revivalist thought. In his opening gambit, Dehlwi reveals his motivations for producing the compilation amidst the backdrop of Indian decolonial thinking which realised several manifestations of Islamic scholarly responses. Lewis argued, South Asian Islam “has either generated or profoundly shaped three of the most important Muslim traditions today: revivalism, Islamism and modernism” (2002, p.8). Dehlwi, it is surmised was concerned with revivalism, the ethnographies in this research demonstrate the societal manifestation of such work in acts of preservation through generations of customary practice until today.

Dehlwi’s sermon like forward is rooted in resentment towards British colonial rule in India which saw to the decimation of Islamic intellectualism and suppression of Islamic teaching and preaching Islam publicly (1987). Dehwi argued “...the events of 1947 shattered the brain as the indifference of religion that had already ensued during the British Rule had further accumulated. Religious dialogue which was previously heard and inspired was now being openly opposed. Specifically, they have turned cool to the subject of interregnum and return of the soul to their respective bodies” (1987, p.v). The sentiments expressed here provide an indication of the purpose of the text, to call Muslims to attention and remind them of the transience of this world, to reject anti-Islamic ideologies and invest their faith in preparing for the inevitability of death. Dehlwi, wrote the book specifically to benefit “...common people [to] refrain from the life of transgression and non-belief” (1987, pp. v, vi).

The book is a two-volume compilation of Dehwi’s cumulative readings of the scholarly works of al-Qurtubi, Jalal ad din as Suyuti, Qazi Sana Ullah Panipati, Rabbani Abdul Wahab Sherani and Ibn Qayyim’s Kitab ar ruh, regarding death and the events up to entry to paradise or hell fire (Dehlwi, 1987). Although not specifically mentioned, the opening statement of the conditions in the grave are reminiscent of al-Ghazali’s work in describing

how “the greatest kings ...demurred even at a hint of death, but when the promise of the Almighty (the time of death) came to pass, they were thrown into a pit and were tumbled from their high palaces to the depths of earth ...and they were given over to worms and insects...” (Dehlwi, 1987, p.vii). Al-Ghazali’s introduction begins, “Praised be God, who with death did break the necks of tyrants, shattering with it the backs of Persia’s kings, cutting short the aspirations of the Caesars, whose hearts were long averse to recalling death, until the true promise came to them and cast them into the pit. From the loftiest of palaces into the deepest of graves they passed ...into sustaining insects and worms...” (Winter, 2020, p1). The similarities are likely since al-Ghazali’s work is considered as the foundational text studied by the scholars that are named but came after him, thus meeting al-Ghazali’s objective of amalgamating and testament to the scholarly efforts of preserving works for future reference in different languages over the centuries. The 400+ page book has been translated from Arabic, Persian and Urdu to English which is commendable but also exposed to negligible grammatical and spelling mistakes, although not significant enough to disrupt the flow of reading. The use of the words interregnum, purgatory and limbo to describe the barzakh is analysed in Chapters 1 and 2 but is described as “a particular state ...in which every mortal (human being enters) immediately after death and lives till the Day of Judgement which every mortal has to pass in waiting after death” (Dehlwi, 1987, p.1). It is argued that the lengthier description of the barzakh is more astute than the transposition of the term interregnum which can lead to misinterpretation.

Dehlwi continues his introduction with metaphoric examples of someone furnishing their home with niceties while alive and then lamenting when deceased that he wishes he had he only invested more in the preparation of death and the hereafter (1987). The main body of the book contains a collection of narrations from well-known hadith collections such as Bukhari, Muslim and Tirmidi which are accompanied with several iterations of similar and varying version of the same hadith and includes narrations from lesser-known sources such as Dailmi, Ibn Manda, Maleeni, Nashur, Ghayat and Zawajir, rendering the text somewhat overwhelming and questionable in the eyes of modern generations of lay-Muslims.

The overall content is relating to death in the metaphysical sense but also contains significant information around the etiquettes of death while alive such as the virtues of the remembrance, recommended acts of worship at the time of death, supplications etc. Although it cannot be asserted that this text is an informative contribution for South Asian Muslims in terms of pedagogy based on the content, it can be argued that the concept of death and preparation for it plays a significant role in Islamic creed and therefore text like these serve as conscious reminders for the inevitability of death and a series of events that

follows thus Muslims are scrupulous when it comes to posthumous organ donation especially.

British Muslims social and religious studies

Lewis, P. 2002. *Islamic Britain. Religion, Politics and Identity among British Muslims*. I.B. Tauris Publishers.

This book began as a Ph.D. thesis, originally published in 1994, post Satanic Verses and pre-911; thus, between two milestones of British Muslim identity (Lewis, 2002). Lewis collaborated with the Institute of Islamic Research in Pakistan and with Muslims in Bradford as part of his research (2002), which provides an element of the emic perspective.

In explaining British Muslim identity Lewis traces early encounters between Muslims at the battle of Poitiers in 732, through colonialist history and throughout World Wars One and Two in which Muslims are framed in broad terms as enemies, allies, and subjects (2002). While also paying attention to notable Englishmen like W.H. Quilliam who “embraced Islam in 1887 after visiting Morocco” and went on to establish a mosque in Liverpool while inviting others to Islam and sustaining international diplomatic relationships between Muslims overseas and within British society (Lewis, 2002). Although this study is more concerned with the South Asian labour migrants post World War Two who settled in North of England to provide the academic references to support the participant ethnographies, especially in Chapters 1 and 2. Lewis describes the labour and chain migration trends, coupled with the British legislative changes like the 1962 Commonwealth Immigration act which ended “automatic entry for Commonwealth citizens” (2002, p.17). Which then then drove families who were separate to reunite in Britain, whereas they may not have considered their long-term plan to either settle in Britain or repatriate. In addition to utilising his network connections to explain the societal context, Lewis uses statistical analysis where available to reconcile other societal factors like numbers of those registered in schools by ethnicity to provide approximations of Muslims in Britain before the census started to collate information about religious affiliation. Thus, this work is empirical and regarded as an important pre and post 911 academic contribution to studies of British Muslim societies. In the preface to the second edition, Lewis argues that he intends to counter the mainstream narrative of Muslims which has become almost synonymous with the notion of ‘fundamentalism’ (2002). One limitation perhaps, is the omission of personal ethnographies which give agency to those being discussed and are therefore all the more empowering. Given the depth of detail provided in his study and the inclusion of generalised stories of South Asian Muslims, it is argued that Lewis has ameliorated social and religious studies in this regard.

Chapter 1 – Death. An Islamic theological and philosophical review including the transitional phase prior

Islamic doctrine regards the concept of the lifecycle as an infinite model, living continues in some form after death occurs in this life. Broadly speaking, in Islamic theology the dying person has metaphysical experiences prior to death, then transitions through several phases after death. Death marks the end of free will, and the sepulchral reawakening signals accountability (Smith and Haddad, 2002). The purpose of this chapter is to demonstrate why lay Muslims are reluctant to donate organs after death; almost all the participants interviewed believed the body perceives pain after death and they do not want to be responsible for inflicting suffering on the deceased. Owing to the broad scope of discussion, this chapter is divided into three parts beginning with an introduction to the metaphysical realms after death, supported by participant ethnographies and academic references to offer insight into how death is understood from an Islamic perspective. Part two, addresses the definition of death for brain stem deceased patients with medical and Islamic jurisprudential emphasis. The final section seeks to reconcile Sunni Islamic mainstream theological positions with philosophical views from ethnographies of medical practitioners, to demonstrate plausibility within the concerns expressed by the interview participants.

Part 1 – What happens after death

In adopting a lay persons lens, this part of the research will comprise of analysis of the pedagogical tools used throughout three generations of South Asian Muslims who participated in this study. First and second-generation Muslims referred to the translated works of Ahmad Saeed Dehlwi, who authored a conglomeration of scholarly works in his book 'Marne Ke Bad Kia Hoga' (What Happens After Death); further details can be found within the Literature Review (1987). Second and third generation referred mainly to online lectures and Islamic Question and Answer websites which comprised the analysis later in this chapter.

Speaking of Dehlwi's book, first generation participant Ayesha recalls:

"We had the book on our bookshelf ever since I can remember ...we all did [within the close community of neighbours and relatives]. I have tried to read it a few times [during childhood], but felt scared; as an adult, more so. I know the basics like the ruh [soul] leaves the body

and is in limbo until the body is buried. When the last mourner at the graveside has left a certain distance, then the soul returns, and questioning begins.”

Referring to his Islamic pedagogical experience through attending a local madrassah (Islamic school) like Ayesha did and in reference to reading Dehlawi’s book, second generation participant Saeed remarked:

“We learnt about the questioning in the grave as if preparing for a test, but we were baffled about how we can answer questions in Arabic. We wondered about people who died a very long-time ago, do they suffer more! It became clearer to me later as I learnt about Allah through his names that He is Just - Al-Adl. This has given me comfort and helped me accept certain things. Everyone has an opinion, and it can get confusing, but there is peace in prayer.”

Dehlwi addresses the lay Muslims specifically, in his impassioned foreword which reads like a sermon being delivered to a congregation of followers, he calls for Muslims to prepare for the inevitable death from this world (1987). Writing within the decolonial context, Dehlwi argues, “...to hanker after something which is transitory is the height of folly. ...O those who keep faith! Let not your goods and your offspring make you headless towards the remembrance of God.” (1987, p.viii). The remainder of the 400+ pages, two volume book contains numerous ahadith, many from lesser-known narrators. There are also stories of dreams that arguably a modern reader would find obscure due to the absence of traceable references.

An unreferenced hadith of the Prophet is cited under the heading of ‘the conditions of the barzakh’, “...the act of breaking a bone of the dead body causes him as much pain as felt by a living person” (Dehlawi, 1987, p.60). The hadith is narrated in Abū Dāwūd, with additional text in Muṣannaf ‘Abd al-Razzāq. Butt argues that the scholarly opinion provides clarity in this regard, that the “prohibition of deliberate denigration of the human body, whether alive or dead” (2019, p.53) is addressed here rather than a proclamation that the deceased perceive pain which is arguably a prominent pre-held belief amongst South Asian lay Muslims. Therefore, in the absence of explanatory notes, the text contained in Dehlwi’s book is subject to literal interpretations which has arguably informed generations and therefore adopted an almost doctrinal position within the consciousness of lay Muslims.

When interview participants were asked why they were reluctant to consent to posthumous organ donation, their almost unanimous response was similar to that given by Saeed:

“What really worries me is what happens in between when the person dies and is buried. We know the soul leaves the body, but what is it going through until it is buried. We know we have to be gentle with handling the janazah, so we don’t hurt them. Surely then, if a knife is taken to remove their organs, they’ll feel the pain until they’re buried.”

Third-generation participant Muna, a university medical student is a granddaughter of research participant Ahmad, she explained that to determine a theological or fiqhi (Islamic jurisprudential) position, she and her peers usually undertake online searches, her response is almost identical to all other participants of the same generation:

“I like listening to lectures online, I find scholars like Mufti Menk have a good way at explaining things. I listen to Yasir Qadhi occasionally, the content of his lectures can be a bit much. I now see how deep Islamic Studies from an academic perspective is. If I have a specific question of fiqh, I’ll ask on Islam QA, but there are other websites that I go to too if I can’t find what I’m looking for.”

Although Muna understands the permissibility of organ donation in Islam from an ethical and jurisprudential perspective, she has opted out because as she elaborated:

“Organ donation is a good thing to do, for me, it kind of encompasses the meaning of sadqah [voluntary charity]. But Allah has given us the choice, that’s why I’d happily donate what I can while I’m alive. It bugs me though that essentially there’s no proof that the deceased don’t pain after death, how would you know? What’s more, what about my parents? The grief of seeing all the scarring would be too graphic. I find it helps to understand the difference between traditions and Islam. I don’t want to follow blindly.”

Similarly, Yunus, a third-generation student said:

“You know what, I’ve read up on it, and think, sure we should donate. But I have opted out of consenting because my parents have opted out. I never pressed the issue because I’ve seen their grief, my brother died a few years ago, and the topic seems too sensitive”.

Arguably, as the generations of South Asian Muslims have had more engagement with other Muslims either in person or online, they have been faced with alternative interpretations of Islamic practices. The growing prominence of Muslim scholars online has arguably enabled a virtual Muslim community to connect with their Muslim identity beyond the confines of their own family and local community; quite distinct from the way the first generation of South Asian Muslims learnt about and practiced Islam which is discussed in Chapter 2 and 3.

The following analysis adopts the approach described by Muna and other third-generation participants by assuming the mindset of the lay Muslim in trying to understand the

permissibility of organ donation in Islam. The Islam QA is a popular website amongst the third-generation participants, it is a platform for questions and answers. Anybody can log in and ask questions of a theological or jurisprudential nature, the questions and their responses are archived offering automated responses for a question that has already been answered, the site currently holds 18 results on the topic of organ donation (Islam QA, 2020). In a lengthy response which begins by addressing organ donation types and between live donors and recipients, the unnamed online scholar cites the 1988 Islamic Medical Fiqh Council caveated fatwa outlining permissibility (Islam QA, 2020). Thus, a valid explanatory response is available on a popular online forum and has been viewed over half a million times online since it was posted in 2007 (Islam QA, 2020). Although, the qualitative research findings of this study realized that almost all participants did not think that posthumous organ donation is permissible. It is argued however, that online searches can be convoluted for the lay Muslim because they provide a multitude of opinions; unless these are methodologically researched there is a risk that readers are left none the wiser because they have plenty of opinions but no real guidance to help them adopt their own position rooted in Islamic ethics.

A simple google search of the word 'barzakh' found it had been translated into English to mean 'purgatory'; which like 'limbo', (discussed in Chapter 2) is misleading because purgatory has its origins in the Roman Catholic doctrine to denote a place entered after death for the expiation of sins. Smith and Haddad assert that there "are no references to barzakh in the canonical traditions" (2002, p.8). Theological positions as to what happens between death and resurrection vary between the Abrahamic traditions and from within them. The analogous notion of purgatory as a temporary place for the expiation of sins itself was contested between Mu'tazila theologians and the traditionalist Ash'ariya within the context of punishment for believing Muslims (who have sinned), after death and before the Day of Reckoning (Haddad and Smith, 2002). In their analysis, Haddad and Smith demonstrate that the debate is nuanced insofar as being influenced by several Qur'anic exegetes and Christian theological reasoning to draw parallels between the punishment of purgatory and 'Gehenna' (2002). The "punishment in Gehenna ...is different from that of other sinners in degree only and not kind, and while Christian purgatory is for the soul alone, Muslim Gehenna is a place of torment for the resurrected body in its totality" (Smith and Haddad, 2002, p.93). Thus, making it clear that a merging of theological positions leads to misconceptions. Importantly, the positioning of purgatory for this discussion is misplaced in the sequence of after death events for the purpose of pain perception to donate organs because the period in question is indeed prior to burial. Whereas the barzakh is described in

Islamic theology as a metaphysical domain, i.e., a barrier (or place) between this world and the next.

The etymology of the barzakh can be traced to the Qur'an for descriptions in the physical and metaphysical sense. A physical explanation is found in the Qur'an, 55:20; "They [two bodies of fresh and salt water] meet, yet there is a barrier between them they do not cross" (Haleem, 2010, p.353). There is scholarly consensus that the word barzakh in Arabic thus means 'a barrier' or 'distinct space in-between two places' (Qadhi, 2021). The word barzakh used to describe the metaphysical context appears in the Qur'an, "When death comes to one of them, he cries, 'My Lord, let me return (Q.23:99) so as to make amends for the things I neglected.' Never! This will not go beyond his words: a *barrier* stands behind such people until the very Day they are resurrected (Q.23:100)" (Haleem, 2010, p.218-219). The metaphysical notion of the barzakh is the focus of this discussion to make connections between how lay Muslims have understood the period between when death occurs (the soul departs the body) and when the body is buried (soul is reunited with a form of the body). By scholarly consensus, Qadhi argues the soul is returned to a form of the body at the place of burial, irrespective of the location or condition of the corpse; whether lost at sea or incinerated in a fire (2020). Therefore, inferring that the body is merely symbolic after death. The process of death is described briefly in the Qur'an (Q.56:83), "...the soul of the dying person comes up to his throat and in Q.6:93, death is described as a ...flooding in process (ghamarat al maut) at which time the angels stretch forth their hands and ask that the souls be given over to them" (Smith and Haddad, 2002, p.32). Moreover, death is described in Q.35:22 in contrast to life to signal a difference between the two states of being. Therefore, theologians have relied on secondary and tertiary scholarly sources to develop an understanding of what happens after death (Smith and Haddad, 2002). Acclaimed Islamic academic T.J. Winter translated the works of twelfth century Shafi jurist and theologian Al-Ghazali entitled the 'revivals' which are the cumulative scholarly works of the last ten years of al-Ghazali's life while he was on the path of Sufism. Winter argues that "By Ghazali's time, Sunni thought had already investigated and ordered the eschatological content of the Qur'an and the hadith as part of magisterial expositions such as the discourses of al-Ash'ari" (2015. p.xxvii and xxviii). Nevertheless, al-Ghazali defended "orthodoxy against Arab philosophers" (Winter, 2015, p.xxx). Therefore, it is argued that despite using sources beyond the Qur'an and Sunnah by using hadith narrations of the companions of the Prophet after his death and using scholarly interpretation of dreams, al-Ghazali's work is pivotal even amongst those groups who reject Sufi influences.

In 2020, globally renowned Sunni Muslim scholar Yasir Qadhi released a series of lectures, delivered in an academic forum but also made available online via YouTube titled 'The Life in the Barzakh', the ten-part series comprising of circa hour-long lectures each is arguably one of the most comprehensive multimedia studies on the topic in recent times. In his thoroughly analytical lecture series, Qadhi provides Sunni mainstream and alternative scholarly views on the transition of the soul from the dunya to Yawm al-Qiyamma (Day of Judgement). The crux of his explanation leans heavily on Ibnul Qayyim's Kitab ar-ruh, while also incorporating scholarly refutations (2020). Additionally, Qadhi carefully deconstructs with Arabic lexical analysis, several scholarly opinions of the theological sources; Qur'an, Qur'anic tafseer (exegesis of various scholars), Hadith and a range of Islamic scholarly texts on the transition of the body and soul, from this world to the aakhirah (hereafter). Over the course of his lecture series, Qadhi discusses chronologically how an angel of death approaches a dying person prior to their soul exiting the body (Jas'd) in dunya, then transcends to an initial realm until the soul is returned to a place of burial, and then enters the barzakh (2020). In Islamic eschatology, transcendence through the barzakh continues after life until the trumpet is blown to signal the beginning of Qiyamah which is the day of judgement for all beings from the beginning of time (Qadhi, 2020). Notably, there is great emphasis on the on the journey and experience of the soul, while comparatively the state of the cadaver is less significant in this discussion. Arguably, this is because there is precedence on what happens to the deceased body in this world, (i.e., the ritual cleansing, shrouding, prayers, and burial conditions etc.)

Muslims have an acute awareness of death as a transition from this world to the hereafter and are therefore naturally curious as to what happens after death, as first-generation participant Khadija explains:

"We learn about what happens to us after death from a young age, it may seem strange in other cultures that we often discuss death even in social gatherings. We learn to prepare for death the same way as others plan holidays, we know what we'll wear but we are conscious of our deeds because we'll take them with us. That's why we teach our kids, so they know that they can still do something for us when we die, they can pray for us and give Sadqah Jariah for our reward in the hereafter."

Similarly, third generation participant Suleiman said:

"My non-Muslim friends think it's weird that we are so in tune with death. Like when we actually 'hands on' take part in the burial and are not physiologically disturbed afterwards. Of course, I feel sad for a while but then strangely recharged and reminded that I will die one

day, so I have to prepare. Even, casually, we discuss death or share memes, death is part of life!”

Conversely, second generation Altaf remarked:

“It really scares me [what happens when we die]. We learn about it, but I can’t seem to make connections and understand how. I get confused and then just avoid the subject. I mean, if I do something bad, I think what will the punishment be like in the grave, can I make things better by praying Surah Mulk before bed”.

There is an abundance of Islamic teaching available in books and online about what happens after death. The hermeneutical experience for each individual yield varying outlooks, as the interview excerpts indicate. Hermeneutics, McAuliffe argues is the the study of interpretation, using traditional non-scientific methods that consider culture, context of historical tradition, own inherent prejudices which can influences how text is interpreted (1991). Death, for some, it is a reminder to prepare for the inevitable, for others the thought of death can become somewhat overwhelming. Nevertheless, it can be argued that Muslims have an innermost awareness of the inevitability of death, the continuation of being afterlife, and what follows as ultimate accountability before Allah on the Day of Judgment before an infinity in heaven or hell.

Part 2 - Definition of death

Despite scholarly consensus from all four main Sunni madhabs that the deceased do not perceive pain after death (Butt, 2019), the overwhelming argument against posthumous organ donation put forward by interview participants across all three generations is that they believe that the deceased feel pain after death. “...there is no clear and reliable textual evidence that the deceased perceives pain of any kind due to being handled or treated inappropriately. In fact, Ḥanafī legal manuals emphatically state that the deceased does not perceive pain, and that any such notion is inconceivable. ... It is thus clear that the notion of posthumous pain perception due to third party assault or intervention is not congruent with any of the four schools, and so it can be concluded that the deceased does not perceive any pain during the process of organ retrieval” (Butt, 2019, p.87-88).

Given the participants main objection to posthumous organ donation is the notion of pain perception after death, the question of donation from brainstem deceased patients did not form part of the primary research. However, worthy of analysis through the non-scholarly

lens to consider the notion of pain perception after death. Additionally, it is regarded as a controversial topic; despite the patient being declared medically deceased Mufti Zubair Butt considers it impermissible to remove their organs (2019). Mufti Butt argues that absolute death must be confirmed by complete cessation of heart and lungs insofar as even a few minutes pass until death can be confirmed (2019). While other scholars differ on the subject, “Rashid argues that the phenomenon of declaring someone dead is not the domain of philosophy, metaphysics or theology but falls squarely within the realms of Islamic law” (Ali, Maravia, p.15, 2020). The definition of death therefore is contentious from an Islamic theological perspective. On one hand scholars refer to ancient scholarly manuals that were written prior to medical developments in organ transplantation, on the other, they rely on medical research findings to establish a jurisprudential position on the matter. In my undergraduate dissertation, regarding the significance of a Islamically credible definition of death for the purpose of donating organs after brain-stem death, I wrote; “For posthumous organ donation, there is a distinction regarding two medical definitions of death; firstly, circulatory determination of death (DCDD) which means death is certified by observing complete organ failure, i.e., when the oxygen and blood supply system fails to operate and the brain, heart and lungs cease to function. The second definition is brain-stem death (DDDB); whereby the brain is not responding to stimulation, but other major organs are functioning such as the kidneys, liver, heart and lungs (Butt, 2019)” (Fargin, 2020, p.19). Commenting on the research supporting the fatwa of Mufti Zubair Butt, I elaborated that, “Mufti Butt applies Islamic theology as the basis for defining death, insofar as using the physical signs outlined from the four main Sunni madhabs (2019). Butt argues that in the Ḥanafī manuals, evidence of death must be ascertained without doubt before the body can be prepared for janazah; meaning that if there is any doubt (i.e., that the patient may be in a coma), then janazah can be delayed until putrefaction (bodily decay) is evidenced (2019). Similarly, Butt argues that within the Mālikī, Ḥanbalī and Shāfi‘ī madhabs it is permissible to await a few days to be certain the patient has died before janazah preparation can commence (2019). Thus, Mufti Butt cites analogous evidence to assert that brainstem death alone does not constitute death in Islam. Overwhelmingly, Mufti Butt argues that the Shariah maxim of ‘removal of doubt’ must be applicable”. (Fargin, 2020, p.19). Furthermore, “In spite of his own assessment and that of other prominent scholars, Mufti Butt explains that some contemporary Islamic scholars do consider irreversible brain-stem death as complete death (2019). This is evidenced in the publication of the 1995 Fatwa of Muslim law (Shariah) Council, which considers brain-stem death as a “proper definition of death” (Butt, 2010,

p.10). Although, Mufti Butt argues that the fatwa was not represented by either Deobandi or Barelwi scholars; it is therefore argued that scholarly disputation can be confusing for the layperson.

Thus, according to the fatwa of Mufti Zubair Butt, brain-stem death alone does not constitute death in Islam (2019). The bone of contention here is arguably that the benchmark for Mufti Butt's argument is rooted in ancient scholarly manuals that were written prior to medical science methods to assert that death has indeed occurred with confidence. As is the case with the views expressed by Islamic scholar Dr Rashid, who "views the functions of the soul described by Ibn al-Qayyim al-Jawziyya ...and other scholars like al-Ghazali as the soul's control over most of the conscious activities which also resembles the cerebral cortex's higher brain functions ... Rashid accepts that while the cerebral cortex is the nearest instrument and implement of the rational soul, it is impossible to draw a clear distinction between a sentient person and a sentient non-person. Rashid concedes that in the absence of a universal accurate anatomical criterion for a higher brain formulation of death, the brainstem death criteria should be the closest and most accurate one to employ". (Ali, Maravia,

2020, p.15). "Moreover, the controversy in how death is determined i.e., period of elapsed time after removal from support machine and response to light or throat probe is also present amongst medical professionals themselves as Butt reveals in his report (2019)".

(Fargin, 2020. p.19). To summarise the significance of this debate, I argued "successful organ transplantation is hinged on the time it takes to transfer organs between bodies. E.g., When the patient is declared brain-dead their blood and oxygen supply are still functioning, meaning the organs are in receipt of the crucial components for effective function. When the organ is removed from the body or the person has died by means of circulatory death; their organs are no longer in receipt of a natural oxygen supply and blood flow, and therefore begin to deteriorate. The medical term for when the organs are preserved in this stage is called 'cold ischemia' and is especially relevant to organs such as the heart, liver and kidneys (Steiner, 2008)." (Fargin, 2020. p.20). Therefore, a review of the transitional phases prior to death through Islamic theological lens supported with ethnographies for philosophical insight from medical professionals is regarded important to aid the debate of pain perception after death within the context of brain-stem death.

Hamdy writes extensively about the contested status of brainstem death as complete death, albeit within the socio-political context of Egypt from the late 1970's. Where the prevalence of kidney disease meant increased public awareness and live kidney donor sales on the black market with unchecked transplant operations, thus, calling for government regulations

to be introduced (Hamdy, 2012). This unethical practice meant that due to increasing demand for kidneys; poor people in society were exploited, the human body was being monetised, practitioners were profiteering; contravening sharia principles. Thus, doctors, social and political commentators called for a national organ transplant initiative to tackle the issues mentioned, calling opposers complicit to the societal transgressions (Hamdy, 2012). In Egypt, muftis hold a prominent position in politics; however, it is not unusual for them to be accused of corruption for releasing a fatwa in support of government policies (Hamdy, 2021). In 1979, Shaykh Gadd al-Haqq declared in his highly influential fatwa (throughout the Arab Muslim countries) that “the preservation of life is an overwhelming principle in Islam, dire necessity, in the case of a dying patient, overrides what is otherwise forbidden – that is cutting into and extracting a body part of another person, living or dead” (Hamdy, 2012. p.55). This is caveated with prior consent required from the donor and conditioned that financial compensation is forbidden (Hamdy, 2012). Thus, placing ownership on medics to implement ethical judgement that the recipient is indeed in ‘dire need’. In his fatwa, Shaykh Gadd al-Haqq clearly stated that that brain-stem death does not constitute complete death. A decade later, the definition of death debate was reignited; medical and ethical proponents lobbied Shaykh Tantawi who issued a fatwa that placed ethical responsibility on medical professionals to determine death (Hamdy, 2012). With this context in mind, it is therefore understandable that at societal level the question of living donors was not disputed (Hamdy, 2012). Curiously, the general opinion amongst Muslims in Egypt around 40 years ago regarding posthumous organ donation was aligned to the views echoed by the interview participants of this study that our bodies belong to God, and the deceased perceive pain. Therefore, it can be argued that Islamic pedagogy rooted in ethical principles has the potential to enable lay-Muslims to confidently discuss contemporary moral conundrums as opposed to focussing on rules or historical stories.

The fatwa of Shaykh Tantawi held less sway than that of Shaykh Gadd al-Haqq who did not alter his fatwa in response (Hamdy, 2012). Hence, it can be argued that the status of brainstem death as complete death is still contested as the findings of a medical study in 2016 revealed. The study was conducted in Qatar over ten years, researchers George, Thomas, Ibrahim *et al* found that; “the median and mean somatic (bodily) survivals of braindead patients ... were 3 and 4.5 days respectively” (2016. p.2). A similar study conducted in the UK found that of 609 brain-dead patients, “the median somatic survival ... was 3.5 – 4.5 [days]” (George, Thomas, Ibrahim *et al*. 2016. p.3). Thus, outlining the period of survival for those patients who were declared brainstem dead albeit with medical

breathing and or circulator support (George, Thomas, Ibrahim *et al*, 2016). Incidentally, upon discussing this with interview participant Ayesha, she inquired:

“If the medics know that patient is going to die, why put them on the machine? I think this is just to preserve the organs and get consent from the family to transplant them to patients on the waiting list”.

During the days while the patient is considered brain-dead, families were presented with the opportunity to consent to donating the organs of the brainstem deceased patients for transplantation to a patient in ‘dire’ need. Despite these statistics and an established fatwa in support, the study realized that in Muslim majority countries like Qatar and Kuwait; families are averse to organ procurement from brainstem deceased patients (George, Thomas, Ibrahim *et al*, 2016). Even though, the fatwa of Shaykh Tantawi endorses medics as suitably qualified to determine death in brainstem deceased patients and recommend organ transplantation for a patient in dire need as an Islamically viable option. Thus, inferring that the decision is not simply hinged on knowledge of Islamic theology and medical science, but rather a philosophical, more personal choice.

Part 3 - Phases prior to death, between death and burial

All the participants interviewed for this study believed that the deceased perceive pain, and many referred to their experience of either performing the ritual cleansing and shrouding for burial or undertaking the actual burial as their rationale to be ‘gentle’ with the deceased. As first-generation participant Ahmad explained.

“I have performed the gusl on countless janazah’s and helped to bury them and every single time we are reminded that we have to be gentle with them, that they can feel pain.”

Such sentiment is arguably rooted in Islamic doctrine and could well be derived from the works of al-Ghazali either directly or via other scholarly sources who have relied on his works. Al-Ghazali argues “...the dead man has intelligence and is able to perceive and know the varieties of pain and pleasure, nothing in his mind having been transformed” (Winter, 2015, p.145). Al-Ghazali made the argument based on the hadith of Ata ibn Yasar who narrated a conversation between the Prophet and his companion Umar Ibn al-Khattab, in which the Prophet asked “O Umar! How shall you fare when you are dead, and when your family go to measure out [shroud-cloth] three cubits by one and a span, then return to you and wash you and set you in [your grave], then pour earth over you and bury you? For when

your family have departed, the two tormentors of the grave, Munkar and Nakir, shall come, whose voices are as rolling thunder and whose eyes are like dazzling lightening, who trail their hair and scrutinise the grave with their fangs [apparent], terrifying and frightening you? How shall you fare, O Umar? And Umar asked, "Will I have a mind like that which I have now?" and he said "Yes." "Then," he said, "I shall be a match for them!" This constitutes evidence that the mind does not change at death, but only the body and limbs change. Thus, the dead man has intelligence and is able to perceive and know pain and pleasure, nothing in his mind having been transformed." (Winter, 2015, p.145). Thus, the intangible mind that perceives pain is integral to what constitutes 'being', it still exists and continues. (Winter, 2015). Such a pivotal text arguably informed generations of Muslims the world over.

In explaining the period between death occurring and the burial, Smith and Haddad draw upon the works of al-Ghazali amongst other scholarly works, they argue "...death is considered a difficult and painful experience is quite apparent in Islamic tradition. ...but on the whole the period from the first realization of impending death to the time when the departed spirit sees its body washed and prepared for burial is understood to be an agonizing one" (Smith and Haddad, 2002, p.37). Smith and Haddad also cite a Hadith, between the Prophet and his wife A'isha whereby the Prophet described the utterances of the 'disembodied spirit', as the spirit observes being cleaned and shrouded for burial (2002). In the narration, the disembodied spirit cries out to his beloved to be gentle with them because they are sensitive to the water temperature and the tightness of the shroud (Smith and Haddad, 2002). Moreover, the deceased is reported to be in emotional distress at being separated from their loved ones and observing their grief (Smith and Haddad, 2002). Although the interview participants made no direct reference to the aforementioned statements, it can be argued that their messages have been filtered through to the Muslim societal discourse throughout generations.

In Islamic theology, prior to the final moments of life in this world, every dying person with the exception of the sha-eed (martyr) will inevitably experience *sakaraatul mawt*; often referred to as 'the pangs of death' (Qadhi, 2020). It is important to point out that the soul and the body are considered to be two components of a person. According to the ahl Sunnah wal jama, the soul however, is not thought to reside in a specific part of the body; the soul does however transcend from this world at the moment of death and is embodied in some form after burial (Qadhi, 2020). Al-Ghazali's analysis indicates that the spirit is situated with the heart while the person is alive (Winter, 2015). It is mentioned in the Qur'an 50:19; "The trance of death will bring the truth with it: This is what you tried to escape" (Haleem, 2010,

p.341). Thus, Qadhi argues that the sakaraatul mawt as per the definition used by Haleem is a *trance* (2020), meaning it is a metaphysical experience rather than simply a reference to the physical pain that is being experienced from the purview of this world. Therefore, it is argued that reference to the sakaraatul mawt as the 'pangs of death' is a reductive analogy. Moreover, al-Ghazali explains, "The pain felt during the throes of death, however assails the spirit directly, and engulfs every one of its fractions. The dying man feels himself pulled and jerked from every artery, nerve and joint, from the root of every hair and the bottom layer of his skin from head to foot. So do not ask about the suffering and pain he endures" (Winter, 2015, p.38). In her ethnography, Hamdy described how Egyptian Muslim doctors who studied in Europe were generally horrified at the practice of procuring organs from brain dead patients while they were being kept alive by a ventilator (2012). "Their hearts are still beating; they are still breathing. They don't turn off the machine. And they split him open and take from him what they want. They open the rib cage and pull out the heart while it is beating! *I seek refuge in God!* What do they think this is? A lamb to be slaughtered?! We treat our animals better than that!" (Hamdy, 2012, p.51-52). Another doctor described how he was troubled by the procedure, "he was willing to swear before God that the soul of the person was still present in the brain-dead body ...after they took all the organs and the machine was turned off, they would also take the corneas. The first thing they would take were the lungs, kidney, and the heart, *all before they turned off the machine.*" (Hamdy, 2012, p.52). Thus, these first-hand accounts reveal natural despondency of organ procurement from brainstem deceased patient that are not as succinctly actualized through science and theology.

When considering the sakaraatul mawt as a trance, it could be argued that the timeframe of the sakaraatul mawt is distinct and therefore incomparable to the timeframe of this world. In his lecture series, Qadhi addresses questions from the audience, one student asked if the person who dies seemingly peacefully in their sleep experienced the sakaraatul mawt (2020). Qadhi explained with Qur'anic lexical analysis that sakaraatul mawt is comparable to states of semi-consciousness as one experiences when intoxicated or asleep (2020). The word 'sakaraat' has the same root as 'sukraan', which is the word given to an intoxicated state; both relate to states of semi-consciousness (Qadhi, 2020). Suggesting that while the body is apparent in this world, the soul encounters an alternative experience. Qadhi concluded that "sakaraatul mawt, sometimes occurs in a state that people around cannot detect" (2020, Episode 1, 59:12-01:00:38). For comparative purposes, medical Anthropologist, Margret Lock defines the brain-dead patient in intensive care as, "betwixt and between ...they appear to hover eerily between life and death, dependent on the assembly

of machines” (Hamdy, 2012, p.49). Similarly, in regard to space parameters, the physical boundaries defined as the standard size for a grave (kab’r) for Muslim burials in the UK is 8’ by 3’2”, with space of 12” in between (Bury Council, 2020). Whereas, in the metaphysical sense there are numerous hadith narrations describing the dimensions of the grave as ‘vast’. (Qadhi, 2020). Thus, the two spaces are not equivalent because the notion of space differ in this world and the realm of the next.

Broadly stated, it can be argued that according to Islamic theology, sleep is analogous to death, Hadith narrations and Qur’anic ayahs Q.6:60 and Q.39:42, refer to the soul being taken during sleep, Q.39:42; “God takes the souls at the time of death and the souls of the living while they sleep. He keeps hold of those whose death He has ordained and send the others back until the appointed time: there truly are signs in this for those who reflect” (Haleem, 2010, p.298). Detailed analysis of sleep from a neurological and Islamic theological perspective are out of scope for this research because it requires advanced studies relating to neurologic activity at varying degrees and advanced Islamic exegesis respectively. cursory analysis to support the lay argument however demonstrates that there is basis to reconcile sleep studies through Islamic theological lens. In a peer reviewed report published on the Sleep Foundation website, Suni and Dr Vyas described ‘the sleep cycle’ comprised of four varying levels which can occur in between four and six sleep cycles based on duration (2020). Studies are typically undertaken in laboratories and therefore within controlled research conditions on humans and on animals and can include neurotransmission receptors to track brain activity. Other, more common tests found in medical journals relate to tests undertaken by participants after the sleep cycle that are focussed on results to assess alertness and cerebral responses. The table below provides examples of the variations of sleep.

Sleep Stages	Type of Sleep	Other Names	Normal Length
Stage 1	NREM	N1	1-5 minutes
Stage 2	NREM	N2	10-60 minutes
Stage 3	NREM	N3, Slow-Wave Sleep (SWS), Delta Sleep, Deep Sleep	20-40 minutes
Stage 4	REM	REM Sleep	10-60 minutes

NREM – Non-Rapid Eye Movement Sleep. (Suni, Vyas, 2020).

The varying stages of sleep are explained as N1 signalling the initial phase of falling asleep, while the body begins to relax (Suni and Vyas, 2020). When the sleep is unbroken, the body shifts into N2, where the muscles are relaxed further, and the bodily temperature is reported to be cooler and breathing slower. In N2, "...brain activity slows, but there are short bursts of activity that actually help resist being woken up by external stimuli" (Suni and Vyas, 2020). Again, if undisturbed, the body transitions to N3 which is referred to as 'deep sleep', whereby the body continues to relax further, as detected through the symptoms described in N2 (Suni, Vyas, 2020). At sleep stage N3, "...brain activity is reduced, there is evidence that deep sleep contributes to insightful thinking, creativity and memory" (Sunni, Vyas, 2020).

REM sleep relates to the period of sleep prior to waking up, wherein the body is undergoing "a temporary paralysis of the muscles, with two exceptions: the eyes and the muscles that control breathing" (Suni, Vyas, 2020). It is important to interject here with referral to brainstem death criteria to clarify that pupil reaction to light is a vital factor in determining brainstem death. If the patient being assessed for brainstem death responds to light by the movement of pupils, they are not considered to be brainstem dead because the eye movements signal a connection with brainwave (Peever and Fuller, 2017). Moreover, this analysis does not confirm if tests were carried out on cerebral cortex activity while asleep to compare with Dr Rashid's analysis for the determination of brainstem death. Therefore, this synopsis merely provides scientific weight to support the Islamic theological analogy of sleep to death because the symptoms described during the N3 deep sleep phase are similar albeit while the sleeping person is undisturbed. Furthermore, in a Harvard Medical report on Rapid Eye Movement sleep (REM), Peever and Fuller argue that the discovery of REM can be dated back to 1953, and that, "...the first description of REM sleep was met with scepticism and indifference, the initial report is now widely viewed as a true watershed moment in science, having forever changed the way scientists and the medical community view the sleeping brain" (2017). Hence, however tentative, it can be argued that for analytical purposes of the theological position posit by al-Ghazali that the deceased is in a state of sentience after death and, prior to burial although they cannot communicate with this world is one that resonates with lay Muslims.

Additionally, when describing the time of death, Qadhi provides low level details of each encounter insofar as the first stage when the soul of the dying person is visited by an angel of death (2020). In this moment, only the dying person encounters the transcendental; only they can see an angel of death. Onlookers, however, witness the dying person taking their last breaths in this world. According to the authentic graded hadith of Al Barrah Ibn Aazib,

“an angel of death (malakal maut) sits at the head of the dying person” (Qadhi, 2020 Episode 2, 19:20-19:30). In his lecture series, Qadhi provides and full English translation of the hadith with critical analysis throughout, the hadith continues, “...then, the angels of the heavens come down as if their faces are suns/bright, and they have with them the shrouds of Jannah (heaven) and the perfumes of Jannah ...and they see [a delegation of angels] as far as the eye can see ...then the angel will say ‘oh pure and peaceful soul, now is the time to exit ...and I welcome you to Allah’s magfirah (pleasure)’ ” (Qadhi, 2020, Episode 2, 19:3023:00). At the time of death, al-Ghazali argues “a man passes from Terrestrial and Visible Realm [*alam al mulk wa’l shahada*] to the Realm of the Unseen and the Kingdom [*alam alghayb wa’l-malakut*], and is no longer to beheld by the physical eye, but rather with an eye which is apart” (Winter, 2015, p.149-150). Based on the description provided; this is when the dying person commences their journey from this life (Qadhi, 2020). Thus, the dying person is present within two concurrent spheres; the body is in this world while the ruh (spirit/soul) has transcended momentarily to the Realm of the Unseen and the Kingdom (*alam al-ghayb wa’l-malakut*). In this world, the encounter appears to be a ‘millisecond’, made apparent by the movement of the eyes of the dying person in an upward direction (Qadhi, 2020). Yet given the two timeframes are not equivalent, it can be argued that the seemingly millisecond transcendence is incongruent with this world (*dunya*), meaning an equivalent timeframe to the experiences of the body and the soul cannot be applied comparatively. Consequently, the duration of the concurrent metaphysical experience of the soul just before death cannot be quantified for a like for like context of time. As such there is basis for an argument to suggest that even the timeframes are not equivalent. Accepted, this hypothesis can be regarded tentative without thorough metaphysical analysis, nevertheless while it cannot be disproved it cannot be completely discredited.

One interview participant mentioned her own encounter with a brain-stem deceased patient:

“My mother-in-law died from a head injury, I was there with her, even when I was calling the ambulance, I knew she had no chance, she was gone, don’t ask me how, I knew it. In A&E, they told us that she was brain-stem dead, and I kind of remember having the discussion about organ donation with my husband and the doctors. She was hooked up to machines, I couldn’t understand why she was hooked up to machines when she was thought of as dead anyway. Was it just so her organs stayed fresh to donate? ...We didn’t donate, my husband was distraught at the idea of it”.

Within scope of discussion of the final stages of life for brain stem patients, this research relies upon the ethical considerations for medical practitioners during the procurement process of organs from brain-dead patients, Hoeyer and Jensen discuss the notion of 'aggressive organ harvesting' (2012). This is in the context of those brain-dead patients awaiting organ donation but suffer cardiac arrest abruptly, and therefore need to be rushed into the Intensive Care Unit (ICU) where the already deceased patient undergoes a series of defibrillation shocks and cardiac massage to keep the organs active (2012). This insightful report details the first-hand experiences of medical practitioners who must respond in such circumstances. Sometimes, a patient will be with their loved ones who are bidding their final goodbyes, when the patient suffers cardiac arrest and needs to be rushed to ICU (Hoeyer, Jensen 2012). Medical practitioners describe having to rush patients into the operating theatre while the patient displays signs of physical distress (i.e., vomiting), their invasive treatment can result in breaking breast bones to preserve their organs for donation (Hoeyer, Jensen 2012). The ethnographic study was carried out in Denmark at their Centre of Organ Donation (DCO) in 2012, it includes interviews and focus group responses of medical professions including ICU nurses, anaesthetist and neurosurgeons who have first-hand experience of dealing with the procurement of organs from brain-dead patients. The study was initiated in response to feedback from DCO staff who found aspects of organ retrieval from brain-dead patients 'troubling' (Hoeyer, Jensen 2012). Additionally, the authors reflect upon how the enactment of medical practices are conducive of shifting the positionality within this context from what Timmermans described as 'normalization of deviance' (Hoeyer, Jensen 2012). In other words, around the 1990's the issue of procuring vital organs from brain-dead patients was considered controversial in countries like Japan and Denmark (Hoeyer, Jensen 2012). Since it can be facilitated within the hospitals it has become standard practice thus normalized something that was previously regarded unnatural. Hoeyer and Jensen argue "In Denmark, the introduction of brain death was relatively controversial and came into effect after 20 years of debate, in which wide-spread popular and political scepticism was expressed" (Det Etske Rad, 2008, p.603). The treatment of brain-dead patients in an emergency situation of suffering from a cardiac arrest provides a glimpse of what the patient experiences physically, which can add some weight to support an argument that the [brain]-dead do feel pain. For those medical practitioners who are responsible for treating the patient, their own experience is paradoxical because they undertake the same procedure as when they need to 'save the life' despite the patient already being declared dead. Timmermans (1996) argued, "In an uncanny way, treatment of cardiac arrest is an act of violence with benign intent. The almost violent physicality of

resuscitation is usually justified as being the only possible way to rescue the patient” (Hoeyer, Jensen 2012, p.604).

A participant of the study who worked as a nurse in the ICU said “It relates to this thing that we somehow are playing God, ...the patient is sort of dead once and now he's not allowed to die the second time he wants to do so. Really, what are we up to? Can you allow that? What do the relatives think and what do my colleagues think who stand right beside me? So, I think you kind of step over a frontier which is already transgressed once ...perhaps” (Hoeyer, Jensen 2012, p.604). In another first-hand account, an ICU nurse stated, “Really, it is an extremely undignified situation, to be totally stripped and having, I don't know how many people, throwing themselves on top of you, administering a lot of medicine and everything getting into a frenzy! It is very, very much in contrast to the other situation [donor care] where we gently and quietly administer Dopamine and attend to the small things, walk softly, and treat the patient with dignity” (Hoeyer, Jensen 2012, p.605). Another arguably unnerved colleague pointed out that, “I just believe it's deeply rooted in us to exit life in a proper manner ...it is not compatible [emergency cardiac arrest treatment for brain-dead patients] ... - vomit floating all over the body, cardiac massage, and breaking the chest [bones]”. (Hoeyer, Jensen 2012, p.605). It is argued that these research findings demonstrate not only the imposition experienced by medical staff when carrying out what they themselves describe as ‘aggressive’ procedure on a patient who has already been pronounced ‘dead’ to save their organs; but also, the subjectivity involved. The senior practitioner at the scene is responsible for declaring when ‘life saving’ action is futile; they themselves differ in their opinion on when to stop. On the subject of performing defibrillation shock on an already deceased patient, a neurosurgeon remarked “Well, I think it is irrational if you don't have any medical [faglig] reason for reaching it, but base it on something emotional that has no solid grounding in the reality that you face - because it's your own boundaries you need to cross, and I guess you can say it's no fun having to transgress one's own boundaries” (Hoeyer, Jensen 2012, p.608). Arguably, rendering this debate as one of subjective ethics over medical science.

From a philosophical point of view, ICU medics described the sudden cardiac arrest in a brain-dead patient awaiting organ donation as divine intervention. “One anaesthesiologist said that in case of cardiac arrest, she would ' ... go and tell the relatives "I'm sorry, but it was others than us deciding” (Hoeyer, Jensen 2012, p.608). “When we asked who those ‘others’ were, she responded “Well, then I'd say it was some kind of divine authority, or the body itself saying stop” (Hoeyer, Jensen 2012, p.608 and 609). Additionally, the research provides several interview extracts from the family of patients and medical practitioners,

alluding to also to some kind of metaphysical inclination. A nurse who is ambivalent to the procedure stated, "It might also be that it's the body's way ...to say "Stop!", eh, that "I don't want this anymore" (Hoeyer, Jensen 2012, p.609). Therefore, it is argued that the issue of defining death is multifaceted from medical science, theological and philosophical viewpoints, thus difficult to convince.

To conclude this chapter, "Roger Cooter (2000) suggests that during the 20th century, the dead body underwent even greater changes than the living: it moved out of the home and into institutions; the average person stopped seeing and touching the dead; and with autopsies and tissue procurement, the dead body became a resource for the living rather than merely laying claim to their resources with demands for funerals and sacrifices". (Hoeyer, Jensen 2012, p.600). From the Muslim perspective on organ donation not much has changed because arguably Muslims have direct interaction with the deceased insofar as carrying out the janazah gusl, ceremonial prayer and burial themselves as opposed to delegating the responsibility to a third party such as funeral directors. Thus, casting light on why lay Muslims will default to erring on the side of caution and opt out of organ donation after death for fear causing undue pain to a loved one.

Chapter 2 – South Asian Muslim Labour Migration to Northern England post, World War 2

Islam is a universal religion comprising mainly of Sunni Muslims and a Shia minority. Muslims, albeit unified by creed are representative of diverse societies with inherited cultural traditions that overlap and are assimilated to their national context for citizenship. In a Pew Research report focussed on the global religious population growth, the researchers predict that Islam is the fastest growing religion by 2050 owing to the average young ages of Muslims, comparatively high fertility rates and new conversions to the faith (2015). According to the Office of National Statistics, there were 3.3 million Muslims in Britain in 2017 (approximately 5% of the overall population), although this is an indicative figure based on those residing in private residence (ONS, 2018). When released in 2022, the results of the 2021 census will provide a much more accurate view. A Pew Research report published in 2015, stated that the global Muslim population amounts to circa 1.9 billion Muslims which is 23% of the global population; in 2010, that figure was 1.6 billion (2015). Muslim communities across Britain range between a stronghold of South Asian, but also inclusive of all global nationalities; thus, Islam as a lived reality is diverse.

Lewis traces 'Muslim presence in Britain' (2002, p.11) to over three centuries when the 'lascars' (Indian merchant navy) laboured at British ports for the East India Company; some of whom settled around London and across several British ports (2002). The Suez Canal opened in 1887 paving the way for merchant navy labour migration from Yemen, amounting to circa 15,000 Yemeni Muslim population in Britain, regarded as the oldest established of which there is still a Muslim stronghold community in Liverpool today (Lewis, 2020). During the Second World War, approximately 20% of the British merchant navy were South Asian (Lewis, 2002). Post-World War Two, migration from the British Commonwealth was arguably ramped up to help rebuild Britain with a labouring workforce (Lewis, 2002). Lewis describes four phases of South Asian migration, beginning with "the pioneers, then ...chain migration of generally unskilled male workers, followed by the migration of wives and children and finally the emergence of a British-born generation". (2002, p.17). Within this paradigm, once settled with a job and lodgings, the migrants were able to sponsor others to come and work in Britain within the voucher system. The voucher system enabled sponsorship of A, those individuals with an assurance of a job, B, those skilled and qualified and "C, unskilled and without firm promise of work – preference was given to ex-servicemen" (Lewis, 2002, pp.1718). The following chapters include the ethnography 81-year-old Ahmad who migrated to

Yorkshire on an A type voucher from a Gujarati village in the late 1950's to work in a textile mill. Ahmad who identifies as Deoband, believes that live organs donors are permissible, but post-humous organ donation is impermissible because the deceased perceive pain and burials must be carried out as soon as possible. Chapter 3 includes an ethnography from his daughter Ayesha, a first-generation British born Muslim who was born in the mid 1960's, thus providing an analytical overview of intergenerational relationship differences.

Ahmad recalls making arrangements to move to the UK as a Labourer in the late 1950's as a teenager:

"In my village, I worked on the farm every day. I attended school and madrassah, but always helped on the farm. With my family, I would help collect water from the village well, help harvest crops every year, I would look after the animals, feed them, clean, and prepare packages of crops for the street vendors to sell in the city. They were happy days with happy memories. The work was hard but very rewarding. When I was asked about moving to England for work by my family elders, I didn't know what to expect, or for how long I'd be away from home. I loaned the ticket money for the flight from my UK sponsor, and I promised to pay him back as soon as possible, I did so a year later after arriving in Yorkshire and working in a carpet factory. I saw my purpose of being here to work".

"I didn't know how long I would stay in England. I came, I worked, I paid my bills and sent most of my savings back home [to India]. I always desired to go back, but it wasn't to be. I married here, my children, grandchildren and even great grandchildren are here. This is home!"

Ahmad described the culture shock, in terms of suddenly having to acclimatise and the financial responsibility to sustain living in the UK while also sending money back home to his family in India.

"I had never felt so bitterly cold before in my life. I didn't have the right clothes [warm coat, leather shoes]. I and my brothers, we walked everywhere, nobody had a car, and it wasn't until a few years after I'd been here that I caught the occasional bus because we didn't understand the timetable, our English language was poor, and money was precious. I lived in a shared house with several others until years later when with my brothers we saved enough to buy a house, between us, we saved the entire cost of the house around £2000 [for a three story, three-bedroom mid-terraced house in the 1970's]".

Ahmad also explained that he and his community of friends and family would save money and offer loans to each other to avoid consuming interest (riba) while sustaining 'halal

finance management'. According to the shariah, "Interest/usury (riba) is viewed as unjustly profiting from another's labour and property" (Esposito J.L, Delong-Bas N.J. 2018, p.231), but arguably also conducive of an unfair economic paradigm which enables the rich to become richer through profiteering from higher return payments for loaned sums, while the poor become poorer by trying to keep up with repayments above their initial borrowed amount. The distribution of loans for the exact amount rather than an inflated return over time was by all accounts an anti-capitalist societal norm within the first generation of South Asian Muslims in the UK, perhaps inadvertently. As Ahmad said:

"We didn't have Mufti's in our community back then, amongst us we identified who were the elders and most learned on matters concerning our religion. We would often gather after Namaz [congregational prayers], and discuss dilemmas such as taking loans, funerals, praying Jumma on time when we were at work [midday Friday congregational prayers]. We held mashwara [consultations] until we made connections with the wider Muslim community to understand how to make sure we stayed on the right path [adherence to Shariah]".

This initial ethnography demonstrates the centrality of the shariah for South Asian lay Muslims, the first generation were conscious of their Islamic principles and managed to navigate their way in British society while holding firm on to their beliefs.

Yahya, is a second generation South Asian Muslim (Berelwi), who was raised in the same community as Ahmad, Yahya explains:

"My parents' generation were devout, massive respect to them [community elders], they paved the way for us to be Muslim in this country; thanks to them we can negotiate time off for Ramadhan and Jumma prayers. Yes, we compromise, we have to make up the time elsewhere or take annual leave, but it is something that we can easily discuss with our employers these days because the first generation set the precedence".

On the topic of organ donation however, Yahya expressed some disgruntlement with what he explains has become standard practice to discuss issues at community level,

"I find it frustrating that personal decisions often become part of community debates, it then just slows progress down. For example, my son needed a stem cell donor for his cancer treatment. It was difficult to get a match so I had to ask my extended family for a donor, some queried if it was 'halal', can you believe being in that that critical situation and it is then debated as if saving the life of another should be questioned in Islam".

On the contrary however Aamina, first generation Indian Muslim (Deoband/Naqshbandi) recalls how 15 years ago, blood and stem cell donors from within her community 'lined up' in

efforts to help her son who was suffering from cancer that had travelled to his blood and bone marrow.

“When people heard that my Haroon was ill, they came to offer blood and stem cells. Young, old, family, neighbours, friends of friends, they all came to help find a matching donor, we didn’t ask, they came”.

It can be argued that the first generation of South Asian Muslims strived to establish Islamic values at societal level, wherein they researched theological reasoning to enable them to live as Muslims in a non-Muslim majority land. In doing so, they developed cultural practices to suit their context through acts of preservation. As Yahya explains:

“Growing up, we questioned a lot, like should we sing hymns in school. We’d be in trouble with the teachers if we didn’t, but it felt like betrayal of Islam. I even remember molisab [mosque teacher] saying ‘just move your lips’. Then we’d get caught out by the teachers and get into trouble”.

When asked about the relationship between the youth and community elders, Yahya said:

“We’ve always been taught to respect our elders, and it is frowned upon to ‘answer back’, some even say it is haraam. In the old days, we wouldn’t challenge, but now things have changed, people my age sit on mosque committees, and we come forward with new ideas. Everyone has an opinion, some are so scared to commit sin that they play it safe, others are a bit more open. In my experience, issues will be debated for a long time without firm conclusion”.

Additionally, regarding the NHS organ donation presumed consent laws, Yayha said:

“What bothers me more, is how come this change has gone through the law now? During covid! I mean, bodies are being handed over in body bags, do we even know if they’ve been tampered with? Look what happened in Sri Lanka, astagfirullah, [government enforced cremation during Covid, including for Muslims]. Look at the Uyghur Muslims, how their organs are harvested. If we let our guard drop, they’ll come for us next. It’s a slippery slope, you can’t let standards drop!”

Thus, demonstrating that the topic of organ donation is far more nuanced than a mainstream narrative that runs seamlessly throughout British Muslim experiences. In 2019, it was reported to the Human Rights Council that “The Chinese government is harvesting and selling organs from persecuted religious and ethnic minorities on an industrial scale. ... Detainees were killed to order... cut open while still alive for their kidneys, livers, hearts, lungs, cornea and skin to be removed and turned into commodities for sale. ...there was also

possible evidence, though in less volume, of forced organ harvesting in detainees from the Uighur Muslim minority, as well as Tibetans and some Christian sects.” (Withnall, 2019). Furthermore, the Human Rights Council was also alerted to the issue of forced cremations in Sri Lanka during the coronavirus pandemic, “despite international and Sri Lankan medical experts saying there is no evidence that Covid-19 is communicable from dead bodies” (Wintour, 2021). Moreover, in the UK, the 2002 Donaldson Report found that children’s organs were retained post-mortem (Haddow, 2005). Therefore, adding weight to support to Yahya’s concerns that extend beyond himself for the Muslim ummah that manifest as mistrust of authoritative structures.

The ethnographies here are accounts of three individuals only, however they refer to communal experiences, and therefore one argues that these interviews are indicative to a certain extent of societal norms within those communities. Therefore, one argues that posthumous organ donation will continue to be viewed through a lens of scepticism until there is an established precedence and trust of the government in those Muslim communities.

Chapter 3 - Epistemological Insight into Islamic Pedagogy within South Asian Muslim

Communities in Yorkshire from 1960's

The typology of participants mainly being discussed in the next two chapters are mainly female, married, aged over 35 years, born in the UK with South Asian heritage. The interviews were conducted individually, participants were not privy to each other's interviews to assure impartial research findings.

The initial phase of research found that all five second generation participants interviewed stated that they were not aware of any permissibility in Islam to donate organs after death. Upon reading a summary of the fatwa and rationale provided by Mufti Zubair Butt for the legitimacy in Islam to donate organs after death; each participant expressed that they were open to reconsidering their position. Their foremost basis being that they had not inquired past their pre-held judgements based on literal understanding of hadith and adherence to societal normative practice. Although all the participants had already opted out of donating organs after death, they remarked that they are interested in changing their status to 'deemed consent'. When asked if the fatwa is sufficient to help them decide, each participant individually stated that they would need to discuss it further with their husbands because they are their 'mahrams', inferring that their husbands are essentially their decision makers. In the endeavour of conducting epistemological research in this regard, one argues that from a lay-persons perspective; as Barlas has argued, the manifestation of prevailing cultural normative position counters the ethical interpretations of Qur'an in respect of the relationship with men and women as equal vicegerents of Allah on earth (Barlas, 2019). Additionally, the notion of the 'mahram' is subject to dichotomous interpretation of pedagogy and unquestionable societal discourse resulting in deeply embedded cultural views throughout generations of South Asian lay Muslims. This twofold argument is discussed here by citing interview excerpts to provide the societal context and epistemology of Islamic pedagogy. The notion of mahram will be discussed extensively in Chapter 4.

To provide historical context to the community of lay Muslims being discussed, one begins this chapter with an interview with 54-year-old Ayesha (first generation, British-born), daughter of Ahmad from Chapter 2. Ayesha is a two decade long established tradesperson, based in the heart of a bustling Yorkshire market town which is also her birthplace and hometown; her father, migrated to England as a youth in the late 1950's. In a candid telephone interview, Ayesha talked about how her father, his siblings and her grandparents initially moved to the northern mill town as labourers and somehow navigated their way

around British society with limited English language. In modern history, Lewis traces British Muslims through the trajectory of British imperialism as colonialist subjects, “military and ideological threat, political allies, trading partners, objects of intellectual curiosity, ripe for imperial conquests and latterly, as fellow citizens” (2002, p.10). Moreover, Lewis argues that the driver for labour migration was motivated by short term economic gains insofar as the salary offered in Britain was estimated at 30% greater than the equivalent work in rural Pakistan (2002). Ayesha however explains that:

“My father never wanted to move to Britain, he always said that he had to, I think a lot happened regarding their land ownership and financial circumstances after the partition that meant he had to come to England. His intention was to work, save, send money back home and then move back, he wasn’t even married when he moved here”.

One argues that the estimated financial advantage of a 30% increase is somewhat disproportionate given the difference in cost of living between India and Britain, and it dismisses factors such as the costs for the flight and transfers, lodgings, unexpected expenditure such as climate and culture suitable attire all of which are significantly high in the initial stages of migration. Ayesha recalls her father saying that he did not have sufficient funds to pay for his flight to Britain and had to loan the cost from a family friend, a debt that took him almost a year to repay by working ‘overtime’. Moreover, the emotional upheaval is understated, Ayesha says:

“I remember my dad feeling homesick quite a lot, he told me about having to buy thermal vests and jumpers and suitable shoes to protect against the rain and cold. He really missed his home comforts, he felt couped up, whereas back home he would be outside on the farm and out with his friends all day. He never seemed to complain though, just like he felt sad and just got on with it”.

Being one of the first British born in her local community, Ayesha recalls as a child accompanying her parents and their friends to hospital appointments and other meetings between English only speakers to translate conversations into their native mother tongue. As the eldest English reader and writer in their immediate community, Ayesha fondly reflects on the kindness expressed to her by the elders who relied on her translation services which also extended to administrative tasks such as making important phone calls from the red phone booth until they afforded a house phone and form filling, in return she remembers being gifted with her favourite confectionary as a child; ‘Kendal Mint Cakes and Tunnock Teacakes’.

We met a year after the NHS organ donation status had changed to 'presumed consent' in England. Ayesha begins:

"I'd known about the change for at least a year before the law changed, I remember everyone on my Facebook saying we need to opt out or else we won't have a choice; they'll [the state] take our organs".

Instinctively, Ayesha opted out of donating organs after death. Additionally, she had advised her elderly parents, her husband, siblings, several children, and their spouses to opt out too. Moreover, Ayesha widely shared the link with her WhatsApp contacts encouraging them to do the same. Although, she admits:

"I just forwarded the message, it came from someone, I can't even remember who".

After undertaking a search by the words 'organ donation' on one of her prominent WhatsApp groups, Ayesha found that there were "loads" of messages on the topic. Ayesha found one apparent originator message with the NHS weblink to 'opt out' attached, stating that "we must act now and opt out before the law changes". Ayesha thinks she 'opted out' immediately upon reading the message without question. Like most of the participants interviewed for this research, Ayesha affirmed that she had pre-held beliefs that organ donation is forbidden in Islam because the body feels pain after death. Despite being aware of the counter arguments against organ donation in favour of haste in burying the deceased and being buried in the form the body was in when the soul departed because the bodies will be raised again in the hereafter; Ayesha had discredited them based on her own independent research rooted in her knowledge of critical analysis of hadith and Qur'anic tafsir.

"I spoke to a scholar about why we rush to bury our deceased and he explained that we should unless there is a genuine reason to delay. I'd say as a community we just rush through as a habit".

Therefore, Ayesha agreed hypothetically that if one is to accept that donating organs after death is permissible in Islam, then it is a valid reason to delay burial. In regard to keeping the body intact, Ayesha cited an ayah from the Qur'an (75; 3-4); that Allah will reassemble us in the hereafter to our very fingertips.

"I've always believed that our bodies belong to Allah, and that our bodies feel pain after death and because nobody can actually prove otherwise, I just opted out".

Central to Islamic doctrine is the acceptance of life after death, however there are phases afterlife as we know in this world, discussed extensively in Chapter 4. Firstly, when the ruh

(soul/spirit) departs the body there is an initial phase until the body is buried. Arguably, it is not uncommon for lay Muslims to refer to this phase as a 'limbo-like' state, reflective of their British societal discourse. One argues that the use of terminology that is not found within the Islamic doctrine is subject to the blurring of theological reasoning and thus leads to confusion within lay Muslim discourse. The concept of limbo was found in the Catholic tradition up until 2007 when the Church's International Theological Commission admonished it as "unduly restrictive view of salvation" (Pullella, 2007). Prior to 2007, according to Catholic doctrine; limbo is the where unbaptized babies would reside (Pullella, 2007). Moreover, limbo carried negative connotations of those who had not otherwise attained salvation because they had not been baptized and therefore confined to the 'edge' or the 'borders' of Hell (Pullella, 2007). Thus, transposition of non-Islamic terminology to explain Islamic theological phases leads to misunderstandings.

Growing up in the early 1970's, Ayesha recalls:

"We didn't have a local masjid. My father and his friends who were all neighbours would get together to pray [congregational Salah] at our house. My parents used to teach me how to read the Qur'an and as more and more children [siblings and neighbours] came along, my dad held regular classes from our front room. It was mixed, boys and girls and we just learnt to read the Qur'an in Arabic. My dad was not an Imam, he just taught us the Qur'an as he knew it".

As the Muslim congregation grew, a local family donated the downstairs floor of their home to the community to serve as the local masjid whereby locals could attend the congregational prayers daily, and children would attend classes in the evening. Eventually, the community outgrew this designated space too and had raised sufficient funds to construct a purpose-built mosque, it can now host in excess of a thousand worshippers at one time. Ayesha recalls the gradual but progressive transition of a minority South Asian Muslim community in England over the last fifty years through her own experience and that of her children. Here, Ayesha describes the core Islamic text used in mosques and the teaching approach applied for the earliest generation.

"My father and his friends called [sponsored] Imams from their village back home to come and teach in the local madrassah. That's when they started to introduce something more like a curriculum, so we had the 'kapti/takti' [basic Arabic alphabet suitable for beginners], then the Qai'dah to help with learning to read the Arabic Qur'an, including the grammatical rules. Then Amma para [the thirtieth part of the Arabic Qur'an alone], then Hafti [a corpus of the first five parts of the Arabic Qur'an], and then the whole Qur'an in Arabic. Alongside the

Qur'an, we learnt the kalima's [declarations of faith in Arabic], some dua's [supplications] and namaz [ritual salah] too. Looking back, we just learnt to memorise and read in Arabic. We had an idea of what they meant but didn't really delve deeper as in question what we were learning. As we progressed through this path of learning to read the Qur'an, we also had a kitab [Urdu textbook], I remember reading 'Allah Ke Rasool', it was a bit alien to me. Again, I feel daft saying this, but I don't know how I learnt to read Urdu or understand fully what I was reading because Urdu is not my mother-tongue. I think I did get the gist of it. I think Allah Ke Rasool was like a nice overview of the Seerah [biography of the Prophet]. One of my dad's friends used to buy Islamic books from India and South Africa, he supplied all the books we needed. In time, his collection grew with demand for more Islamic books, and he had a kind of bookstore in his front room. People came from all over to buy his books, from other local towns and the Midlands. It was normal to see the same books in every house. As a teenager, I remember there being a big push to complete the Qur'an, meaning to complete reciting it once at least in Arabic from beginning to end, I seem to think there was more pressure on the girls so we could leave the mosque before puberty. Afterwards, I would attend a weekly taleem [Islamic teaching gathering] every Thursday with my mum and sisters, it was run at one of her friends' houses, they were a very Jamati family [religious congregation that travels to preach and teach Islam]; and had segregated spaces for men and women. There we listened to bayaan [lectures], mostly it was an Aalimah [female scholar] who emphasised the need to do constant zikr [remembrance of Allah] and she read parts of Beheshti Zewar. I've only recently learnt that it means 'jewels of Jannah'. Now, when I look back, I see that the emphasis was on how to conduct yourself as a woman. We were taught rules; maslah, maslah, maslah [rules]. When I asked questions about why, why, why, I never got an answer".

Lewis argues that Beheshti Zewar by Deoband Sufi scholar Ashraf Ali Tanawi, was originally produced in 1906, an Urdu 'encyclopaedic' text until it was translated later into English (2002). As a pedagogical tool, it was designed as Ayesha describes to be read aloud in groups to encourage debate rooted in "correct belief and practice" (Lewis, 2002. p. 79). Conversely, Ayesha describes her learning experience as 'one way' because discussion of the topic was not encouraged.

Ayesha has consistently studied Islam throughout her life. In her youth, she recalls replaying audio cassette recordings of lectures that her family and friends brought back from trips to India, Pakistan, South Africa, Mecca, and Medina, and feeling particularly inspired in adulthood by what felt to her at the time as nuanced Islamic lectures.

“I loved listening to the different kiraat [recitation], especially by Abdul Basit Abdul Samad, and different stories of the Prophets, ones that I can’t remember learning as a child. There was this one tape with a recording of Maulana Tarik Jameel, he emphasised the mercy of Allah. In the lecture, he kept repeating ‘Allah forgives, Allah forgives, Allah forgives’, it stuck with me ever since I heard it”.

Ayesha explained that the overall theme of Jameel’s lecture was centred upon the mercy of Allah and was a refreshing change from the way she was taught Islam which she described as “a rulebook of do’s and don’ts”. One argues that the audio tapes however had their limitations because it lacked direct engagement with the respective society. Nevertheless, Ayesha continues:

“I find Islam so fascinating, every time I indulge, I find something new, something hopeful, something comforting. When we got scanners [transmitter radio’s] in our homes and could listen to the Azaan [call to prayer] and lectures from many of the local masjid’s, I found it became a lifeline for me. The imams were talking about what was happening in our community and were responding to our queries”.

Arguably, the introduction of local radio transmission from the mosques to homes meant an increased frequency of topical Islamic lectures, thus a demarcation from hackneyed sermons.

As her community diversified and with the prevalence of the internet, Ayesha delved into alternative modes of Islamic teachings to help inform her life choices.

“I’ve noticed lots of differences of opinion within my own local Islamic community particularly in the last couple of decades. My local community was always kind of ‘same old same old’, we went to the same mosques, read the same kitabs [Islamic books], but now there are people within my community who are from different countries, so we have Hanbali’s and Salafi’s in our community too. I actually like to see that the Salafi’s can provide answers to my questions, when I ask why, they give me daleel [proof] from Qur’an and Hadith, something that was lacking in my previous teachings”.

Returning to the topic of organ donation after death, Ayesha conceded that despite her personal endeavours to base all major life decisions on Islamic principles, she has not reconsidered her position on posthumous organ donation.

“I know I’m going to contradict myself; I know of the Hanafi fatwa permitting organ donation, but I have chosen not to look into it properly. Until recently, I thought it was haraam

[impermissible] *and since this came to my knowledge, I still want somebody to prove how they know that the dead do not feel pain. It worries me*".

Despite empathising with the notion of donating organs as an ethical practice aligned to the Islamic teachings of kindness and the reward of saving the life of another. Ayesha acknowledges her own contradictory stance, she accepts that:

"I understand the concept of living through another, meaning how rewarding it is to donate organs to give somebody else a chance at life. But what I don't know is what the deceased feel, what do they go through. I've performed a lot of gusls for janazah's [ritual cleansing of the deceased] over the years, [locally and across diverse Muslim communities] and every single time, there is so much emphasis that we need to be gentle with the deceased, handle them with care to not hurt them at all".

Thus, reinforcing the pre-held and unquestioned notion of the metaphysical that the deceased feel pain. Arguably, the inability to question this position has resulted in normative societal praxis that to veer away from it is considered sacrilegious. It is clear that Ayesha is grappling with her own positionality, as she herself states:

"I also know that if I or a child of mine or a loved one needs an organ, I'm sure I would find the daleel [proof] to take one, whether the donor is dead or alive. That doesn't seem right, that makes me feel hypocritical. I have seen attitudes towards medical innovation change over the years too. When once IVF was thought to be haraam, as if we were unhappy with what Allah has ordained for us that we feel the need to 'play God'. But now IVF is common practice. Why then are we so set in our ways about organ donation after death, and even things like donating stem cells. The ethical people are not progressing, not just Muslims, everyone. Why have the government prevented it in the past? Why restrict stem cells? Only people that knew, knew. Why have we stuck to traditions in the past?"

One argues that Ayesha is clearly frustrated with selective intransigence that she herself has witnessed at societal level over generations. Moreover, she can see how the pendulum of moral dilemma can swing from one position to another based on personal motivation.

Ayesha bemoans:

"I know people in my community who because they are rich have gone to Pakistan and had a kidney transplant there on the black market, rather than wait here for a match. People change their minds when they're desperate. That must be wrong in Islam, its exploitation surely! We know that we could be waiting years for a kidney match, I know a guy who has patiently waited for over a decade, he has dialysis, and it is really difficult for his family, they

haven't found a match in his family, they have no choice but to keep waiting hopefully."

Ayesha continues:

"I know that I haven't looked into organ donation because I'm not interested unless I or a loved one needs an organ. That does not always rest easy with me and how I understand Islam. I'm not interested in organ donation unless I need to be. Islam doesn't teach me to be selfish in this way, I'm taught to be charitable, kind, compassionate; giving charity isn't just about paying money, it is also about your time and effort, what you do for the community too. Unfortunately, the way I see it, unless there is a cultural change, unless the people in our communities openly say they are happy to donate organs after death, people will be hesitant about donating organs, especially after death. I remember a time, when we thought donating blood, or a spare kidney was like interfering with Allah's will and now when people need to, they accept and donate".

Arguably the qualitative content of the interview with Ayesha casts light on the anthropological trajectory through the lived experience of a South Asian lay Muslim over fifty years in British society. This study highlights the challenges faced by migrant Muslim labourers in the 1960's, how due to their newfound circumstances; they persevered to hold firm to their beliefs and practices to the extent that inherited traditions are entrenched in community practices today. Additionally, the pedagogical framework demonstrates emphasis on preservation of Islamic scripture which has led to lay Muslims engaging Islamic teachings through binary expressions of halal and haram and has to some extent become counter intuitive for living Islam in a principled manner which is arguably attainable through the lens of the maqasid as sharia.

The janazah process is well established within the community, Ayesha described how a team of volunteers from the local mosque are readily available to provide support for the grieving family and help to facilitate the janazah from an administrative, logistic, and theological perspective.

"We're blessed really, when somebody dies in our community, people flock to help out. It is really overwhelming when a loved one dies, so having people to help with things like when, where, how to get the death certificate, sending messages out to the community, transporting the body to the mosque, actually doing the gusl, having somewhere for people to pay their respects is such a blessing. It takes the worry out of it and allows us to grieve. They even have the kafan [shroud]. Back in the day, we'd have our kafan's in the house, my parents always told us where they were kept in the house, so we'd know".

To their credit, the early generations laid the foundations of Islam in their new British communities with negligible agency and facilitated the legacy of a Muslim presence despite their minority status. Therefore, one cannot overlook their achievements from being on the fringes of British society as a majority of migrant workers, who established their British Muslim identity while working discombobulating, long and bi-weekly alternate day and night shifts that were vital to their sustenance but contributed to the wider Muslim community too. One argues that it is circumstantial that the lay Muslims relied upon the resources available to them at the time, i.e., to what is now considered hackneyed text and audio recordings throughout the 1960's, 1970's and 1980's. Thus, the advent of the internet, diversity of local communities and social ascent to some extent by contrast demonstrates a steady progression towards renewed Islamic pedagogy. Furthermore, given a majority of those labour migrant workers had visions of 'returning to their homeland', they simply took pragmatic steps in response to their immediate circumstances. One accepts, this is an ethnographical overview through the lens of lay Muslims in a small northern mill community and it omits the trajectory of the Islamic academic institutions such as the Darul-Uloom that they themselves called for, funded, and supported for decades. As Ayesha describes, this is the case for the 'stereotypical South Asian Muslim family' within her community.

With this context in the foreground, one argues that although Islamic pedagogy has continued to evolve in time and place; it is the infrastructure resulting from pre-held beliefs of janazah proceedings that make it difficult for individuals to make alternative choices today. With that being said, this research shows that attitudes are changing, certainly within recent generations of lay Muslims whereby the interview participants are very much inclined to donate organs after death but have opted out on the say so of their respected elders. One argues that a gradual shift in favour of posthumous organ donation will occur, but a systematic shift in this regard can be realised via a multipronged approach, in the background; Islamic pedagogy that allows enquiry at local community level. Having understood and questioned the legitimacy of organ donation after death will enable the individual to be prepared for making a potential life critical decision. Moreover, there is potentially an opportunity for posthumous organ donation to be accepted as an Islamically viable option if the established process represented in current janazah praxis whereby the affiliated third-party support from within the community when ushered in to support the bereaved allow for the choice of organ donation to form part of Islamically legitimate process.

Chapter 4 - Understanding Islam through lived realities. Patriarchy vis-à-vis matriarchy as a social construct

In December 2020, I met with Asma, a 37-year-old law graduate; originally from a South Asian Muslim community in London but living in West Yorkshire for almost the last two decades. After graduating, Asma married and moved into a multi-generational household for the first time. At our first meeting in December 2020, Asma was unaware of the spectrum of permissibility of organ donation in Islam and expressed an interest in considering the possibility of donating organs after death, Asma was reinterviewed in June 2021. This second-generation ethnography provides the insider view on the symptoms of societal discourse that has the potential to impede lay Muslim autonomy to some extent through their individual lived experiences as Muslims, British and of South Asian ethnicity.

“It was exciting to move in with a new family [in laws], my sisters in-law are modern, one is a solicitor the other a teacher. My husband runs the family business in the city. As we started our own family, we outgrew the house, so the other siblings moved out. We stayed with my husband’s parents and his grandparents. It’s really sweet for our kids to grow up like this”.

During the coronavirus, BME (Black and Minority Ethnic) communities in Britain gained significant press attention because as the Office for National Statistics proved, BME were subject to disproportionate coronavirus cases (Haque, Becares, Treloar, 2020). In a comprehensive report for the UK’s leading independent think tank, The Runnymede Trust; Haque, Becares and Treloar found that; “pre-existing racial and socio-economic inequalities ...have been amplified by COVID 19” (2020). The report found that factors such as “types of employment they hold (BME men and women are over-represented among key worker roles); having to use public transport more; living in overcrowded and multigenerational households more; and not being given appropriate PPE (personal protective equipment) at work ...[meant], most BME groups are more likely to be over-exposed and under-protected compared with their white British counterparts (Haque, Becares, Treloar, p.4. 2020). In addition, “Racial inequalities have been a recurring theme, with NHS and Royal College of Nursing staff surveys highlighting inequities in access to PPE. This is particularly pertinent because rates of mortality have been higher among BME health and social care workers compared with their white counterparts” (Cook, Kursumovic and Lennane, p.17. 2020). In summary, the authors place the responsibility squarely on the government to acknowledge and take action to address the social and economic inequalities faced within British BME societies.

Asma explains the contrast between multigenerational lodgings 1950's and 1960's to her personal lived reality:

“During the Covid peak, I felt stigmatised for living in a multigenerational house. In my culture it is seen as an honourable act, but in the news, it was made out to be really bad, somehow linked to poverty. I noticed how people were behaving differently towards me when I was queuing up in shops – as if I was a more likely than others to be carrying Covid. I don’t think people thought of Major Tom [Moore] in the same way. We choose to live in a multigenerational household, we could move if we want, but it’s about caring for our elderly. It would be heartless to leave them. My husband’s grandfather still lives with us now, he’s in his 90’s. We had to be extra careful with Covid, and the kids had to keep out of his way when schools were still open. It was hard. I’m not sure he understood why the kids were suddenly less affectionate, but things are getting back to normal. At least he was at home with us”.

Asma’s ethnography provides the insider view of how mainstream media discourse has seeped into the societal consciousness to perpetuate the view of BME as ‘other’ and not fellow citizens who are disproportionately impacted by social poverty.

When we met first met for a video conference during lockdown in December 2020, Asma told me that she didn’t think organ donation was permissible after death.

“Generally speaking, I understand organ donation to be a good thing, to save lives. From an Islamic viewpoint, I’ve always thought it is not allowed. I remember when I was at high school, we had a talk on organ donation, they gave us a card, so I filled it in and kept it in my purse. One day, my uncle saw it, and he said, that’s haraam, and that I should destroy it. My mum told me that our bodies are an amanah [blessed gift] from Allah and that we should be buried the way we die. I think it is in the Qur’an about our bodies belong to Allah. But it is in the Qur’an about saving a life is like saving humanity, so I’m not sure”.

After reading a summary of the spectrum of permissibility based on the fatwa and findings of Mufti Zubair Butt, Asma said:

“I see how donating organs when we’re alive is a good thing in Islam. If one of my children or a family member was ill and needed a kidney, I would consider it of course I would, to give them a chance to extend their life. Things like donating blood, I’d do that. Then again, maybe I could choose to donate my organs when I die to someone who I know needs it. I think it is up to the dying person to decide”.

Asma’s musings are almost identical to that of Ayesha referenced prior. Arguably, given their pre-held notions of organ donation as impermissible; there is no foresight to make provisions

for organ donation after death. Interestingly, the basis of her objection is in a similar vein too; based on the condition of the body immediately after death prior to burial.

“And, what about the wounds? I mean how would my loved ones feel if my body is all scarred from where I’ve had my organs removed, it would be traumatic. I guess, because we do gusl for our loved ones, although I haven’t done one myself. I don’t think I’m comfortable with the idea of it to be honest though, but maybe my way of thinking has been influenced with childhood experiences”.

One argues, that because Muslim’s are proactively involved in the janazah-gusl (after-death cleansing ritual) and burial process; they feel great affinity with the deceased in terms of envisaging their reawakening after burial and therefore have an innate aversion to veer into the unknown. In other words, death in this world is not the final destination. Having said that, from personal experience of undertaking the janazah gusl, one argues that the process is dignified in the sense that the body is never fully exposed; typically loved ones of the deceased undertake the cleansing in sections of the body by upper, mid, and lower, in turns from under a dark coloured sheet to provide privacy for the deceased. The process is swift and systematic due to adherence of established practice and usually carried out by close family members of the same gender and under the supervision of experienced practitioners.

To conclude our first interview, Asma stated that she is keen to investigate organ donation after death since there is scholarly permissibility but would need to discuss it with her husband, although she had already opted out. We met again in June 2021, just as covid restrictions were lifted. I began by asking Asma if she had thought any more about organ donation after death, her response:

“No. It sounds bad, but it just isn’t something I’ve thought more about”.

“But now I know that it is okay for us to donate organs, I realised that yes of course Allah can re-create us. Look at these poor Palestinians who have been killed, who knows what state their bodies are in under all the building rubble. There was a woman on Instagram, she was crying at the scene of a bombing, I couldn’t bear it, she said that the body parts were here there and everywhere, of course Allah can put this body back together”.

“I feel silly saying this now, I know the power of Allah is limitless, whereas we as humans are limited. And, what do we know of what form our bodies will take in the Aakhirah [hereafter]?”

“I probably would consider donating organs, although it would not be my choice in the end. My husband will decide for me. He will do whatever his family do. His family do the same as they’ve always done. Like for example, where I’m from in London, the grave is planks of

wood in the ground. But here, they're buried in coffins. My husband agreed that that's the proper way, and our preference but we'll be buried here, according to the local customs. His family will go to the mosque they've always gone to. Even though we both disagree, we just accept it".

"That's probably why I haven't discussed organ donation, it seems pointless because I know that choice won't be mine and he'll [husband and his family] just do what's always been done".

"My husband and his family don't really go to an Imam or scholar for advice on how things should be done in Islam, they discuss it within their family and maybe get advice from Mamu [maternal uncle] who's jamaati [joins congregations at the local mosque]. My mother-in-law is the decision maker, she will discuss important things with her sons and daughters and her side of the family. My father-in-law was always busy with work, so mother in law's the boss!"

Contrary to popular opinion therefore, South Asian lay Muslim households are not necessarily patriarchal. Asma's lived experience shows the matriarchal societal construct is the default because men of labour migration work long hours outside of their homes.

"I've recently started to study Islam in my spare time, and I've read some books on the patriarchal interpretations of Islam. This has really made me think about what I know of Islam and made me realise that I just kind of go with the flow and not really stop and think, is this Islamically right or is it our culture".

"I think, because my husband is my mahram, I check his views on everything and even though I don't always agree, I just go with it, I think even that is wrong because my children will pick up on these traits and just go with the flow too. As a mahram, he is responsible to provide financial stability and look out for mine and the children's health and welfare. He does listen to my opinion on things but thinks I'm too Westernised when I suggest something different".

"I know that the cycle of doing what we've always done needs to be broken, but how can one person change traditional cultures?"

"I'd hope in the future, we look into these things and realise that Islam gives us more than we think Insha'Allah [God willing]".

Asma's ethnography casts light on several concerns shared between lay Muslims, as this research has found. Like other women interviewed for this study, when she realised there is permissibility in Islam to donate organs after death; she wanted to discuss it with her husband because he is her *mahram*, which they took to infer that as mahram he is the

decision maker. On the other hand, however, it can also be taken to mean mutual respect and decision making between spouses.

Academic Asma Barlas amongst other such as Wadud, Mernissi and Mir Hosseini have written extensively about patriarchal interpretations of the Qur'an, in this regard Barlas argues that the Qur'an has been interpreted throughout history "by adherents of patriarchies" (iv, 2019), thus revealing more about their socio-political context. This brief research analysis demonstrates how the tertiary text and societal discursive has the potential to inform beliefs about gendered responsibilities and Islam.

It is argued that the notion of the mahram has been conceptualised to adopt the status of family 'decision maker' to a certain extent. The following discussion will consider the societal influences that have informed this view within South Asian lay Muslim societies. Qur'anic analysis of the word 'mahram' and the context of it point to Q.4: 22-23 and Q.24:31. Neither of these verses mention the word 'mahram', rather they outline the rulings on which relations are forbidden for marriage. "You are forbidden to take as wives your mothers, daughters, sisters..." (Abdel Haleem, 2010, p.52). The Qur'anic ayah begins with the Arabic word 'hur'rimat', meaning 'forbidden'. Furthermore, in Q.24:31, the revelation mentions the expression of modesty, as in how hijab is to be observed by women. Although al-Hashimi defines the 'mahram' in the context of the Qur'an insofar as a blood relation forbidden for marriage (2005). However, in his commentary of the ayah (Q.24:31), al-Hashimi argues "She [Muslimah] does not go out of the house, or appear before non-mahram men, wearing perfume, make up or other fineries because she knows that this is haram according to the Qur'an" (2005, p.77). This research has shown that South Asian lay Muslims have in the past relied on books that are readily available for Qur'anic interpretations. Most female participants, especially from the second-generation referred to al-Hashimi in his global bestseller 'The Ideal Muslimah', wherein he commentates on the virtues attributed to an 'ideal Muslimah' as per Qur'an and Hadith (2005). Many participants were either gifted a copy in English at coming of age or for their wedding. Having analysed the text more recently, the participants have commented on the patriarchal sentiment throughout. Asma, exclaimed:

"Gosh, reading this now, I think, what? It's like a man telling women how they should behave. I don't mind that the book has hadith and Qur'an, but it is his comments that are worrying. I don't think I'll be giving this book to my daughters!"

Arguably, the overall text is patriarchal because the male is centred as the authority on

Muslimah behaviour with sub-headings such as ‘She makes herself beautiful for him’, ‘She is tolerant and forgiving’, ‘She knows her place’ (2005). Therefore, iterations of such titles have arguably informed societal standards on the premise that such values are rooted in Islamic theology.

Furthermore, al-Hashimi provides commentary on ideal Muslimah etiquette by hadith interpretation too. In one such Hadith narration taken from Bukhari and Muslim it is deemed ‘haram’ by consensus scholarly opinion for non-mahrams to sit together or embark on a journey without a mahram (2005). In her analysis of the term ‘mahram’ through the lens of Islamic family law, Mir-Hosseini calls for the reinterpretation of hadith which is ethical and contextualises the societal conditions of today as opposed to that of the tribal societies in which they initially applied (2013). Mir-Hosseini argues that patriarchal interpretations of hadith problematise the female body as a fitna (temptation) (2013). Mir-Hosseini cites a hadith of Abdullah Ibn Umar regarding the period of travel permissible for a woman without a mahram as one day and one night, she argues that subsequent scholarly interpretations like that of al-San’ani (d.1768) which incorporates the scholarly opinion of al-Nawawi (d.1277); disregard the time limit and instead apply a general restriction to female travel (2013). Moreover, Mir-Hosseini counters the position with that of Ibn Hazm (1064) presented in his work *Al-Muhalla bi al Athar*, he presents differing versions of the hadith and of scholarly opinions insofar as the timeframe is thought to be up to three days and nights (2013). Furthermore, Mir-Hosseini traces back evidence from the works of Zarkashi (d.1392) and al-Zuhri (d.742); who argued that A’isha the wife of the Prophet travelled without a mahram and critiqued the hadith interpretations of Companions in this regard. (2013). In summary, Mir-Hosseini concludes that the major legal scholarly opinion on the role of the mahram has defaulted to accepting the literal interpretation of the hadith of rather opting for applying ethical reasoning through the medium of *illah* (reason) (2013). Thus, calling for ethical interpretations of terms such as mahram relevant in today’s society where law and order seemingly exists and placing emphasis on the safety of travel for all people including those who are vulnerable.

Additionally, in her research of living with conservative Muslims in Iran, Professor of Anthropology, Wellman argues “mahram is configured and (de)activated not only by the dictums of Islamic law, but also according to contexts such as living circumstances, trust and town politics. Indeed, the significance of mahram extends far beyond marriage exclusion. In everyday life, the boundary of mahram is a matter of context and creation, incorporating a vast ‘fan of referents’ with which to embody and perform mutual (dis)trust, piety, and closeness (Turner 1967)” (Wellman, R. 2018, p.119). Similarly, one argues the notion of

mahram is riddled with ambiguity at British Muslim societal level. Arguably, some interpretations are associated with guardianship or custodians and that is instinctively assigned to the males. Therefore, one argues that the societal understanding of the role of the mahram is conflated when viewed through the lens of scholarly opinion and perpetual customary practice.

The ethnographies of the participants indicate, lay Muslims do acknowledge that some societal practices function under the premise of Islamic theology despite being at odds with their ethical understanding of Islam. The ramifications of straddling between two cultures; of being resolutely South Asian and assimilation to British societies at the same time through the trajectories of labour migrant South Asian lay Muslims from the 1960's in this study demonstrate the multiplex lived realities they find themselves in. Additionally, the incongruence of patriarchal scholarly interpretation within an ethical Islamic way of life has therefore truncated Muslim societies into submission of questionable societal norms without question. Thus, manifesting in the notion that making independent choices on organ donation after death albeit within the realms of Islamic permissibly almost insurmountable. That said, not all Muslims operate under the same family dynamics, as Hamzah explained:

“My wife and I have had lengthy discussions about it [posthumous organ donation], we know that it can be seen as a good, rewarding act to donate after death, but it isn't about the one who died is it? It is about those who are still alive, left to live without their loved one. I mean, in Islam we are allowed to grieve straight away, we don't need to get distracted with putting on a display or fancy flowers and posh cars. ...See, when my wife asked if I would agree to have her organs donated because she might want to, I thought how can I not respect her wishes. Then we both reflected and thought, hold on, she observes hijab [modesty], I mean she won't answer the door or put the bin out without being covered, how can I agree to have her hijab taken away from her in death when she never lived that way? ...And vice versa for my wife, she said she couldn't consent to it because she would be overwhelmed with grief”

Like most participants, when considering the practicalities of post humous organ donation, Hamzah and his wife opted out because they could not envisage a janazah process apart from their own reassuring knowledge.

Conclusions

Over the last two years of study prior to and after the implementation of the Organ Donation (Deemed Consent) Act 2019, it is fair to say that the British Muslim society have given some thought to their positionality regarding posthumous organ donation. Although the title of this research may well be misplaced through inference that this is purely a Muslim concern or that all Muslims make decisions based on Islamic jurisprudence alone; it is argued that essentially the question of posthumous organ donation is rooted in deep meaningful ethical deliberation. This ethnographic research casts light on the broader socio-ethical discourse about the preservation of personal identity, post-mortem rights, bodily dignity within a decolonial context; albeit underpinned and seemingly legitimized through literal lay interpretation of scripture and religious customary practice. Not dissimilar to a concluding summary from Hamdy's extensive study, who argued, it is "largely to do with our tendency to think of religious ethics as a set of codified rules that map onto or constrain practice, rather than viewing religious ethics as an embodied aspect of the self that is contingent on dynamic social processes" (Hamdy, 2012, p.244).

Despite recent fatwas and scholarly consensus between the four main Sunni jurisprudential schools agreeing that the deceased do not perceive pain after death (Butt, 2019), and medical assessments to determine the body does not feel pain after death (Ali, Maravia, 2020); this qualitative research shows many lay Muslims are still erring on the side of caution and opting out of deemed consent because they believe the deceased perceive pain. This research has also shown the distressing reality of organ retrieval through the ethnographies of the ICU practitioners who tend to brainstem deceased patients as they suffer sudden cardiac arrest to render this argument both an ethical and philosophical one. Moreover, when considering the wider context and viewed through the global ummah lens, one cannot ignore the numerous reports on exploitation through organ harvesting, black market trafficking and the proliferation of unregulated organ transplantation clinics, as Shaykh alMarsafawy remarked "show me the day when organs travel from the rich to the poor. Then I might change my mind!" (Hamdy, 2012, p.244). Bringing into the focus the banality of reducing an argument to statistical analysis and survey results.

It is argued that, in developing a trajectory of three generations of South Asian labour migrants within the context of decoloniality, by taking their pedagogical influences into account and considering their philanthropic achievements as they established themselves as British citizens; one can see beyond a binary societal context. The ramifications of British coloniality which stunted Islamic intellectualism (Dehlwi, 1987) on the Muslim mindset is

deeply entrenched within Muslim consciousness, thus; manifestations of spiritual and bodily preservation and the importance of human dignity can be regarded as symbolic of resistance. A prevailing trend indicated throughout this study stems from mistrust of the government with the global widespread of Islamophobia and the reported marginalization of BME manifesting in inequality and social deprivation as highlighted through the coronavirus pandemic has arguably alerted a consciousness of being lesser than citizens and thus British subjects again. Therefore, preservation of established processes can also be regarded as resistance although not articulated as such.

The intergenerational trends highlighted through the ethnographies in this study demonstrate that although there are variances in lay opinion; there is unity in communal practice. While the first generation were generally apathetic to the notion of posthumous organ donation based on their established practices, the second and third generation are grappling with the dichotomous position of opposing posthumous organ donation but conceding that should they need a donor, they would accept it even from a posthumous donor. The third generation expressed views inclined towards posthumous organ donation, although, they had opted out in adherence to their family traditions. In this regard the variation of pedagogical influences throughout the generations casts light on how lay-Muslims engage with Islamic theology and jurisprudence, emphasis on halal and haram has in the past taken precedence over a principled view through the maqasid as sharia lens. The prominence of online scholars and a growing trend of accessing Islamic lectures online will certainly lend itself to facilitating societal discourse to question customary practice.

There is scope to springboard the thematic findings of this dissertation within the wider discursive context of bioethics, health and social care issues that impact Muslim communities which include, the prevalence of kidney disease and diabetes within BME who are five times more likely to develop Chronic Kidney Disease (NHS, 2020). Research shows that Covid 19 highlighted the disproportionate reality of social deprivation within BME (Haque, Becares, Treloar,2020). Consequently, bringing into question the extent of intuitional racism and Islamophobia which has resulted in poor education, IT poverty, poor housing, low paid jobs, women's health, and long-term health issues. Online debates are forefront of everyday Muslim discourse, insofar as the prevalence of coronavirus within BME, resulting in scepticism of modern medicine and a tendency towards prophetic medicine. Topically, and not limited to religious affiliation, social media outlets are in a constant flurry with debates pro and anti-vaccine, further research would be advantageous to understand are Muslims against the notion of doctors playing God or are they suspicious of power structures that have marginalised them throughout their colonial history in efforts to implement collaborative

solutions to identify preventable long-term illnesses and inform the delivery of appropriate healthcare solutions.

Muslims have an innate consciousness of the inevitability of death as well as personally tending to the ritual practices to prepare their deceased loved ones and to bury them. Planning for one's death whether imminent or undetermined is arguably a philosophical consideration, and while Muslims customarily make provisions for their death, the topic of posthumous organ donation had not featured so prominently until recently in the UK, and therefore the growing awareness of the spectrum of permissibility could well mark the start of a shift in customary practices in support of posthumous organ donation in the future.

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Appendix

Contents:

Appendix

1. Sample of ethics approval consent form
2. High level overview of findings



School of Languages Cultures and Societies

Participant Consent Form

Title of Research Project: The permissibility of organ donation in Islam

Name and email address of Researcher: Mariam Fargin, ll16mf@leeds.ac.uk

Name and email address of Project Supervisor: Abdul Bashid Shaikh, A.B.Shaikh@leeds.ac.uk

Brief description of the objectives of the research project: The aim of this study is to understand the considerations of English Muslim 'layperson' in view of the changes in English law to 'presumed consent' for organ donation.

Please initial the following boxes to indicate that you have read and accept the following statements

1	I confirm that I have read and understand the information on the research project given above, which I signed before the interview. I confirm that I have had the opportunity to ask questions about the project.	
2	I understand that my participation is voluntary and non-remunerated and that I am free to withdraw at any time without giving any reason and without there being any negative consequences. In addition, should I not wish to answer any particular question or questions, I am free to decline.	
3	I give permission for members of the research team to have access to my responses.	
4	I agree for the data collected from me to be used in relevant future research.	
5	I agree to take part in the above research project and will inform the lead researcher should my contact details change.	
6	I agree to that all data in relation to this project to be stored securely at the University of Leeds.	
7	I understand that any research carried out by the research team of the University of Leeds using my interview or parts of it will contextualise the contents of my statements in an ethically and scholarly appropriate manner.	
<i>Optional statements, please initial only if you agree with them</i>		
8	I agree that any statements I make during the course of the interview or any research based on them can be published if they are anonymised appropriately, used and re-published for educational, research or any other noncommercial purpose.	
9	I understand that I will be able to request to be notified by the University of Leeds team about the extracts of my interview that they are going to publish beforehand.	

Name of participant

Date

Signature

(or legal representative)

Mariam Fargin
Project researcher

Date

Signature

To be signed and dated in presence of the participant

High level overview of qualitative research findings

Provided below is a thematic summary of the interview findings.

*Most – more than 15

**some – less than 10

***few – less than 5

1. All participants believe that the deceased feel pain after death and prior to burial, therefore cited as the main reason for opting out of posthumous organ donation.
2. Most* participants had already opted out of posthumous organ donation.
3. Most* agreed that organ donation is a rewarding act of charity, however, are inclined towards live altruistic donors such as blood, stem-cells, liver lobe and kidney.
4. Some** participants believe that our bodies belong to Allah, and therefore the condition of the body cannot be altered after death.
5. Some** participants believe that making bodily alterations is an expression of discontent with Allah's will.
6. Some** male and female participants expressed concerns about postmortem bodily dignity.
7. Some** were concerned that if they donate their organs and the donor commits a sin with it, they would be complicit even after their own death, especially regarding liver donations for alcoholics.
8. A few** participants were worried about the bodily image of their deceased if organs are removed posthumously.
9. Some** participants believed that burials must not be delayed unnecessarily, this pre-held notion has significantly reduced from the participant responses of the undergraduate study.
10. A few** participants believe too much emphasis is being given to modern medical intervention which disengages one from their spiritual connection with Allah by detachment from prayer, prophetic medicine and that the notion of 'Qadr' (predestination).
11. A few** participants were worried about the practice of harvesting organs on the black market, in particular of Uyghur Muslims, and those exploited through social poverty in South Asia.

Regarding transplantation:

12. All of those participants asked, agreed that autotransplants such as skin grafts from one part of the body to another are permissible in Islam.
13. A few** participants expressed concerns about xenotransplantation of animal (pig) organs or tissues being transplanted without their knowledge.
14. Of those asked, a few** participants stated that although they feel hypocritical saying it, they would most likely consent to accepting a donor from a deceased patient in a life critical situation for themselves or a loved one.
15. None of those participants asked would consider a transplant from an overseas private clinic in theory.

Regarding the legislative Organ Donation Deemed Consent Act 2019:

16. None of the participants asked were aware of the brain-stem death criteria, when asked; all stated that they would not consent to organ donation from brain-stem deceased patients.
17. A few** participants were suspicious of why the law had changed to deemed consent during the coronavirus pandemic when they were not permitted to see their loved ones. One participant believed that bodies were being handed over for burial in body bags for tayammum (ritual cleansing with earth), meaning they could not ascertain the condition of the body.
18. A few** participants viewed the YouTube videos on the NHS website regarding the permissibility of donating organs in Islam, but still decided to opt out.
19. None of the participants had read the fatwa of Mufti Zubair Butt on the NHS website.
20. One participant believed that the scholarly views presented on the NHS website are all 'paid' and therefore supported post-humous organ donation when previously it was '*unheard of*'.
21. None of the participants were aware of the organs eligible for donation within scope with the NHS, i.e., heart, lungs, liver, pancreas, small bowel, tissue such as skin, bone, tendons, cornea, eyes, heart valves and arteries (2020. NHS website).

Intergenerational trends:

First generation – aged between 65-85

Second generation – aged between 35 and 65

Third generation – aged between 20 and 35

- First generation participants were apathetic towards the notion of posthumous organ donation. Some felt that their organs would not be considered for transplantation owing to their ailing conditions.
- Second generation participants expressed curiosity towards the notion of Islamic permissibility of posthumous organ donation, although, resistant to change.
- Approximately half of the third-generation participants were genuinely interested in donating organs after death, seeing it as a charitable act but they had opted out in respect of their family wishes.
- The other half of the third-generation participants agreed that seeing scholarly permissibility for posthumous organ donation gave them some confidence to be inclined towards the notion of posthumous donation, but they too had opted out in respect of their family wishes.