THE MORAL UNIVERSE OF MUSLIM CLINICIANS

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ACKNOWLEDGEMENTS

- Centre of Islamic Studies, University of Cambridge
- Ethox Centre, University of Oxford

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Need for:

Spaces of deliberation (NHS/non-NHS), Indigenous scholarship

Guidance

Shared learning

BACKGROUND

NHS workforce - published 13 April 2023

- Ethnic minority staff made up 49.9% of hospital and community health services (HCHS) doctors

- Muslim Council of Britain (MCB): 1 in 3 of the ethnic minority population in UK are Muslim

ISLAMIC ETHICS

Level 1
Quran
Hadith

Level 2
Fiqh
Theology
Tasawwuf (Sufism)
Adab, Aqhlaq

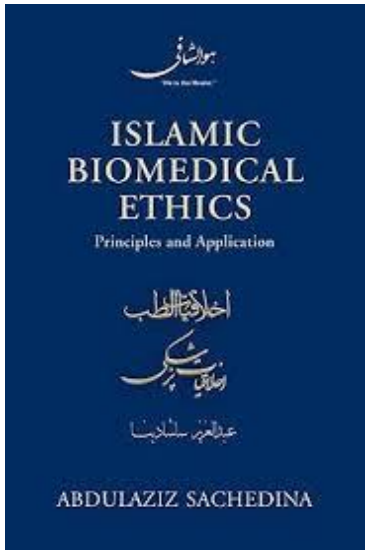
These are the sciences derived from Level 1 through the employment of legal tools such as *Ijma, Qiyas and Ijtihad*

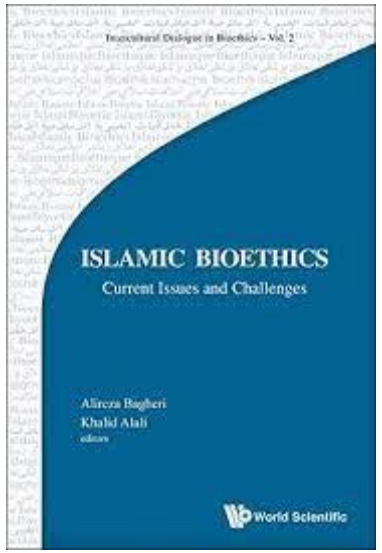
Level 3
Muslim laity

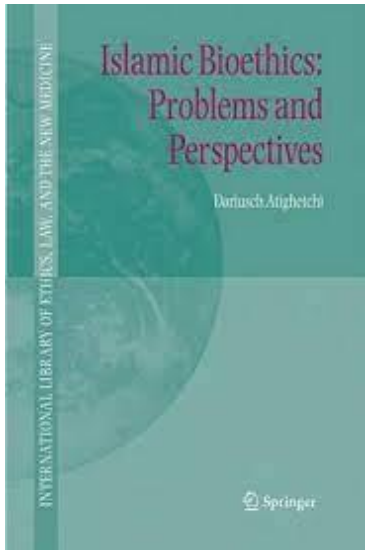
These provide an embodiment of Levels 1 and 2

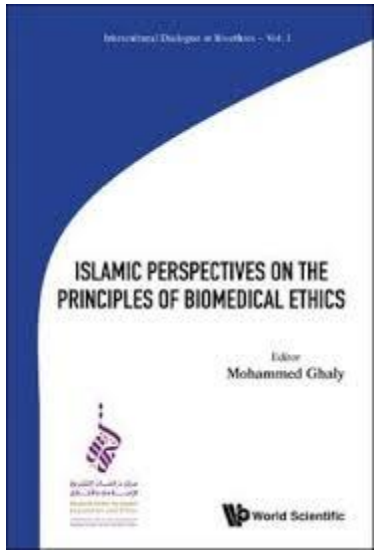
The three levels of the normative sources of Islam and how the different levels interrelate

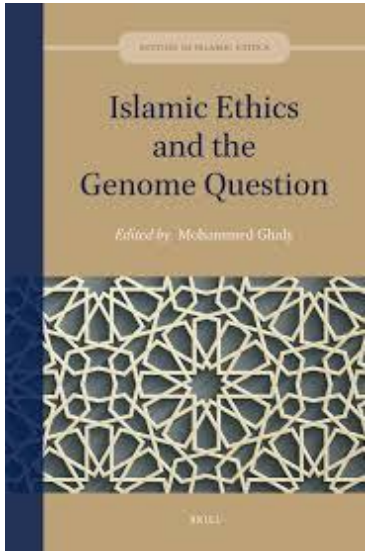
ISLAMIC BIOETHICS

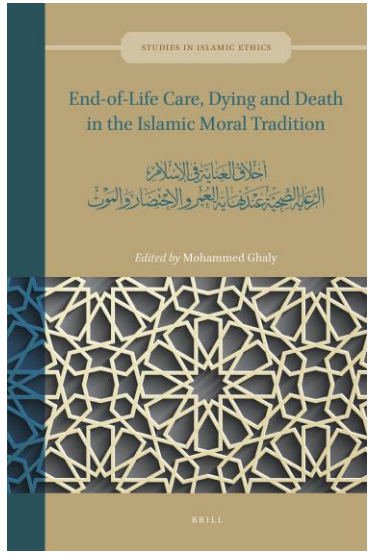






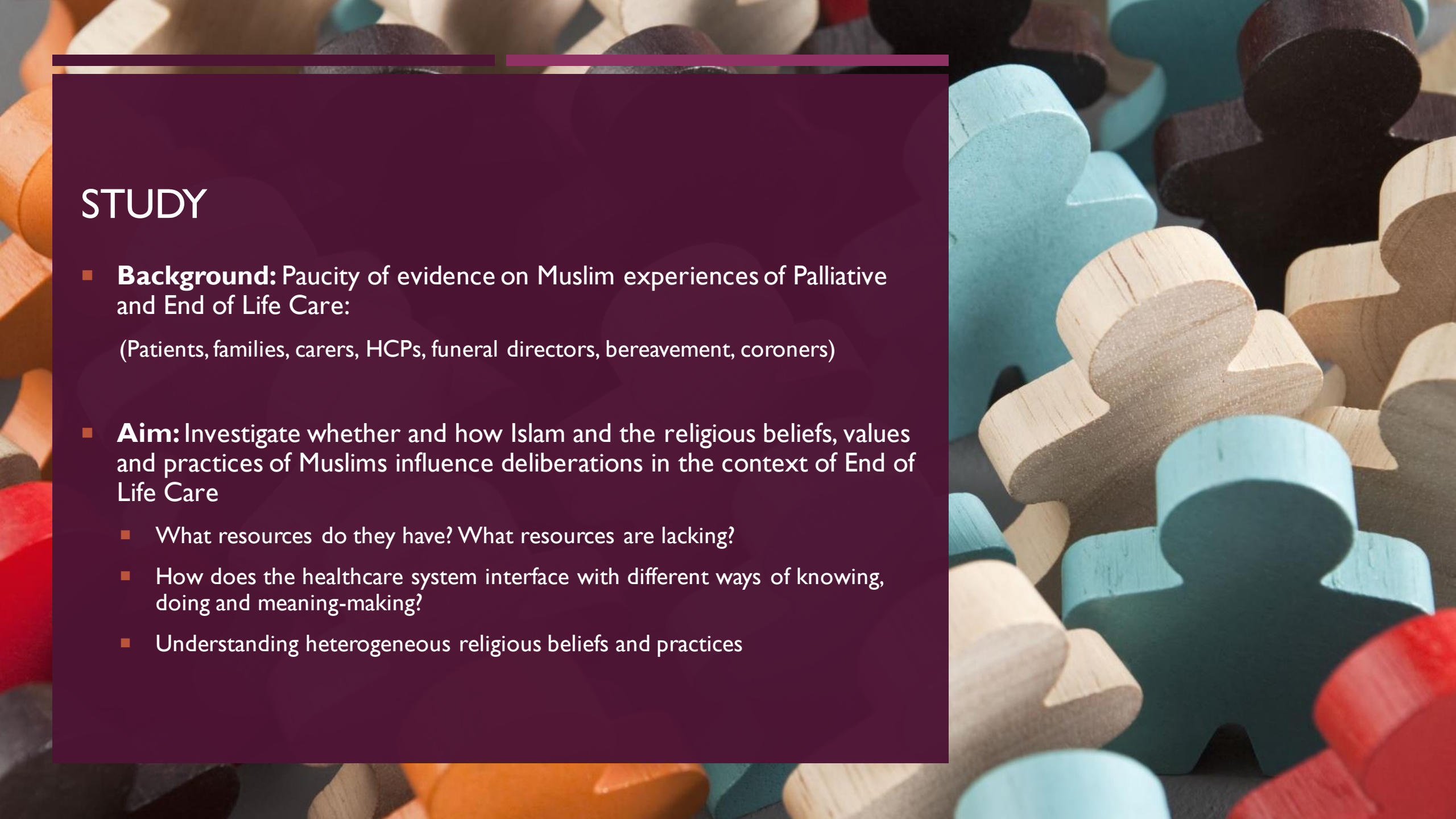






ENCYCLOPEDIA OF ISLAMIC BIOETHICS

ISLAMIC BIOETHICS



STUDY

- **Background:** Paucity of evidence on Muslim experiences of Palliative and End of Life Care:

  (Patients, families, carers, HCPs, funeral directors, bereavement, coroners)

- **Aim:** Investigate whether and how Islam and the religious beliefs, values and practices of Muslims influence deliberations in the context of End of Life Care
  - What resources do they have? What resources are lacking?
  - How does the healthcare system interface with different ways of knowing, doing and meaning-making?
  - Understanding heterogeneous religious beliefs and practices

METHODOLOGY

What does the **academic literature** say about whether and how Islam and the religious beliefs, values and practices of Muslims influence deliberations in the context of end of life care?

What does the **grey literature and case law** say about whether and how Islam and the religious beliefs, values and practices of Muslims influence deliberations in the context of end of life care?

Qualitative Study: What patients, families, carers, healthcare staff, chaplains and imams say about whether and how Islam and the religious beliefs, values and practices of Muslims influence deliberations in the context of end of life care?

METHODOLOGY

- **Interviewing** participants to understand EOLC perspectives
- **Sampling** from hospices, hospitals, GP practices, community centres and Mosques
- **Locations** London & Birmingham (highest Muslim populations in England) & Cambridge
- **Completed 76 semi-structured interviews**
- **NVIVO10 to organise data**

ANALYSIS

Medical interventions

- Administration of intensive care
- Withholding of treatment
- Withdrawal of treatment
- Cardiopulmonary resuscitation (CPR) and Do Not Attempt Resuscitation orders (DNAR)
- Brain death diagnosis
- Euthanasia and assisted suicide
- Organ donation
- Assessing quality of life
- Assessing best interests

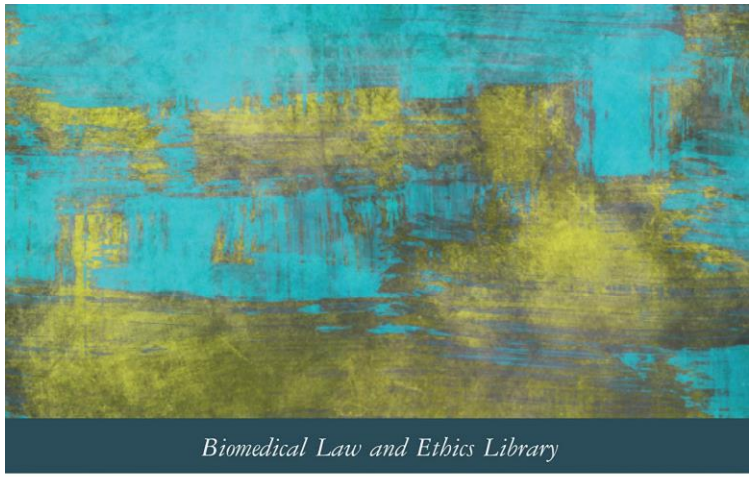
Personal faith – patients, staff, families

Decision makers

- Role of patient & family
- Role of scholars
- Role of chaplains
- Role of healthcare team

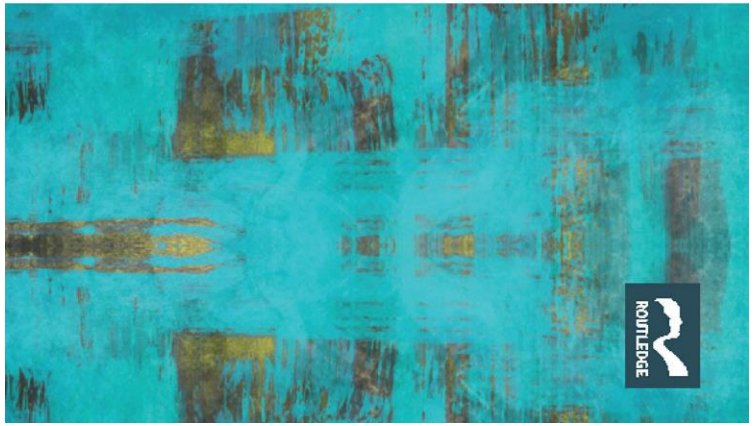
Values

- Dignity
  - QoL
- Harms
  - Futility
- Life as sacred
  - Preservation of life
- Hope & Acceptance



ISLAM AND BIOMEDICAL RESEARCH ETHICS

Mehrunisha Suleman



PERSONAL FAITH

PERSONAL FAITH

“I always used to pray that doing medicine would bring me closer to God. I'm not sure that it has. But I guess I think for every human that actually, whatever they do, it should be an opportunity that every aspect of one's life or everything that we practise should be a means of reaching God. So it plays a big part in my practise, although I practise in an environment which is almost entirely secular and very mechanistic. But I think human beings are not necessarily secular and mechanistic.”

(Interview 8, Cardiologist, London)

PERSONAL FAITH

“I hope my faith influence(s) my whole life” *(Interview 52, Palliative Care Doctor, London)*

“I think for me it's very simple. I think my ethical code really is informed by my religion.” (Interview 7, Ophthalmologist, London)

“I don’t think I walk into work and you know, I'm sort of secular in my beliefs. I guess Islam and being Muslim is too ingrained within me” (Interview 37, Palliative Care Doctor, London)

PERSONAL FAITH

“My perspective when I go in as a doctor ... this sounds really ... in a way I feel guilty in admitting this, but I don't bring faith into it, just because of the way I have been trained” *(Interview 43, GP Trainee, Birmingham)*

“It's difficult because **no matter how much we try to separate our personal beliefs... It's impossible**.” *(Interview 43, GP Trainee, Birmingham)*

PERSONAL FAITH & RELIGIOUS AUTHORITY

- "Shias do something called *Taqlid*. So you find the most eminent or the most knowledgeable scholar, and you follow them in all their edicts. You follow all their rulings… I really just go by Sayyid Sistani's rule(s). In general, I just follow. And in general, a lot of those rules make a lot sense." *(Interview 7, Ophthalmologist, London)*

PERSONAL FAITH & RELIGIOUS AUTHORITY

- "I think a lot of the times I go to the scholars with difficult medical questions, and I get answers that really don't sit comfortably with me. So one that's arisen recently is that I don't carry a donor card and I'm ashamed to say that because the current perspective according to the person who I follow, Sayyid Sistani, is that if you carry a donor card, you can accept organs from anyone, Muslim or non-Muslim. But if you give your organs, they must go to a Muslim. Now that to me sounds so incredibly hypocritical… I feel ashamed to say that. Actually, if I died today, and I get hit by a bus on my way home, I'm not carrying a donor card…" *(Interview 7, Ophthalmologist, London)*

HOW SHOULD WE DEFINE CARE?

WHAT DO WE MEAN BY "CARE"?

- Basic care vs medical treatment
  - **Bland judgement** [*Airedale NHS Trust v Bland (1993) AC 789*]: ANH is a medical treatment that can be withdrawn for PVS patients following a court order – a matter of good practice
  - ***Y* judgement** [*An NHS Trust v Y (2018) UKSC 46*]: not necessary to get a court order to withdraw ANH in persistent disorders of consciousness (PDOC) cases, unless there is disagreement between people, or uncertainty in medical opinion

WHAT DO WE MEAN BY "CARE"?

"…we had an elderly lady with a terminal ovarian cancer, who was completely conscious. **The consultant said, "That's it. She's going to hang on forever. We should withdraw the feeding as well as the hydration." I felt absolutely dreadful. I would go around and try and feed her with teaspoons of water**…

(Interview 8, Cardiologist, London)

WHAT DO WE MEAN BY "CARE"?

"…I was **uncomfortable** about many things about many things during that first year, and the consultant, who was an elderly Indian man, once turned around to me and said, "**You should leave religion until you're retired. This is not the place for it**.""

(Interview 8, Cardiologist, London)

WHAT DO WE MEAN BY "CARE"?

"**I don't see food or fluid as a mechanism to prolong life**, or I didn't perceive it to be prolonging her life. We all have a time. She had a time, and the time would come.

If you made the case to me that, okay, **feeding her is going to result in aspiration** and actually it might make things more difficult (for) her, **I could accept that**…

(Interview 8, Cardiologist, London)

WHAT DO WE MEAN BY "CARE"?

But I think a lot of it was that actually she had to be fed orally. Somebody had to sit there for half an hour or 45 minutes actually feeding her the whole time if it was going to happen. And it didn't happen very well on the wards. And again with the fluids… had to do that. Then you start putting fluids through the veins, and when you can't put them through the veins, you start giving them subcutaneously. Actually it probably doesn't make very much difference in terms of their overall life expectancy. But **I don't see it as a means of prolonging life. I just see it as a basic form of care for the person.** I guess the perception on the other side was that actually she's dying anyway. Why are we stringing this out over weeks and weeks and weeks? Just let her go."

(Interview 8, Cardiologist, London)

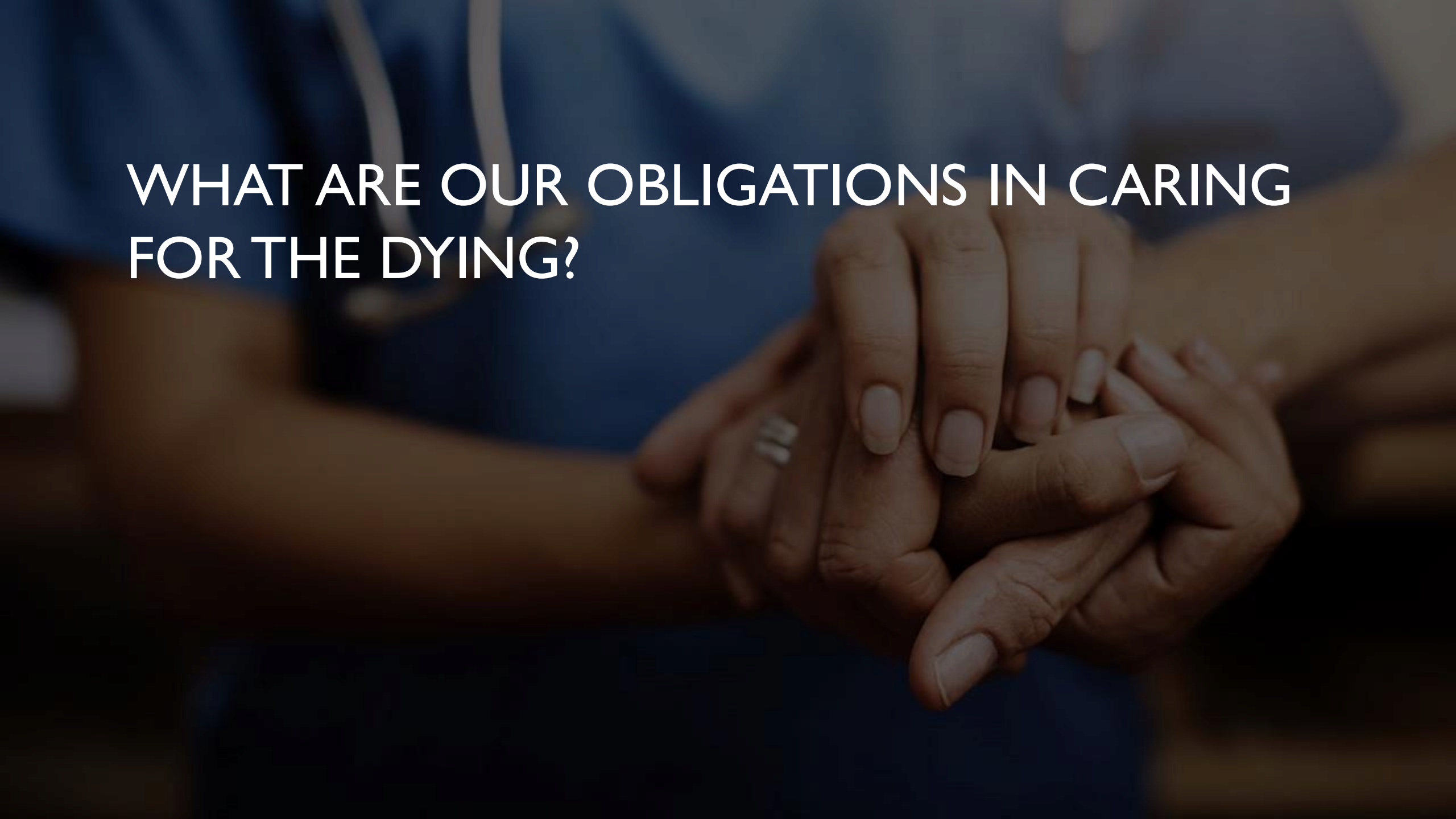
Davies, A., Waghorn, M., Roberts, M., Gage, H. and Skene, S.S., 2022. Clinically assisted hydration in patients in the last days of life ('CHELsea II'trial): a cluster randomised trial. BMJ open, 12(11), p.e068846.

WHAT DO WE MEAN BY "CARE"?

I hadn't very much ethics or anything at that point in time. I think it was very much an instinctive or **maybe the result of my upbringing**, but an **instinctive** sense of wanting to **nurture someone** or to look after them in some way. I guess providing or fluid is the most basic form of care that you can give. **It's not medicine, and it's not fancy**, and it's not ... but it is very, very basic care. I guess I just felt that that's **the minimum that a human being deserves** as a human being."

"I've…flagged it out, but I haven't really had a full-on confrontation, and the times when I have sort of gently suggested that we might do things differently it's just **been ignored or over-ruled**."

(Interview 8, Cardiologist, London)



WHAT ARE OUR OBLIGATIONS IN CARING FOR THE DYING?

WHAT ARE OUR OBLIGATIONS IN CARING FOR THE DYING?

"…it was a patient who was demented. She was in hospital for about four weeks, and she kept deteriorating. We give her fluids, she gets better, then she doesn't eat and drink, she becomes dehydrated, we give her fluids, she gets better, she ... And then every time we put a cannula in, it would tissue up after six hours, you'd put another cannula in. Every time we put a cannula in, it was painful for the patient, and you can physically see her trying to stop you doing that. I had to bring up the discussion with the family to say, "Look, this is the situation. **There is a reversible cause to her deterioration, but I don't know if it's the best thing for us to do. Should we continue to prick her with these needles and cause pain, or should we just let nature take its course?"**

(Interview 43, GP Trainee, Birmingham)

WHAT ARE OUR OBLIGATIONS IN CARING FOR THE DYING?

For me, if I'm the man at the top and I'm having to make a recommendation, and I know that this person may die sooner as a result of my recommendation, I would find that quite hard to make… **It's not necessarily about the stage of clinical training, it's about my perspective.**

That, I guess, influences my behaviour and **the way I interact with others, and that's probably why I push the ball in the patient's court. "You make the decision, get me away from the decision."** But maybe that's just the way that I'm fooling myself, that actually I'm trying to get away from the decision when in reality I'm part and parcel of the decision, whether I recognise it or not."

(Interview 43, GP Trainee, Birmingham)

WHAT ARE OUR OBLIGATIONS IN CARING FOR THE DYING?

"My faith influences probably in two ways. The first is **how I define these things**. What is a life? What is a life that is sacred? **What do we mean by "sanctity"?** So the way I define these and view these things. I think the second thing is is **prioritisation**. Sanctity ... I recognise that life is sacred, however way I define that, but I recognise that that exist. So okay, we recognise that exists, but to what extent can we then say it can be trumped by something else, or it can be outweighed? There is a legal case that talks about the **balance sheet approach** to making best-interest decisions, that you put all the positives on one side and put the negatives on the other side. Let's assume that we have eight negatives and one positive, but **preserving the sanctity of life** is that one positive decision. Does that mean that the balance goes in favour of that one decision, even though there are eight other things on the other side of the scale? **Religion informs my approach of that.** But I still don't know the answer. I still don't know how I would do it. That's why I tend to defer the decision to those at the very centre."

(Interview 43, GP Trainee, Birmingham)

Routledge
Taylor & Francis Group

Global Bioethics

ISSN: (Print) (Online) Journal homepage: https://www.tandfonline.com/loi/rgbe20

When can Muslims withdraw or withhold life support? A narrative review of Islamic juridical rulings

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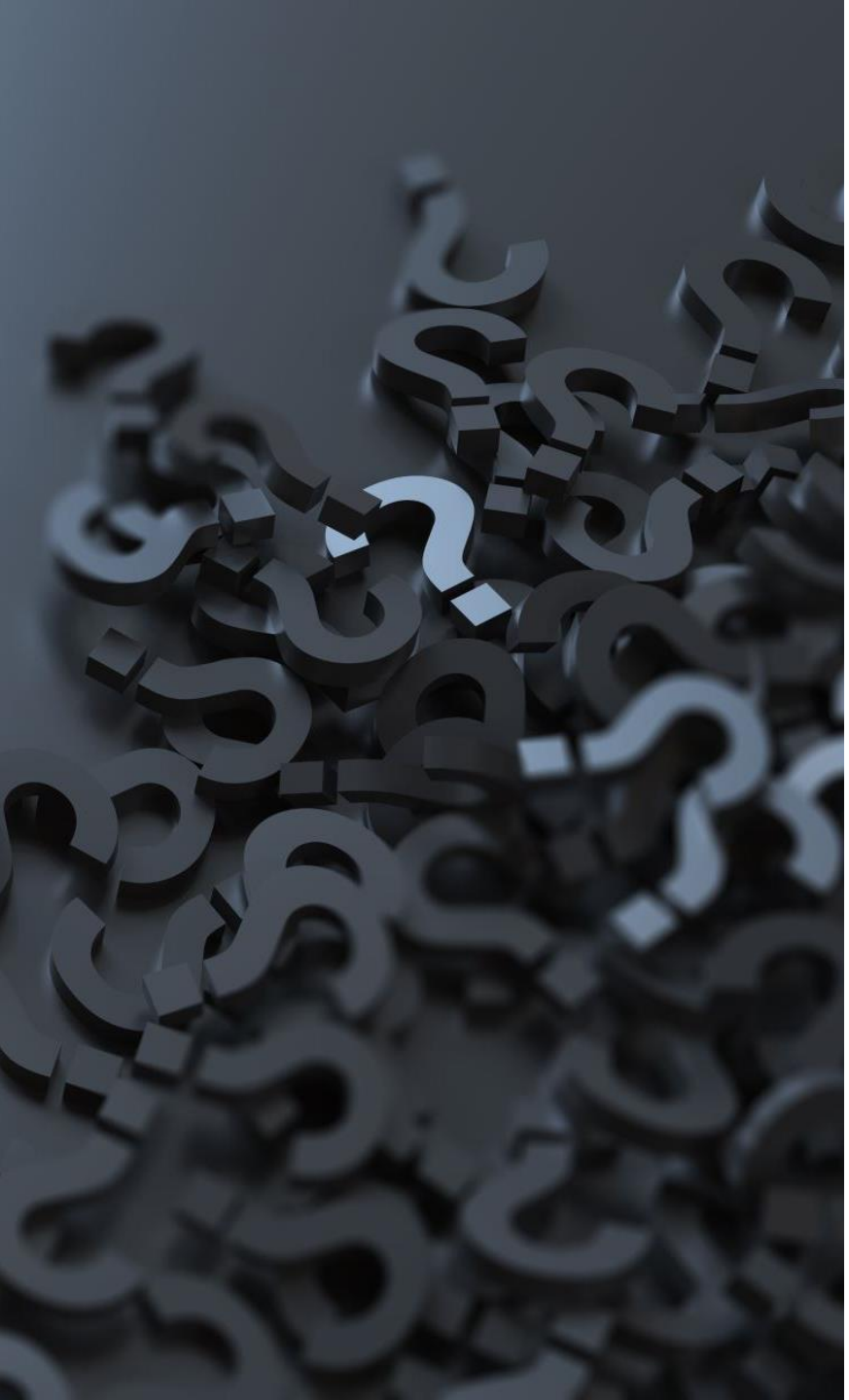
To cite this article: Afshan Mohiuddin, Mehrunisha Suleman, Shoaib Rasheed & Aasim I. Padela (2020) When can Muslims withdraw or withhold life support? A narrative review of Islamic juridical rulings, Global Bioethics, 31:1, 29-46, DOI: 10.1080/11287462.2020.1736243

To link to this article: https://doi.org/10.1080/11287462.2020.1736243

TENTATIVE CONCLUSIONS



TENTATIVE CONCLUSIONS

Need for:

- Spaces of deliberation (NHS/non-NHS)
  - Collaboration between "Islamic/Muslim" representative and research bodies with NHS organisations, medical schools, royal colleges
- Indigenous scholarship
  - Importance of contextual knowledge
  - Emerging questions
  - Growing Muslim HCP population and demand (**epistemic justice and in particular hermeneutical justice** (Miranda Fricker – when experiences are not understood by individuals affected and others)
- Guidance
  - Provide support
  - Prevent moral injury and hardship
  - Retain staff
- Shared learning
  - Challenges not unique to Muslim staff
  - Impacts on identity (self, in team, family, community, society)

QUESTIONS