



UNIVERSITY OF
CAMBRIDGE

Prince Alwaleed Bin Talal
Centre of Islamic Studies



Knowledge, Language, Trust and Authority

Muslim perspectives on End of Life Care decision-making

Overview

On January 31st 2018 the Centre of Islamic Studies will be hosting an interdisciplinary meeting of healthcare practitioners, academics, spiritual leaders and policy makers. The seminar will bring together UK wide experts in biomedical ethics, theology and law to discuss themes on “Knowledge, Language, Trust and Authority - *Muslim perspectives on End of Life Care decision making*. The speakers include Dr Vilas Navapurkar (Consultant in Intensive Care Medicine and Anaesthesia, Addenbrooke’s Hospital, Cambridge), Ms Romana Kazmi (Chaplain, Great Ormond Street Hospital) and Dr Philip Lodge (Consultant in palliative medicine at the Royal Free and Marie Curie Hospice). The speakers and participants will be sharing their insights on caring for Muslim patients, as well as discussing themes including “futility”, “best interests” and “quality of life” as they pertain to decision making at the end of life. They will also discuss the role of faith in healthcare and in particular the contributions made by Muslim chaplains, local Imams and Islamic scholars in end of life care decision making.

Aims

The meeting will bring together key stakeholders enabling them to share their experiences and knowledge. It will also provide attendees the opportunity to input into the Centre of Islamic Studies’ research on End of Life Care, led by Dr Suleman. The study is a qualitative analysis of the views and experiences of Muslim patients, families, healthcare providers, policy makers and chaplains around end of life care. The research is at an advanced stage of data collection and analysis and will benefit from the contribution of experts at the meeting who can provide insights on the study.

The meeting will be recorded in order to enable the publication of a report and for suggestions by attendees to be collated for the on-going study. The meeting will be conducted under Chatham House rules.

Knowledge, Language, Trust and Authority in End of Life Care

End of life care decisions, as with other medical decisions, have transformed dramatically over the past few decades. In particular, the moral authority of health services and health service



personnel, particularly doctors, has been declining.¹ This decline has followed a rise in biomedical advancement and a shift in focus towards technologically driven healthcare. Patients, families and communities have been experiencing a diminished trust in health services that have been gearing more towards a “commodity centric” model of care.² The response to this has been recent calls for patient centred care, shared decision-making and rekindling shared partnerships between healthcare users and providers.³ Traditionally, doctors were the principle decision makers within the clinical context; this authority was often linked to their superior knowledge, training and experience of disease pathologies, management and prognosis. More recently, in the healthcare context, what is emerging is the construction of a shared moral consciousness when negotiating challenging ethical decisions, with the focus being on relationships and partnerships and not individual power and advancement.⁴ End of life care decision making, in particular, involves careful negotiation and may include stakeholders that offer knowledge and support alongside healthcare professionals.

For example, for Muslims, local religious leaders are often looked upon to facilitate the interpretation of religious texts and rulings and to support decisions at the end of life. Understandings about death and dying are central to the narrative of and are integral to the beliefs of Muslims in offering them perspective and informing their end of life decisions. As such, they are keen to rely on members of their community who they consider to be better informed about Islam and its rites and obligations to support such decision making. As death and dying may be understood by Muslim patients and families within a spiritual framework of Islam, they rely on the knowledge of faith leaders and afford them the authority to guide their end of life care decisions.

A family’s local imam, who leads the prayer in the mosque, may commonly be the first port of call when there is a spiritual concern about a patient’s care. Decisions may also involve a Muslim chaplain as well as local and international religious experts. Little research has been carried out to understand the role and nature of the authority that is conferred by patients and families in the UK to local and global faith leaders in the context of healthcare. This seminar will enable participants to explore:

- What is the role of faith in EOLC decision making?
- Who are the stakeholders in EOLC decision making?
- What is the role and nature of authority of the following when Muslim patients and families negotiate EOLC decision making:
 - Hospital doctors
 - Nurses

¹ Stange, Kurt C. "Power to advocate for health." *The Annals of Family Medicine* 8.2 (2010): 100-107.

² Heath I. Patients are not commodities. *BMJ*. 2006;332(7545): 846–847.

³ Frosch DL, Kaplan RM. Shared decision making in clinical medicine: past research and future directions. *Am J Prev Med*. 1999; 17(4):285–294.

⁴ Stange, Kurt C. "Power to advocate for health." *The Annals of Family Medicine* 8.2 (2010): 100-107.



- Allied health professionals
- Muslim healthcare professionals
- Muslim chaplains
- Chaplains of other faiths
- Local imams
- Islamic scholars (local and global)
- Religious edicts (*fatawah*)
- When deliberating the withholding and withdrawal of care, in different clinical contexts, including intensive care and palliative care, what are the ethical challenges when making decisions about:
 - Quality of life
 - Futility
 - Best interestsWho is involved in such deliberations and how are such terms understood and communicated by different stakeholders?
- What is the role and impact of language in end of life care decision making?
 - What is the role of clinical language?
 - What is the role of religious language?
 - What is the role of a shared language?

The key focus of the seminar will be on understanding how Muslim patients and families negotiate end of life care decisions and in what manner healthcare professionals encounter such decisions.

The discussion will centre on the role and extent to which religious views and values influence end of life care decision making and in particular how ethical issues are defined and addressed. The latter is critical to gain a deeper understanding of the moral universe of Muslim patients and families and/or the challenges healthcare professionals may face when working with the Muslim community.

Another important consideration that needs to be made here is that, within the Muslim tradition, although the formulation of religio-ethical opinions has usually been perceived as the exclusive charge of religious scholars, more recently physicians and scientists themselves have taken on this task. It may be pertinent to assess the nature of this emerging multifaceted role of the Muslim physician/scientist and the impact it may have on the clinical ethics discourse.

Some of these themes and tensions will be discussed in the meeting with a particular focus on the types of knowledge and authority that may be involved when healthcare practitioners provide care for Muslim patients and families at the end of life.



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Details of the event

Date: 31st January 2018

Time: 10.15 am - 14.30 pm

Location: Moller Centre, Churchill College, Cambridge

Programme

- 10.15 - 10.30:** **Arrival + Coffee/Tea + Welcome**
- 10.30 - 11.00:** **Knowledge, Language, Trust and Authority *summary of qualitative research findings* Dr M Suleman (20 mins presentation + 10 mins q&a)**
- 11.00 - 11.30:** **Knowledge, Language, Trust and Authority *a clinical intensive care perspective*
Dr Vilas Navapurkar (20 mins presentation + 10 mins q&a)**
- 11.30 - 12.00:** **Knowledge, Language, Trust and Authority *a chaplain's perspective*
Ms Romana Kazmi (20 mins presentation + 10 mins q&a)**
- 12.00 - 12.30:** **Knowledge, Language, Trust and Authority *a clinical palliative care perspective*
Dr Lodge (20 mins presentation + 10 mins q&a)**
- 12.30 - 13.15:** **Lunch**
- 13.15 - 14.20:** **Discussion - led by Dr M Suleman (drawing on responses from key discussants)**
- 14.20 - 14.30:** **Close and feedback forms**



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Speakers:

***Dr Vilas Navapurkar** is a Consultant in Intensive Care Medicine and Anaesthesia and the senior clinician on the John Farman Intensive Care Unit at Addenbrooke's Hospital. Dr Navapurkar has led, developed and delivered a broad range of successful services, research and training in intensive care medicine in the NHS.*

He will be sharing his experiences of caring for Muslim patients with critical illness and discussing the complexities of establishing trust and shared decision making in intensive care.

***Dr Philip Lodge** is a consultant in palliative medicine in London. He provides specialist palliative care with a joint hospital and community nurse team at the Royal Free and for hospice in-patients at the Marie Curie Hospice. His special interest is chronic pain with a clinic at the Royal Free for this group of patients.*

He will be providing an overview of the role of palliative care within modern healthcare systems and will offer insights into caring for Muslim patients and families. Dr Lodge will also explore the different stakeholders and ethical challenges a palliative care specialist may encounter when making end of life care decisions involving Muslim patients and families.

***Ms Romana Kazmi** is a Muslim Chaplain. She divides her time between King's College London and Great Ormond Street Hospital, where she works as a Paediatric Chaplain. She has extensive experience as a national and international spiritual teacher and has a particular interest in healthcare ethics. She obtained her BSc in Psychology in America and is a qualified counsellor.*

She will provide an overview of the work of a Muslim chaplain in paediatric end of life care including key ethico-legal values from an Islamic perspective. She will also explore the role of and challenges pertaining to Islamic authority in healthcare decision-making, including imams, local and international religious leaders and religious edicts.

***Dr Mehrunisha Suleman** is a post-doctoral research associate at the HRH Prince Alwaleed Bin Talal Centre of Islamic Studies at the University of Cambridge. Her research involves an analysis of the experiences of end of life care services in the UK, from Muslim perspectives.*

Dr Suleman will be presenting a preliminary analysis of the qualitative study she is conducting titled "Perspectives on End of Life Care: Caring for Muslim patients". She has been conducting interviews to study the views of stakeholders in End of Life Care services and will be using the meeting as an opportunity to capture the experiences of speakers and attendees for the study.



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Discussants:

Dr Paul Anderson		Assistant Director	Centre of Islamic Studies
Arzoo Ahmed		Director	Centre for Islam and Medicine
Asif Butt		Practice manager	Manchester
Imam Yunus Dudhwalla		Chaplain	Barts NHS Trust
Dr Sabena Jameel		GP and associate dean of GP education,	Birmingham
Dr Shilpa Patel		GP	London
Sharon Hudson		Nurse	St Mary's hospice, Birmingham
Dr Joy Ross		Consultant	Palliative Care, London
Dr Julian Hargreaves		Researcher	Wolf Institute, Cambridge
Ruth Roberts		Nurse	St Mary's hospice, Birmingham
Naved Siddique		Researcher	Wolf Institute, Cambridge
Dr Tony Kyriakides		Chaplain	Marie Curie Hospice, London
Jo Bryant		PhD candidate	Cardiff University
Dr Sabina Patel		GP, CEO, Muslim Bereavement Support Service	
Keith Morrison		Chaplain	Arthur Rank Hospice, Cambridge
Mohamed Omer		Board member of Gardens of Peace Cemetery	
Sue Price		Chaplain	EACH, Cambridge
Irum Cawley		Student Nurse	St Albans
Yassar Zaman		Chaplain	Homerton Hospital, London
Michael Savage		Chaplain	Royal Trinity Hospice
Hassan Tayub		Support@Home	St Mary's Hospice, Birmingham
Jo Franklin		Nurse	Addenbrooke's, Cambridge