



Values in End of Life Care: Caring for Muslim Patients

Event Summary

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Hosted by: Centre of Islamic Studies, University of Cambridge



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On June 29th 2017 the Centre of Islamic Studies hosted an interdisciplinary meeting of healthcare practitioners, academics, spiritual leaders and policy makers. The seminar brought together UK wide experts in biomedical ethics, theology and law to discuss themes on “values in end of life care”. The speakers included Right Reverend Dr Christopher Herbert, Imam Yunus Dudhwalla, Dr Razeen Mahroof and Dr Mehrunisha Suleman. The speakers and discussants reviewed themes including hope, acceptance, futility, suffering and dignity. The seminar focused on Islamic understandings of life being sacred and how such beliefs are negotiated with the increasing mechanicalisation of medicine at the end of life.

Aims of the event

The meeting was organized to bring together key stakeholders enabling them to share their experiences and knowledge through presentations, discussions and informal networking. It was also designed to enable attendees 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 initial stage of data collection and benefited greatly from the contribution of experts at the meeting who provided insights on the data collection, analysis and potential outputs.

Distinguishing factual analyses from value deliberations: a brief introduction

Clinical care requires careful scientific analysis and reliance on evidence-based medicine.¹ The efficacy of healthcare interventions needs to be carefully scrutinized to ensure the appropriateness for patient care, both in terms of safety and effectiveness. Healthcare practitioners also need to be confident of the care they provide and to be able to give reasons for the clinical care decisions they implement. These decisions, however, rely not only on rigorous scientific knowledge and analysis but also on ethical reasoning. This is because many clinical encounters and decisions require deliberation about a combination of factual or scientific details as well as ethical issues. For example, in end of life care, a growing concern is around preservation of life. Although scientific advancements offer a means of prolonging life, is this what we should do? Biomedical science, thus may offer a consideration of facts and the determination of ‘what we can do’; ethical deliberations, by contrast, enable us to consider ‘what we ought to think or do’.

A key distinction between ethical deliberations and the values that underlie them and scientific analyses can be reviewed through the following example:

¹ Sackett, D. L., & Rosenberg, W. M. C. (1995). On the need for evidence-based medicine. *Journal of Public Health*, 17(3), 330-334.



Two or more healthcare practitioners may disagree about a clinical intervention's effectiveness, such as the administration of an experimental drug for a terminal illness. Yet methods are available to scientifically evaluate the evidence base for such an intervention to enable appropriate clinical decision-making. For example, a scientific evaluation will consider the potential benefits, such as survival or symptom control that may be deliberated alongside harms, such as side effects and costs. Although the latter seems to provide an unequivocal means of decision-making, such an evaluation, however, overlooks the underlying values that may be pertinent to the case. For one patient, the risk of an experimental drug may be too great and she may choose to continue in her present state. For another, the experimental drug may offer the chance of much sought symptom control or survival, however slim the chances, and she may be willing to risk the side effects and/or fatal consequences of the drug. So although clinically an intervention may be considered according to the evidence base, a patient may however evaluate her options differently. That we incorporate patient views and preferences within a clinical encounter requires a different type of analysis to that offered by scientific evaluation. An ethical analysis indicates that the underlying values of respecting persons, protecting their dignity and ensuring they have the freedom to choose what care they receive adds essential layers of complexity to clinical decision making. A consideration of such values will be central to this meeting.

In end of life care, clinical encounters that are commonly deliberated by healthcare professionals include:

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

Ethical analyses that may be pertinent to such deliberations include:

- Values and beliefs around the sanctity of life impressing the need to preserve life that may come up against clinical deliberations around the futility of interventions.
- Retaining a sense of hope in the seeking of treatment versus accepting clinical prognostication.
- Ensuring respect for a patient by making clinical decisions reflective of their wishes whilst working in the absence of an advanced care plan/advanced directive.



- Being mindful that a patient's wishes may incorporate familial, religious and cultural concerns that are unfamiliar to the clinical team and/or may be difficult to incorporate within time sensitive clinical encounters.
- That each patient and their individual needs ought to be considered alongside the practical challenges of resource limitations.
- Healthcare practitioners deliberate according to scientific analyses and the ethical training of the medical profession whilst also balancing their own personal moral commitments.

Some of these themes and tensions were discussed in the meeting with a particular focus on Muslim perspectives and whether there are distinct values that ought to be considered when healthcare practitioners and policy makers provide care for Muslim patients and families at the end of life.

Summary of presentations

After a networking lunch and general introductions, Dr Razeen Mahroof, a Consultant in Critical Care Medicine and Anaesthesia at Addenbrooke's Hospital Cambridge University Trust provided an overview of the role of intensive care within a modern healthcare system. He explored its impact on both preservation of life in the critically ill patients and its role in facilitating/extending the boundaries of surgical operations and medical interventions. He also presented the clinical, social, psychological and personal impacts on patients who survive critical illness.

This was followed by a very personal account from Imam Yunus Dudhwalla, the Head of Chaplaincy and Bereavement Services at Barts Health NHS Trust, who provided an overview of the role of the Muslim chaplain and chaplaincy services within end of life care. He also discussed key ethico-legal values from the Islamic perspective that may be encountered in deliberations around end of life care involving Muslim patients and families.

Right Reverend Dr Christopher Herbert, who was Bishop of St Albans from 1995 to 2009, presented on the political and ethical debates about Euthanasia and Assisted Suicide which have taken place in the UK over the past decade. Since the 1990s there have increasing attempts in the UK to change the 1961 Suicide Act, an act which remains in force and which determines current legislation surrounding Euthanasia and Assisted Suicide. The Rt Revd Dr Christopher Herbert was a member of the House of Lords 1999-2009 and was a member of a Select Committee on the subject which reported its findings in 2004. Since then, further attempts have been made to change the Law, so far without success. However, the topic remains a hotly contested one and in this brief presentation Bishop Christopher Herbert, who is Visiting Professor of Christian Ethics in the University of Surrey, outlined the political and philosophical arguments which underlie the debate.



Finally, Dr Suleman presented a preliminary analysis of the qualitative study she is conducting titled “Perspectives on End of Life Care: Caring for the Muslim patient”. She has been conducting interviews to study the views of stakeholders in End of Life Care services and used the meeting as an opportunity to capture the experiences of speakers and attendees for the study.





Event feedback

“All those who presented, reflected their areas of concern and interest with very well thought out points, which respectively raised valid concerns need(ed) for consideration, when tackling a topic like 'Life ending matters...'. I found this particularly useful, for it was clear that a topic like this needs a conversation between those very parties present to develop a better informed perception of a Muslims' end of life concerns and their understanding of death.”

“I found it very useful and enlightening to hear a multiplicity of Muslim viewpoints about the ethics and theology of End-of Life Care.”

“(what was) useful about the event was the network of people who are doing great work in this area”

“Thank you so much for inviting me to the event... it was inspiring and I really enjoyed the opportunity to discuss the important issues that arose. It was particularly helpful having the Muslim chaplain speak as this helped clarify a few issues which I have encountered as an CNS when I look after Muslim patients in there own home.”

“...(to have) the opportunity to meet and network with people that I wouldn't have ordinarily met in my line of work”

“Engaging different perspectives on End of Life Care for Muslim patients”

“Revd Christopher Herbert's 'insider' thoughts on end of life care in the UK including a historical perspective on the legal landscape”

“to be (able to) clarify the issues on morphine was very helpful and is one that comes up in different ways both in Muslim families and homes where they are not Muslim.”

“to have the opportunity to discuss in a non threatening manner which sometimes being a white female in a home with a 2nd generation male regarding his mother/ father can feel very difficult.”



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Demand for future events

All speakers and attendees expressed a keenness for follow up events relating to Muslim End of Life Care perspectives. One of the key themes to emerge from the presentations and discussions was around authority and decision making at the end of life. The CIS will be planning a second event around these themes in December 2017.

Event report

The event was recorded and transcribed and a report is being prepared that will be shared with key stakeholders.



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Details of event

Speakers:

Dr Razeen Mahroof is a Consultant in Critical Care Medicine and Anaesthesia at Addenbrooke's Hospital Cambridge University Trust since 2010. He trained at Oxford, UCL and Southampton, and has an interest in cardiovascular dysfunction in septic shock, ethics of organ donation and end of life care in ICU.

Imam Yunus Dudhwalla is one of the leading Muslim healthcare chaplains in the UK and is the Head of Chaplaincy and Bereavement Services at Barts Health NHS Trust. He is also a regular trainer on national chaplaincy programmes and was elected to the Council of the College of Healthcare Chaplains in 2003. He is a graduate of Darul-Uloom, Bury and Al-Azhar University, Cairo. Imam Yunus was awarded the Healthcare Hero/NHS Employee of the Year 2010 at the HEAL Awards (Healthcare, Excellence and Leadership), hosted by 24/7 Media Group.

Right Reverend Dr Christopher Herbert was Bishop of St Albans 1995-2009. He has an M.Phil and a PhD in the field of Art History from the University of Leicester plus two honorary Doctorates, but has had a lifelong interest in Care Ethics. He is currently editing a book about Care Ethics as expressed by and seen in, the major World Faiths. In retirement he lectures in Art history to groups across the UK and Europe and is also a visiting Professor in Christian Ethics at the University of Surrey.

Dr Mehrunisha Suleman is a 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. Before joining CIS, Mehrunisha studied for a DPhil in Population Health at the University of Oxford titled "Does Islam influence research ethics?" She completed a BA in the Biomedical Sciences Tripos at the University of Cambridge, followed by clinical studies and an MSc in Global Health Sciences, at Oxford University. She has worked with Sir Muir Gray on the Department of Health's QIPP Right Care Programme. She has been involved in the design and construction of Population Based Accountable Integrated Care Systems, as well as developing an online tool for commissioners, clinicians and patient groups on health care systems design. She was co-editor of the NHS Atlas of Variation for Diabetes and Liver Disease.



Attendees:

Razeen Mahroof Cambridge		Consultant	Addenbrooke's Hospital,
Yunus Dudhwalla London		Chaplain	Barts Health NHS Trust,
Christopher Herbert		Professor	University of Surrey
Paul Anderson		Lecturer	University of Cambridge
Mehrunisha Suleman		Researcher	University of Cambridge
Ludmilla Applegate		Administrator	University of Cambridge
Arzoo Ahmed		Director	Centre for Islam and Medicine (CIM)
Jo Archer		Nurse	St Luke's Hospice, London
Judith Bunbury		Senior tutor	St Edmond's College, Cambridge
Asif Butt		Practice manager	Manchester
Obadah Ghannam		GP	Birmingham & CIM (Trustee)
Helen Grist		Nurse	St Mary's hospice, Birmingham
Saad Ismail		GP	Birmingham & CIM (Trustee)
Romana Kazmi		Chaplain	Great Ormond Street Hospital
Philip Lodge		Consultant	Palliative Care, London
Thaqib Mahmood		Islamic Scholar	Oxford
Ruth Roberts Birmingham		Nurse	St Mary's hospice,
Naved Siddique		Researcher	Woolf Institute, Cambridge



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