

Introduction

End-of-Life Care in the Islamic Moral Tradition

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Although the initial preparation for this project occurred prior to the COVID-19 pandemic, the proceedings of the research seminar “End-of-Life Care in the Islamic Moral Tradition” took place in October 2020;¹ the midst of the pandemic and its harrowing impact. As of June 2022, the virus has infected more than 500 million people, harvested the lives of more than six million, and disturbed almost all aspects of life on earth. Navigating this unpleasant situation had its complications, as participants shifted to virtual communication with each other and researchers conducted their work under the unusual circumstances of public lockdown. Yet, this context made the proceedings of the seminar and post-seminar work for this publication quite relevant, as people worldwide realised that the ethical questions related to the end-of-life phase concerned almost everybody now and they were no longer exclusive to a limited number of intensive care unit (ICU) patients.

1 End-of-Life Care and Its Ethical Questions

That all living humans eventually die is one of the empirically verified facts that has never failed throughout human history. Thus, dying and death represent an integral part of the shared human experience that cuts across our historical, cultural, ethnic and religious differences. Individuals, families, societies and nations have always been trying, in considerably different ways, to cope with the unavoidable phenomenon of death and the associated intense feelings and emotions that arise when death approaches their milieus. Some of the questions related to this phenomenon are transhistorical in nature, which have long engaged the minds of thinkers. For example, why are humans generally inclined to fear death? How must one take care of a terminal patient or dying person and secure a “good” death? Why is there an association of suffering with death? How far can, or should, medical treatment be sought to improve the health condition of terminal patients? What happens to people after they die

1 The outcome of these seminars has resulted in a number of publications, including Ghaly 2016; Ghaly 2018; Jureidini and Hassan 2019; Hashas and al-Khatib 2021.

and where do they eventually go? How should those who are near and dear to the deceased behave when their beloved ones die? What obligations do living people have towards the dead?

With the advent of the modern biomedical revolution, the very concept of death changed and the dying process was considerably medicalised. This revolution has produced an increasing number of tools which can keep many human organs functioning for long periods, through the assistance of expensive and cutting-edge advanced medical technology. All of these developments paved the way for newer methods of “managing” the dying process that had not been available before, thus expanding the scope of end-of-life care (EoLC) and transforming its related ethical questions and dilemmas. Many of the resulting transhistorical questions assumed new dimensions and necessitated revisions of many of the key concepts and values which had long constituted people’s moral world. Indeed, new questions were triggered by the modern context of medicalised dying, such that biomedical scientists and ethicists deliberated issues like forgoing life-support machines, life-sustaining treatments, and artificial nutrition and hydration.

As outlined below, this volume approaches EoLC as a rich and complex concept. It, therefore, examines the Islamic perspectives that reflect upon both the transhistorical questions that have always occupied the minds of humans and the novel shifts and questions created by the modern biomedical revolution.

2 This Volume

Against the above-sketched background, this volume is intended to be a reference work for researchers with interests in EoLC and in Islamic Bioethics in general, while also opening up new avenues for future research. The diverse pool of this volume’s contributors demonstrates that Islamic bioethical discourse can, and should, be enriched by engaging different disciplines, such as biomedical sciences, psychology, social sciences, in addition to the wide range of scholarly disciplines rooted in the Islamic tradition.

In order to do justice to complexity of EoLC and to the diverse nature of related ethical questions, the volume is divided into three distinct but related parts. The first part, “Methodological Issues,” includes two chapters that provide proposals for finetuning and improving certain methodological aspects in the EoLC discourse and the field of Islamic bioethics in general. The second part, “End-of-Life Care in Islamic Studies,” comprises four chapters that dig into the rich Islamic tradition to unravel a number of relevant historical discussions that relate to the abovementioned transhistorical questions. The

seven chapters included in the third part, “End-of-Life Care as a Bioethical Issue,” examine Islamic perspectives on the modern bioethical questions that EoLC, as a scholarly field, is currently engaging with. Below, a detailed overview is provided of each part and the chapters included therein.

2.1 *Methodological Issues*

The two chapters included in this part focus on methodological issues whose consideration is key to developing a thick discourse rooted in the Islamic tradition that concurrently shows awareness of, and critically engages with, EoLC’s biomedical and bioethical complexities. The main goal here is to show that the Islamic discourse on EoLC, and by extension dying, death and other bioethical issues, should be premised on consistent methodological considerations and not just sporadic quotations, without serious effort to engage with the context of the rich and vast scholarship in the Islamic tradition. Unfortunately, we have seen numerous superficial writings in the field of Islamic bioethics and that is why methodological studies are needed to help in maturing this emerging field.

In “End-of-Life Care, Dying and Death in Islamic Ethics: A Primer,” Mohammed Ghaly uses EoLC as an applied example to show how the Islamic bioethical discourse can address one of its oft-repeated critiques, namely its almost exclusive focus on juristic perspectives and thus, ends up something closer to medical jurisprudence rather than bioethical discourse. He explains how an ethical discourse on EoLC can be interdisciplinary by benefiting from, and engaging with, a wide range of scholarly disciplines and genres anchored in the Islamic tradition. The chapter starts with an extended overview and typology of the main ethical questions brought forth by EoLC as a field of scholarly inquiry. The greater part of the chapter expounds on how these questions can be examined from within the Islamic tradition. Besides outlining the possible contribution from the disciplines of Islamic jurisprudence (*fiqh*) and legal theory (*uṣūl al-fiqh*), the chapter provides extensive analysis on how to engage with Qurʾān and *ḥadīth* studies, the disciplines of Islamic theology, philosophy and Sufism. The chapter also explains how the EoLC discourse can benefit from specific genres, including eschatological manuals and works written for consoling people who have been afflicted with calamities and misfortunes, known in Arabic as the *tasliyat ahl al-maṣāʾib* genre.

In “Muslim Disquiet over Brain Death: Advancing Islamic Bioethics Discourses by Treating Death as a Social Construct that Aligns Purposes with Criteria and Ethical Behaviours,” Aasim Padela makes a strong case for the argument that the ethical discourse on EoLC is strongly influenced by the way that key concepts like death and dying are defined, understood and

approached. He stresses that ethical deliberations on certain EoLC practices should show awareness of the particularities of our modern context, where the dying process has been medicalised. To do justice to this modern context, Padela suggests that bioethical deliberations would better approach human death as a construct that conflates various dimensions and aspects, including the purpose for death declaration, the criteria for certifying death, and what are sometimes termed as “death behaviours,” the types of actions that stakeholders are to carry out when a person dies. Judging the ethical or unethical character of one dimension or aspect, he argues, should rest upon a broader ethical evaluation of the other related dimensions. The academic literature produced by bioethicists on the concept of brain death is used as an applied example to highlight the shortcomings in Islamic engagement with this modern concept and how such shortcomings can be addressed by approaching death as a construct.

2.2 *End-of-Life Care in Islamic Studies*

The four chapters included in this part examine EoLC within the broad scope of Islamic Studies. The point here is to show how the death-related moral world in the Islamic tradition looked like before the advent of the modern biomedical revolution. As outlined above, death, dying and a wide network of related concepts have all been part of the human experience throughout history. The scholarly disciplines rooted in the Islamic tradition contributed to shaping, constructing and expounding different aspects of the death-related moral world in Islam. Thus, any modern perspectives on EoLC should show awareness of, and serious engagement with, the related pre-modern perspectives as recorded in these scholarly disciplines. The chapters included in this part give detailed examples of how pre-modern philosophers, theologians, Sufis, poets, jurists and pious public figures contributed to discussions on a wide range of concepts and issues, which remain relevant to the modern EoLC context, including fear of death, plague-related (mass) deaths, pains and agonies of the dying process, etc.

In their “*Muqārabāt Falsafīyya Akhālqiyya li-Ruhāb al-Mawt fī l-Ḥaḍāra al-Islāmiyya: Dirāsāt Ārāʾ Muḥammad b. Zakariyyā al-Rāzī wa-Abī ʿAlī Miskawayh wa-Ṣadr al-Dīn al-Shīrāzī* (Philosophical-Ethical Approaches to Thanatophobia in the Islamic Civilisation: A Study of the Views of Muḥammad b. Zakariyyā al-Rāzī, Abū ʿAlī Miskawayh and Ṣadr al-Dīn al-Shīrāzī),” Hamed Arezaei and Asma Asadi provide an analytical review of the contributions of three Muslim philosophers on how to understand and/or address the phenomenon of thanatophobia or fear of death. The three selected philosophers are Abū Bakr al-Rāzī (d. 313/925), Miskawayh (d. 421/1030), and Ṣadr al-Dīn

al-Shirāzī (d. 1050/1640). Besides sporadic references to possible comparisons with perspectives of classical Greek and modern Western philosophers and ethicists, Arezaei and Asadi's focus is to outline the heterogeneity of perspectives within the Islamic tradition. Some of these philosophers stressed that the best approach is to avoid pondering death itself, whereas others argued that thinking, and feeling afraid, of death can be beneficial and that it is not only something natural but even indispensable for humans. One of the agreed-upon points in this regard is that overcoming the excessive fear of death is conditioned by debunking certain myths and developing the right understanding of what dying, death, and related concepts mean in the Islamic religio-moral system. It is to be noted that other Muslim scholars, not mentioned in this chapter, also contributed to these discussions – their writings are highlighted in the chapter “End-of-Life Care (EoLC) and Islamic Ethics: A Primer,” which is included in the first part of this book.

In their “Jalāl al-Dīn al-Rūmī wa-Falsafat al-Alam wa-l-Mu‘ānāt (Jalāl al-Dīn al-Rūmī and the Philosophy of Pain and Suffering),” Shahaboddin Mahdavi and Amir Abbas Alizamani argue that Sufism represents the best candidate, among other scholarly disciplines, to constructing spiritual care tailored to Muslim terminal patients. The authors chose the prominent poet Jalāl al-Dīn al-Rūmī (d. 672/1273), because of his wide influence that crosses the boundaries of language, culture, religion and time, to represent the vast Sufi literature on pain and suffering. Following a brief overview of Sufi literature in general and al-Rūmī in particular, the chapter focuses on unfolding his multi-level and multidimensional contribution to the theme of pain and suffering. In their analysis of al-Rūmī's insights, the authors touched upon aspects related to semantics, ontology, teleology and typology, in addition to the ethics of dealing with, pain and suffering.

In “Plague, Proper Behaviour and Paradise in a Newly Discovered Text by Zakariyyā al-Anṣārī,” Hans Daiber shows the particular relevance of the classical treatises on plague to EoLC discussions, especially in relationship to the appropriate conduct of a religiously and ethically committed Muslim during such overwhelming calamities. Daiber's contribution is of special relevance to the COVID-19 pandemic, which was at its peak when the seminar took place. He focuses on a text written by Zakariyyā al-Anṣārī (d. 926/1520), known as a jurist and judge who also made important contributions to the disciplines of *ḥadīth* and Sufism. Al-Anṣārī's work is not just inspired by scholarly interest, but by personal experience as well. He lost one of his sons during a plague and another son drowned in the Nile River. Daiber provides an extensive overview of the fourteen chapters of al-Anṣārī's work entitled *Tuḥfat al-Rāghibīn fī Bayān Amr al-Ṭawāʾīn* (“On the Gift for Those Who Like to Get Information

on the Topic of the Plagues”). Daiber also enriches the chapter by including a number of literal Arabic quotations, together with English translations. He pays special attention to the last chapter of al-Anṣārī’s work, which is dedicated to the main etiquettes (*ādāb*) that one should abide by in the face of plagues or similar calamities.

The last chapter in this part of the book is “Islamic *Ars Moriendi* and Ambiguous Deathbed Emotions: Narratives of Islamic Saints and Scholars on the End-of-Life” by Pieter Coppens. The author elaborates how deathbed stories recorded in historical sources, particularly the hagiographies that represent different epochs of Islamic history, can help our understanding of the death-related moral world in the Islamic tradition. Coppens focuses on the deathbed stories of religious luminaries in two classical sources from the 5th/11th century, namely *Ḥilyat al-Awliyā’* (“The Ornaments of the Friends of God”) and *Risāla fī l-Taṣawwuf* (“Treatise on Sufism”), in addition to two works from the late 19th–early 20th century, namely *Ḥilyat al-Bashar* (“The Ornaments of Humanity”) and *Ta’rīkh ‘Ulamā’ Dimashq* (“The History of the Scholars of Damascus”). The objective of the author is to construct something similar to the popular *ars moriendi* (art of dying) genre in Christian literature. Such a genre generally functions as a tool to teach and guide believers on how to behave and manage one’s emotions in the face of an imminent death. Coppens has deliberately chosen sources from different historical periods in order to examine whether certain shifts took place between deathbed experiences from early Islamic history and those from the late era, when the Muslim world was at the verge of “modernity.” In doing so, the author attempts to fill a research lacuna in the field of spiritual care and chaplaincy from an Islamic perspective.

2.3 *End-of-Life Care as a Bioethical Issue*

In addition to the transhistorical moral questions and ethical dilemmas pertinent to the phenomena of dying and death, the modern biomedical revolution brought forth its own unique contribution to this area of inquiry. As outlined above, the medicalisation and technologisation of death caused people worldwide, Muslims being no exception, to revisit their long-established moral world and look for answers to novel and complex questions. Concepts including suicide and deliberately terminating one’s life to put an end to pain and suffering are to be revisited in light of “new” information and/or “novel” medical techniques, which created their own terminology like the term “euthanasia.” The EoLC discourse had to address additional questions about the scope of using advanced medical interventions for terminal patients, such as life-sustaining treatments (LSTs), e.g., ventilators and cardiopulmonary resuscitation (CPR), and the (imp)permissibility of forgoing artificial nutrition and hydration

(ANH), which are examined more than once from various angles throughout the chapters included in this part.

This part starts with an overview chapter which examines one of the most discussed topics in the EoLC discourse, namely palliative care (PC). In “Palliative Care and Its Ethical Questions: Islamic Perspectives,” Mohammed Ghaly starts with introductory remarks about the overarching concept of medical treatment (*tadāwī*). He explains how modern biomedical advances problematised some of the previously held ethical generalisations in this regard. These modern advances, he argues, have created morally relevant differences and nuances to the extent that *tadāwī* cannot be judged as one simple or indivisible concept. The chapter is comprised of two sections, the first section examines the possible tension between palliative treatment which focuses on treating diseases, through pain management and curative treatment, at the hand of “life-sustaining treatments” (LSTs). Within his discussion of LSTs, the author further differentiates between cardiopulmonary resuscitation (CPR) and mechanical ventilation, on one hand, and artificial nutrition and hydration (ANH), on the other. The second section is dedicated to the dilemma of balancing conflicting values, where important ethical values or virtues cannot all be honoured or implemented within the PC context. This issue is analysed at the hand of two concrete examples, the first of which is administering analgesics, typically used to relieve pain but also used to impair one’s consciousness or hasten death. The second example is communicating bad/sad news and how to balance between the value of veracity and that of compassion.

In the second chapter of this part “Suicide Prevention and Postvention: An Islamic Psychological Synthesis,” Khalid Elzamzamy examines how insights from modern disciplines, like psychology and mental health, interact with the classical and modern Islamic perspectives on the prevention and postvention of suicide. Elzamzamy approaches suicide as a rich, complex and multi-dimensional concept whose rigorous analysis necessitates interacting with a wide range of sources that belong to different scholarly disciplines from inside and outside of the Islamic tradition. Besides some introductory methodological remarks and notes about the prevalence of suicide among Muslims, the chapter is divided into two main sections. The first section focuses on suicide prevention and engages with literature from both the fields of mental health and Islamic psychology, including reports from the World Health Organization (WHO) and *fatwās*. Moreover, the author sheds light on how the role of religion is perceived in both types of sources. The second section reviews the issues related to the aftermath of suicide by adopting the same interdisciplinary and synthetic approach. By consulting various theological, juristic and psychological sources, the author discusses issues encompassing how committing suicide

would affect the religio-moral status of the deceased and the obligations of the suicide's survivors towards him/her, including funerary rituals. In addition, he discussed the psychological needs of the survivors.

In "Limits to Personal Autonomy in Islamic Bioethical Deliberations on End-of-Life Issues in Light of the Debate on Euthanasia," Ayman Shabana explains that the "old" concept of self-murder, suicide, has undergone considerable shifts and revisions after the modern biomedical revolution. A distinct and technical term, viz., "euthanasia," was coined to frame discussions on the possibility of intentionally ending the life of a terminal patient as the last resort to put an end to one's suffering. Thanks to modern advances in biomedical sciences, it is claimed that the dying process would be as painless as possible. The newly introduced term is indicative of not only linguistic modifications, but more importantly, of changes in the medical, philosophical and moral landscape. Besides the impact of modern medical advances, no one can deny the parallel influence of the concept of autonomy, which plays a central role in modern philosophical and bioethical deliberations. Against this background, the chapter provides an analytical overview of the modern Islamic juristic discussions on the concept of euthanasia, in its active and passive forms, and situates these discussions within the context of classical normative discussions on "old" concepts like self-murder and suicide. The author argues for a nuanced approach where not all forms of autonomy are necessarily incompatible with the Islamic religio-moral system and that not all types of euthanasia are indiscriminately prohibited.

The fourth and fifth chapters included in this part address two of the leading EoLC issues, namely life-sustaining treatments (LSTs) and artificial nutrition and hydration (ANH). In "An Islamic Bioethical Framework for Withholding and Withdrawing Life-Sustaining Treatment," Rifaqat Rashid argues that improving the contemporary Islamic bioethical discourse on LSTs necessitates widening the narrow scope of discussions on the religious obligations assigned to healthcare providers, patients and/or their family to include a more nuanced understanding of "futility." This would eventually clarify *when* foregoing LSTs would be morally justified from an Islamic perspective. The proposed nuanced approach is premised on developing quantitative and qualitative evaluations of life. This can be achieved by prioritising the goal of serving the patients' best interests and incorporating the principle of removing harm to oneself and to others. Concurrently, the broad scope of harm that includes both physical and non-physical forms, e.g., violating bodily dignity and loss of benefit to afterlife, should also be taken into consideration. In order to enhance the applicability of the proposed approach, Rashid also explores specific clinical situations to show when forgoing the LSTs would be permissible or prohibited.

In “Artificial Nutrition and Hydration at the Terminal Stage of Dementia from an Islamic Perspective,” Hadil Lababidi focuses on dementia patients and examines how introducing modern forms of medically-assisted nutrition and hydration, e.g., through a gastrostomy tube or a nasogastric tube, raises complex ethical questions in the EoLC context. The chapter sets the scene by introducing the medical and technical aspects of the main disease discussed in the chapter, dementia, and the procedures employed to feed patients with such a life-limiting and life-threatening disease, viz., artificial nutrition and hydration (ANH). The chapter further focuses on the Islamic perspectives on ANH, especially with relevance to the cases of patients who are at the terminal stage of dementia. By reviewing the diverse perspectives on ANH within the contemporary Islamic bioethical deliberations, Lababidi shows how classical concepts formed parts of this modern discourse, e.g., the “duty to feed,” the higher objectives of Shari‘a (*maqāṣid al-Shari‘a*), and the case of killing detainees by depriving them from eating and drinking, or the so-called *qatl al-ṣabr*, which was frequently discussed in the early works of Islamic jurisprudence. The author concludes her analysis of opposing positions by calling for a nuanced approach that differentiates between different uses of ANH in various contexts. For instance, the short-term use of ANH would be morally justified in the event that a dementia patient loses their consciousness as a result of falling into a coma. On the other hand, forgoing ANH can be justified in the terminal stage of dementia when two or more physicians confirm that harms outweigh benefits and the patient or the relatives agree with the physicians’ recommendation.

The last chapter in this volume “Child Loss in Early Pregnancy: A Balancing Exercise between Islamic Legal Thinking and Life’s Challenge” is by Beate Anam. The chapter serves as an example that demonstrates the need to enrich the EoLC discourse by engaging some of the underrepresented voices in Islamic bioethical deliberations. In her study, Anam engages with Muslim parents, midwives, and grief counsellors to explore how the emotionally overwhelming phenomenon of spontaneous miscarriage is actually perceived and experienced by Muslims. She unfolds and analyses the dilemmas of Muslim parents, who experienced spontaneous miscarriage, by trying to balance between honouring the ethical norms of their religion, on one hand, and providing their miscarried child with the most dignified EoLC that they can afford, on the other. The chapter also touches upon the question of religious authority for Muslims in Europe and how adopting hard-line positions that ignore the diversity of perspectives within the Islamic tradition can create difficulties for such parents and obstruct paths towards an efficient religiously motivated bereavement counselling.

Indeed, we believe that the Islamic bioethical discourse in general would greatly benefit from more studies that employ the tools and methodologies of social sciences to examine similarities, differences and discrepancies in perceiving the related Islamic moral world, as theorised by religious scholars and experienced by Muslim individuals and societies.

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