**Call for Research Papers**

**End-of-Life Care (EoLC) and the Islamic Moral Tradition**
**20-22 October 2020, Qatar**

**Background Paper**

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## Background

The idea of this seminar was developed while working on the published study *Palliative Care and Islamic Ethics: Exploring Key Issues and Best Practice*,[1] which was presented during the 2018 World Innovative Summit for Health (WISH), held in Qatar. After concluding this study, it became clear that large-scale and interdisciplinary research is still needed. Interested applicants are encouraged to review this study to obtain more background information. However, we stress that this seminar is aimed to be an extension of this study, and other relevant published works, rather than replicating earlier studies or paraphrasing their results.

Besides specialists in Islamic Studies, Ethics and Bioethics, we also encourage researchers with expertise in social sciences and legal studies to examine the questions outlined in this Background Paper from the perspectives of their own fields.

## Keywords

*Adab*, bereavement, death, dying, eschatology, *ḥisba*, interdisciplinarity, Islamic jurisprudence and legal theory, Islamic philosophy, Islamic theology, law, legal studies, Muslim patients, palliative care, social sciences, Sufism

[1] The English version of the study is available via think link and the Arabic version via this link.

## (A) Broad Scope

End-of-Life Care (below, EoLC) is to be approached in this seminar as a rich and complex concept, whose scope would go beyond palliative care. EoLC, we argue, relates not only to theorizing and philosophizing about death, but also about perceiving what life is and should be, because both life and death remain inseparable in many aspects.

Additionally, modern biomedical technologies managed to revolutionize the EoLC in many aspects. The dying process can now be "engineered" by managing the accompanying physical symptoms or by "prolonging/hastening" death itself. Such interventions questioned and problematized long-established understandings of key moral concepts, such as good life, quality of life, pain, suffering, good death, appropriate death, dying well, etc.

We are looking for papers that will seriously and critically consider this broad scope of EoLC and the interrelatedness between death and life on one hand, and medicalization/technologization of the dying process and the related moral concepts and values on the other hand.

## (B) Key Questions

The board question of the seminar reads: How should the multifaceted EoLC moral questions be addressed from interdisciplinary perspectives within the Islamic tradition?

In this section, we identify some of these key EoLC moral questions, triggered or intensified by the technologization of death, under distinct headings, so that they can be of help for interested researchers while preparing their submissions for the seminar.

- **Thanatophobia** (excessive fear of death)

The shift from the *natural moment* to the *technologized process* of death can create various forms and degrees of death anxiety, or thanatophobia. Related questions here include: How can EoLC teams optimally address the (terminal) patients' fears of nothingness, losing loved ones and possible divine punishment afterwards? Does the patient actually fear death, although he/she never died before, or does this fear express deeper concerns related to expected pains from deteriorating diseases that modern technologies may not be able to mitigate? Do they regret what one has (not) done in life before, anticipating divine punishment in the hereafter, etc.?

- **Medical (Non-) Intervention**

EoLC is characterized by going beyond the routine medical interventions and employing the so-called "heroic" or "extraordinary" measures. Such measures include Life-Sustaining Treatments (LSTs), like using ventilators for patients who cannot do natural breathing, cardiopulmonary resuscitation (CPR) to assist the heart keep beating, etc. LSTs are quite expensive and are usually employed as part of life-keeping measures rather than curing diseases. Further, the health condition of the (terminal) patient is sometimes so poor that physicians would question the likelihood of these extraordinary measures to effectuate a beneficial outcome and, thus, would rather judge some cases as medical futility.

Such situations raise a wide range of ethical questions, including: How should the goals of EoLC be determined and prioritized, e.g. treating diseases, saving life, keeping someone alive irrespective of the quality of this life? Is there a type of life whose quality is (not) worth saving by employing extraordinary measures? How to manage the fair allocation of such scarce resources? When would medical non-intervention, morally speaking, be the better course of action? How should the boundaries between morally significant dichotomies be demarcated, e.g., ordinary vs. extraordinary measures, withholding vs. withdrawing these measures, and natural vs. unnatural death? What are the criteria to judge a certain case as futile and who has the authority to make this judgement? Would Artificial Nutrition and Hydration (ANH) fall within the scope of LSTs or should it be classified within the category of basic needs of life that should always be given to the patient?

Additionally, EoLC usually involves administering analgesics and palliative sedation, which is meant to reduce the patient's pain. Despite this benefit, such measures also reduce or remove the patient's awareness, which can be considered a harm from social and religious perspectives. They may also entail the risk of 'hastening' death – coming closer, in the eyes of some ethicists, to 'euthanasia in disguise'. The moral questions revolving around the mechanisms of harm-benefit assessment in this context are usually analyzed through the lens of the moral principle "Double Effect (DE)".

- **Beyond Clinical Care**

EoLC specialists stress the significance of addressing the needs of the "whole person" rather the those of the "patient" only. The main thesis here is that different patients may have similar health conditions with equally painful diseases, but the severity of feeling pain (viz., suffering) and quality of life would considerably vary, depending on non-clinical and non-physical factors. Thus, a holistic EoLC plan should also consider the emotional, social and spiritual aspects. Spirituality in this context does not necessarily mean religious aspects only, but would comprise the complex web of relationships that gives coherence to one's life, including relationships with ourselves, with significant others, with groups and communities, and with God. Further, the EoLC team frequently deal with theodical questions that their patients and family members struggle with, e.g., What is the wisdom behind their pains? Does God care about them and their suffering, and if yes, how? What would this overwhelming experience tell these patients about their fate in the hereafter? The way these questions are addressed usually have great impact on the patients' and their families' (in)ability to cope with their difficult situations.

Some of the key questions in this regard would also include: How should the EoLC plan comprise spiritual components to assist the patient and family in finding meaning and purpose in the remainder of the patient's life and the prospective dying process? How should the EoLC team facilitate and frame discussions about beliefs in what happens after death? How can EoLC holistic plans help the survivors cope with the patient's (approaching) death and associated grief, mourning and bereavement? How can the patient's and family's intense feelings and experiences be transformed into a catalyst for spiritual growth?

- **Moral agency**

Many of the EoLC complexities and questions intersect with the concept of moral agency. For instance, how far can/should support be provided to empower the patients to identify and prioritize their own values and to take decisions in alignment therewith? Which criteria should be adopted to measure the presence/absence of moral agency in an EoLC setting and how would this affect the perception of the patient's autonomy and the whole process of informed consent? Would these criteria differ from one situation to another, e.g. decisions about withholding/withdrawing certain LSTCs vs. enrolling the (dying) patient in a research trial? Who should have the right to decide on behalf of the incapacitated patients? How should the EoLC team proceed when there is more than one person (e.g., patient's family members) who disagree with each other about what should be done? What is actually the moral obligation of the assigned guardian; trying to reach the right decision according to his/her own convictions, or trying to envisage what the patient would have preferred in certain scenarios, irrespective of the guardian's convictions?

- **Communication Issues**

Various researchers consider communication the *sine qua non* of EoLC and that effective communication among the involved stakeholders, especially the patient, family and healthcare personnel, is key to provide quality and ethical EoLC.

The EoLC context is usually loaded with distressing news which can be quite sensitive and stressful for the patient and family. While communicating such news, the EoLC team find themselves divided between conflicting values that cannot be equally cherished, e.g. how to strike balance between respecting the value of truthfulness, by relaying bad news, on one hand and the virtue of compassion, by not offending the patient and his/her family, on the other hand? What should the EoLC team do if the patient's family insist that the patient should not know (all) information about his/her health condition, and what if family members disagreed among themselves on this point? How should the moral worlds of each stakeholder be explained and considered to facilitate the communication process (e.g., the physician feels committed to conveying accurate information about the approaching death, whereas the patient and/or family may feel that the physician is acting like God who can decide the moment of someone's death)?

## (C) Interdisciplinary Approaches

In this section, we provide an overview of the scholarly disciplines and genres of sources within the Islamic tradition that can contribute to the modern EoLC moral deliberations, especially the ones outlined in Section (B) above.

### Death and Afterlife Genre

To start with, researchers can consult the genre of works which focused on eschatological issues related to dying, death and afterlife. As examples, one can refer to the relevant works of al-Ḥārith al-Muḥāsibī (d. 243/857), Abū Dawūd (d. 275/889) Ibn Abī al-Dunyā (d. 281/894), al-Bayhaqī (d. 485/1066), al-Ghazālī (d. 505/111), al-Qurṭubī (d. 671/1273), Ibn al-Qayyim (d. 751/1350) and Ibn Rajab (d. 795/1393). Besides presenting an extended repertoire of the relevant Qur'anic verses and Prophetic traditions, theological concepts like *ajal* (the fixed term set by God for each one's death), the nature of death and comes after, this genre can also be of help in addressing the questions under the heading "Thanatophobia" above.

### Theology

Within the broad theme of *samʿiyyāt* (viz., matters to be known, primarily or exclusively, through revelation), theological works can help the researchers address some of the questions under the heading "Thanatophobia" above. Additionally, works in this discipline include rich discussions on theodicy. Under headings like "causing pain for children (*īlām al-aṭfāl*)", many theologians from different schools, including Abū al-Ḥasan al-Ashʿarī (d. 324/936), al-Qāḍī ʿAbd al-Jabbār (d. 935/1025), ʿAbd al-Qāhir al-Baghdādī (d. 429/1037), al-Juwaynī(d. 478/1085) and al-Zamakhsharī (d.538/1144), showed the diversity of theological interpretations in this regard. These discussions are with paramount significance for the EoLC theodical questions that both patients and their families would grapple with, as outlined above under the heading "Beyond Clinical Care".

### Philosophy

Many Muslim philosophers presented insightful analyses for the interplay of life and death and how both human body and soul would play a role therein. These insights can be of added value in addressing the overarching EoLC moral questions. Some philosophical treaties, like *Hayy Ibn Yaqẓān*, where death was depicted as one of the first lessons of metaphysics, provided significant and thought-provoking ideas about the meaning of dying and death for a living person. Some philosophers also wrote about their own narratives of losing their loved ones, like Abū al-ʿAlāʾ al-Maʿarrī (d. 1057). Additionally, the phenomenon of death anxiety (*al-khawf min al-mawt*) was addressed by various Muslim philosophers and scholars, e.g. al-Kindī (d. 873), Miskawayh (d. 1030), Ibn Sīna (d. 1037) and Ibn Ḥazm (d. 1064).

**Jurisprudence and Legal Theory (*Fiqh & Uṣūl*)**

Almost all *fiqh* manuals have a distinct chapter entitled *al-janāʾiz* (lit. funerals or funerary practices), which provide important information for Muslim patients and families who ask how to frame their response to the tragedy of death within the parameters of their religious normativity. Additionally, both classical and modern *fiqh* works include rich discussions, dispersed throughout other chapters and distinct works, with relevance to many of the questions outlined above, especially those under the heading "Medical (Non)-Intervention".

Works on Islamic legal theory (*uṣūl al-fiqh*) provide expansive discussions on key themes like *taklīf* (obligation) and *ahliyya* (capacity), which are of relevance to some of the questions outlined under the heading "Moral Agency". In the age of modern nation state, the legal and judiciary systems of healthcare in the Muslim world also developed their own frameworks that largely determine how these concepts should be interpreted in the EoLC context.

**Sufism**

For the set of questions subsumed under the heading "Beyond Clinical Care", Sufi literature gives access to the views of Muslim scholars who explain how disciplining one's psyche (*riyāḍat al-nafs*) can be instrumental for making the believer ready to face and overcome difficulties in life, including death itself. In their discussions of the spiritual stations and states that God's servant or the wayfarer (*al-sāʾir*) goes through, Sufi scholars touched upon various relevant issues, e.g. the station of intense yearning (*shawq*) to the Beloved, viz. God, esp. their reference to the concept of anxiety (*qalaq*), and the station of contentment and satisfaction (*al-riḍā*). Additionally, Sufi literature also elaborated on the concept of "death before death", whose actualization would eventually save the person from the agonies of real and unavoidable death and what comes thereafter.

***Tasliya* (consolation/solace) Genre**

For the aforementioned questions related to grief, mourning and bereavement under the heading "Beyond Clinical Care", there is a great number of consolation (*tasliya*) treatises, mainly written for bereaved parents, including those written by Ibn Khalaf al-Ḍimyāṭī (d. 705/1305), Ibn Abī Ḥajala (d. 776/1375), Abū ʿAbdullāh al-Manbijī (d. 1383), al-Sakhāwī (d. 1497) and al-Suyūṭī (d. 1505). Some of these works gave detailed proposals for psychological support that researchers can use and build upon to develop counseling mechanisms for the EoLC context of our today's world.

**Etiquettes of the Physician**

The works which detailed the proper *adab* (code of conduct or etiquettes) that a virtuous physician should stick to, provide rich information with direct relevance to the set of questions delineated under the heading "Communication Issues". Representative examples of this genre include the seminal works written by the physicians al-Ruhāwī, who lived in the third/ninth century, and Abū Bakr al-Rāzī (d. *ca* 313/925). Additionally, many of the writings on regulating the work of various professionals, including physicians, (*ḥisba*) touched upon similar issues, such as the *ḥisba* works of al-Māwardī (d. 450/1058), al-Shayrazī (d. 589/1193), Ibn al-Rifʿa (d. 645/1247), Ibn al-Ḥāj (d. 737/1336) and many others.

The classical *adab*-based approaches were updated or modernized by contemporary writings that tried to provide modern versions of *adab al-ṭabīb*. The works of physicians like Muḥammad ʿAlī al-Bār and religious scholars like ʿAbd al-Sattār Abū Ghudda serve as examples. The *ḥisba*-based approaches were modified or completely replaced by the legally binding professional codes developed by Ministries of Health or other assigned institutions in the Muslim world.

## (D) Selection Criteria

The suggested questions outlined above and the proposed scholarly disciplines to engage with are not comprehensive. Thus, researchers can always address other questions and engage other disciplines, as long as the submitted papers pay attention to the following criteria:

- The paper falls within the scope of the seminar, as explained in Section (A) "Broad Scope", and address some of the EoLC moral questions, as outlined in Section (B) "Key Questions", by engaging one or more of the scholarly disciplines illustrated in Section (C) "Interdisciplinary Approaches", including social sciences, legal studies or other relevant fields.
- The paper shows full and critical awareness of previous studies with relevance to its key questions. The submitted paper is meant to go beyond published studies rather than replicating their purport or paraphrasing their results.
- The paper explores new research frontiers, provides rigorous and in-depth analysis of the material it deals with in a way that leads to producing scholarly knowledge with added value to the addressed topic.
- All submitted abstracts and full papers will be evaluated by an academic Review Committee whose members will collectively decide which submissions are accepted/rejected.

## Practical Information & Deadlines

Prospective applicants are kindly requested to send:

(a) An abstract (300-500 words), describing the research's core ideas, main and sub-questions, and how they will be addressed in the light of this Background Paper, and

(b) A brief biography (max. 500 words) outlining the applicant's academic background, main research interests and key publications.

Authors whose abstracts are accepted will receive an invitation to send their full papers (between 7,000 and 9,000 words) within the deadline specified below.

**Languages**

Submissions (abstracts, bios and full papers) can be written in either **English or Arabic**.

**Plan of the Peer-Reviewed Publication with Brill:**

After the seminar, the full proceedings will undergo a double-blind review process. The papers which will successfully go through this process will be published as part of a thematic issue in the peer-reviewed *Journal of Islamic Ethics (JIE)* and/or an edited volume in the peer-reviewed book-series *Studies in Islamic Ethics*, both published by Brill.

**Benefits**

CILE will offer the authors of accepted papers the following:

- Peer-reviewed publication
- Cover of the costs of making the publication available via open access.
- Travel and accommodation costs during the three days of the seminar.
- Simultaneous Arabic-English translation throughout the seminar.

**Important Dates:**

- **May 5, 2020**: Deadline for receiving abstracts and bios.

- **May 15, 2020**: Authors whose abstracts are accepted will be notified and invited to write the full papers.
- **August 10, 2020**: Deadline for receiving full papers.
- September 10, 2020: Authors whose papers are accepted will be notified.
- **October20-22, 2020**: The proceedings of the seminar
- December 01, 2020: Deadline for submitting a revised version of the post-seminar full papers, based on the remarks raised by the Review Committee and the deliberations during the seminar.

**Contact Us:**

Submissions must be sent to bioethics2020@cilecenter.org. *Please note that only submissions sent to this e-mail will be considered and evaluated.*

For any inquiries about this call-for-papers, or about the accompanying Background Paper, please contact Dr. Mohammed Ghaly mghaly@hbku.edu.qa, who directs the CILE research unit 'Islam and Biomedical Ethics'.

For inquiries about the *Journal of Islamic Ethics* or the book-series *Studies in Islamic Ethics*, please contact jie@brill.com or visit https://www.editorialmanager.com/JIE/default.aspx