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COMMENTARY

The evolving landscape of end-of-life care in Saudi Arabia: A socio-cultural, religious and legal perspective

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Abstract

The increase in life expectancy over the last century has brought with it new challenges of providing quality care towards end-of-life. Saudi Arabia has embraced this new challenge and incorporated it within its governing Islamic principles. The country has invested heavily in building the necessary legislative framework and infrastructural support systems to not only enable provision of palliative care but also improve the quality of end-of-life care. Saudi Arabia's commitment to enhancing end-of-life care, aligned with its Vision 2030, reflects a dedication to providing comprehensive, compassionate support to individuals facing life-limiting illnesses and to their families. The country has found innovative local solutions in order to address the challenges unique to its population. It has made significant progress in recognising the importance of palliative care and addressing the cultural, legal, and ethical aspects of end-of-life care appropriate to its ethos.

Keyword: *end-of-life care, palliative care, vision 2030*

Introduction

Life expectancy has increased worldwide over the last few decades. During the years 1960 to 2021, life expectancy in Saudi Arabia has increased from 47.50 to 78.77 years for females and 44.48 to 75.59 years for males against a world average of 53 to 74 years for females and 49 to 70 years for males [1]. This advancement comes along with considerable new clinical, ethical, socio-cultural, legal, and economic challenges to the values and goals of patient care. One important and much discussed consequence of this increased life expectancy is that it can, at times, be construed as delaying the dying process as opposed to prolonging life [2]. End-of-life care (EoLC) is care given in the period leading up to death, when it is acknowledged by all involved that death is inevitable [3]. The main aim is to address symptoms such as physical pain, and psychosocial and spiritual issues that impact patients and their families' quality of life [4]. In this article, we explore how the services have evolved over the years and how the country plans to take this forward.

While palliative care (PC) is not synonymous with end-of-life care, it does encompass the end-of-life care principles towards the later stages when death is imminent. Palliative care service in Saudi Arabia formally began over three decades ago. Earlier, this service was primarily provided by healthcare professionals with special interest, volunteers and non-governmental organisations (NGOs) [5]. The specialty received much needed attention and direction since the Ministry of Health launched the PC/Last Phase Initiative as part of the Transformation of Healthcare — Vision 2030, in 2016 [6, 7]. Vision 2030 is a Saudi government-led blueprint that plans to diversify its economy, improve public engagement and quality of life, and evolve into a vibrant society, and has been driven largely by the vision of the ruling monarchy [6, 7].

Islamic viewpoint of illness and death

Islam is the predominant religion of Saudi Arabia and its legal and ethical principles related to End of Life (EoL) are also rooted in Islamic principles [6, 8]. A brief overview of the Islamic philosophy on illness and death is warranted to understand the rationale behind some of the legal positions in Saudi Arabia.

"Death", as described in medical parlance, is viewed in Islam as a transition point. Initially, the human being was with God. (S)he is then given life and brought to earth. After the earthly existence, ie, death, the soul is returned to God. Human beings are then brought back to eternal life. The Holy Quran states that the purpose of the "earthly existence is to worship God" [9]. Islam views illness as a trial or a test of faith from God and not necessarily as a punishment [11, 12]. Suffering from illnesses can be an opportunity for expiation of one's sins and an atonement for the shortcomings of "earthly existence". At the same time, Muslims are obligated to seek treatment and may not terminate life [12]. Summation of the deeds of earthly existence determines the final predisposition in the everlasting second life [13]. The ethical dilemmas that a Muslim family faces when their loved ones are in the final stages of their life should be viewed with this basic understanding of Islam's viewpoint regarding illness and death.

Islamic principles and their interface with modern ethics and law

A short explanation of the relevant Arabic terms is warranted here. *Shariah* refers to the normative religious law of Islam with the *Qur'an* (the religious text that Muslims believe to be divinely revealed) and the *Sunnah* (the sayings, acts and approvals of Prophet Muhammad, the final Messenger of Islam) as its sources. Islamic jurisprudence (*Fiqh*) engages in understanding of these texts and formulating rules and rulings to cover all human activity,

including new issues that humans face as society evolves. Those trained to provide religious rulings based on *Fiqh* principles are called Islamic jurists or *faqih* and the ruling is called *fatwa* [14].

Fatwas address specific issues relevant to a particular place and time, so their applicability is limited by both location and context. The legal enforceability of *fatwas* varies depending on the country's legal system. While there is a single unified body in Saudi Arabia that issues *fatwas,* making them legally binding, in a country like India, *fatwas* are issued by numerous religious authorities and have limited legal scope. While the principles of deriving Islamic jurisprudence are beyond the scope of this article, the overarching objectives of *Shariah* can be summarised under the headings: (1) Preservation of Faith (*di' n*); 2) Preservation of Life (*al-nafs*); (3) Preservation of Mind (*al-'aql*); (4) Preservation of Progeny (*al-nasl*); (5) Preservation of Honour (*al-irdh*); and 6) Preservation of Property (*al-ma*) [12].

Although, the Islamic discourse on modern bioethics can be traced back to the latter half of the 20th century, rulings on some of the contemporary issues resulting from the advancements of modern medicine, like withdrawal and withholding of treatment, have not reached consensus among Muslim jurists. One of the earliest Islamic conferences on bioethics, held in Kuwait in 1981, concluded that "the treatment of a patient can be terminated if a team of medical experts or a medical committee involved in the management of such patient are satisfied that the continuation of treatment would be futile or useless."[15] It further states that "treatment of patients whose condition has been confirmed to be useless by the medical committee should not be commenced" [15].

Saudi law permits withdrawal of futile and disproportionate treatment on the basis of the consent of the immediate family members who act on the professional advice of the physician in charge of the case or, as the Saudi *Fatwa* implies, it should be a clear medical decision by at least three treating physicians. The *fatwa* translates as follows

> *If resuscitation of the heart and lungs will be ineffective and inappropriate in a specific case, according to the medical opinion of three trustworthy specialist doctors, there is no need to resuscitate. No consideration should be given to the opinion of the patient's family as to whether or not resuscitation should be applied, because this is not their area of expertise.* [16]

If there is conflict among the physicians in the decision-making process, it will be referred to the departmental chairperson or medical director. Conflict between family and physicians regarding EoL decisions is first referred to the administration which then arranges a multidisciplinary ethics committee meeting to attempt to resolve the issue. If the conflict still persists, the family are given the option to transfer to another healthcare facility [17]. Institutions are empowered with varying degrees of flexibility that allows the Do Not Resuscitate (DNR) orders to be modified to suit individual patient needs. For example, a patient may not be fit for intubation or cardiopulmonary resuscitation, but (s)he can be a candidate for a chest drain to provide symptomatic relief or be considered for non-invasive ventilation or blood pressure support while giving time for antibiotics to work. DNR discussions are multidisciplinary in nature with incorporation of social workers and patient relation representatives to address the needs of patients and family. Saudi law upholds a legally competent person's informed refusal of treatment, or a living will, as valid [14]. While active euthanasia, specific positive actions taken to end a patient's life, is clearly considered illegal under Saudi law, the extent of the right to passive euthanasia is not clearly elucidated [18].

Evolution of policies, programmes and infrastructure

In the pre-modern era, the responsibility for caring for the dying typically fell upon families, with most deaths occurring at home [19]. With the increasing penetration of modern medical infrastructure and facilities in the latter half of the previous century, the absence of adequate home-care services resulted in frequent hospitalisations, prolonged stays, and deaths within hospital settings, with less than ideal facilities for the increasingly ageing population. To address this issue, Saudi Arabia has made substantial investments in the field of EoLC.

Although, the Saudi Home Health Care Service was established in 1980, EoLC was first implemented in the country in 1992 [8, 20]. The first hospice facility of the country was founded at King Fahad Medical City in Riyadh in 1995 [8]. In 2013, the Saudi Society of Palliative Care was launched under the auspices of the Saudi Commission for Health Specialties. Its mission is to excel in promoting high-quality PC, relieving suffering, and enhancing the quality of life for patients and families facing complex issues associated with life-threatening conditions [21]. Palliative care services are provided free to all residents in the country, regardless of nationality. A Master's programme in spiritual care within PC was introduced in 2015 in the Kingdom [8, 22]. The National Palliative Care Program, established by the Ministry of Health in 2016, aims to enhance the quality of life for individuals confronting life-limiting illnesses, and their families. The national policy for initiating and implementing DNR decisions, with the approval from His Excellency, the Grand Mufti of Saudi Arabia, was formulated in 2017. It explains and provides a legal framework not only for DNR decisions, but also for concepts like limited escalation, withholding and withdrawing of care. It clearly lays down rights and responsibilities of physician and family and is extensively used in clinical practice in the country [17, 23, 24]. The Saudi EoLC guidelines and the Saudi Palliative Care National Clinical Guidelines 2019, specify treatment options for effectively managing symptoms in these patients [25, 26]. To further bolster efforts in EoLC, the Ministry of Health (MoH) has instituted regulations and policies, including the Bill of Rights in 2021 [27]. This document delineates the rights of patients and their caregivers concerning the

provision of high-quality care during their EoL journey. It underscores the significance of informed consent and the right to decline treatment.

At present, the Kingdom hosts 15 PC centres across various regions, including six in Riyadh, two in Jeddah, two in the East Province, one in the South Area, and one in the North Zone. Among these, six are training centres that have received accreditation from the Saudi Commission for Health Specialties. Furthermore, the country has over 50 qualified consultants specialising in PC. Palliative care is included in the curricula of undergraduate programmes for medicine and nursing. The Saudi Home Health Care Service currently includes PC among the 13 health services it offers [20, 28].

As part of Vision 2030, the MoH has released a transformative strategy document for the healthcare sector. This document outlines six critical questions that the patient-centred New Models of Care Program must address. One of these key questions is, "How will the system provide compassionate care during the final phase of life?" [29]. The envisioned approach to achieving this includes:

- offering support to patients and their families.
- expanding hospice care services.
- developing multidisciplinary healthcare teams.

Practical challenges in delivering EoLC

Symptom control

Assessing a country's opioid use has been used as an indicator of access to essential pain relief, particularly in countries with low consumption rates. Saudi Arabia's per capita opioid intake is approximately 1.24 Morphine Milligram Equivalents (MME) per 1000 inhabitants per day, which is significantly lower than the global average of 29.51 (17.85 to 48.79) [30]. The World Health Organization (WHO) ranks Saudi Arabia 128th out of 130 countries in terms of opiate use prevalence [31]. While cannabis offers an alternative option for pain relief with fewer effects on the respiratory system, it has not gained popularity among Muslims due to its double impact on consciousness. Muslims generally prefer to remain conscious until the very end to express their final testimony of faith to God [32]. From the Islamic perspective, managing medication-related sedation can be viewed from two angles. On the one hand, alleviating human suffering is seen as virtuous. On the other hand, maintaining a reasonable level of consciousness is highly important to allow for the observance of rites of worship for as long as possible before death. In terminally ill patients, achieving an optimal balance between symptom control and consciousness may be challenging. In such cases, the pros and cons should be discussed with the patient and family, who may prioritise maintaining consciousness over symptom relief [33].

Role of family, surrogate decision makers and EoL conversations

Cultural preferences in some families may lead them to prefer not fully informing a dying relative about their illness. While this is not an Islamic requirement, it is more common in Muslim families. In some cases, both the patient and their family may engage in a form of "mutual pretence", where both parties are aware of the patient's terminal condition but avoid discussing it openly. In Saudi Arabia, physicians can withhold information from the patient if they have a valid reason to believe that sharing the information would cause harm, impair management, or cause distress. In such cases, this should be documented in the patient's file, and consent should be obtained from the substitute decision maker (legal representative) [34].

Given the strong bonds within extended families, decision-makers may include brothers, uncles, and grandparents, as Saudi law does not specify a hierarchy of decision-makers. It is crucial to identify and involve decision-makers within the extended family when making important medical decisions like withholding, withdrawal and "not for escalation", including Do Not Attempt Cardio Pulmonary Resuscitation (DNACPR) decisions. In contrast to Western practices, the Arabic word for death, *mauth* or *mayyith,* is rarely used directly in conversation. Instead, it is customary to refer to death as the "Will of God". This reflects a cultural difference from Western teachings, where healthcare professionals may use the word "death" more directly if needed. Understanding these religious and cultural distinctions is essential for effectively conveying messages while respecting emotional sensibilities [32].

Final rites

Tayeb et al identified three critical domains in EoLC for dying Muslim patients [34]. The first domain involves religious preferences during the dying process, including having someone prompt the dying person to recite the Shahadah (the testimony of faith to God) as their final words, reciting chapters from the Holy Qur'an at the bedside, and positioning the patient to face the Kaaba at the Holy Mosque in Mecca. Some patients may wish to sip Zamzam water during their final hours. For those unable to drink, instilling a small amount of this water into the mouth via syringe is also acceptable. The second domain focuses on maintaining dignity in death, which includes ensuring cleanliness of the body and clothing from bodily fluids, closing the eyes and mouth of the deceased, and ensuring a natural appearance by removing external catheters and tubes. The third domain involves ensuring the well-being of surviving relatives, which is relevant to all individuals [34].

The Prophet Muhammad emphasised the importance of visiting the sick and providing moral support to both the

sick and their families [35,36]. As a result, Muslims often visit the sick in significant numbers, especially during the final stages of life. It is a practice that is accommodated, within reason, in Saudi healthcare settings, but may appear unusual to healthcare professionals from different backgrounds [32]. After death, Muslims are forbidden to cremate the dead body and it is customary for Muslims to be buried as soon as possible [37].

Conclusion

Saudi Arabia has made significant progress over the last few decades in providing comprehensive EoLC to its residents. The concerted efforts of the Saudi Health Council under the leadership of the government have contributed to the recognition and integration of DNAR and PC services into the healthcare system. While there is significant scope for improvement, the Kingdom's Vision 2030 has embarked upon a well-structured road map of sustained investment in education, infrastructure and capacity building to further advance PC and ensure that patients with life-limiting illnesses receive the support and comfort they deserve. Regular auditing and feedback from the end users and other stake holders would ensure continuing progress in the right direction for this much needed and ever-growing service to the community.

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COMMENTARY

Ethics and curricular competencies during a three-hour poetry workshop for health professionals

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Abstract

Poetry is a powerful tool to promote communication, develop insight and empathy, examine ethical issues, and challenge assumptions. We have been using poetry in health professions education for many years and wished to capture its impact on healthcare learners and professionals, with a focus on competencies essential to healthcare providers. A three-hour poetry workshop was conducted during the National Conference for Health Professions Educators, 2022, for volunteers from the health professions. Poems were curated beforehand to highlight ethics concepts, and social and structural healthcare barriers. Participant responses suggested that they connected with the struggles depicted, noticed ethical issues, and experienced empathy. Online feedback from participants after the workshop revealed that the poems motivated self-reflection, gave voice to feelings, and helped understand patient perspectives. Our findings suggest that integrating poetry into the curriculum can improve educational competencies, enhance understanding of illness, and facilitate creativity, reflective learning, and discussions on self-care and burnout.

Keywords: *poetry, communication, competency-based education, empathy, ethics.*

Introduction

Poetry reading has been found to foster engagement with one's own feelings and thoughts as well as with the feelings and thoughts of others [1]. Its use in medical education allows learners to bridge the gap between the theoretical teaching of empathy and learning by actually experiencing it. Poetry can cultivate students' critical thinking on socially relevant aspects of healthcare, challenge their assumptions, help them recognise ethical issues, and appreciate that there could be multiple perspectives [2,3]. It may also prevent provider cynicism, detachment, and burnout [1]. We are medical educators and proponents of the health humanities and have been using poetry in the classroom and during conference workshops. While we have received encouraging feedback from classroom learners [4], we were curious to explore how workshop participants viewed the modality. This article describes our experience with a three-hour poetry workshop for volunteers from the health professions. The data collected during the workshop, and later, from the feedback, was analysed to determine how poetry intersects with the ABCDE attributes (attitude, advocacy, behaviour, communication, diversity, ethics and empathy) of healthcare providers [5]; and also, how it could contribute to achieving curricular competencies [6,7].

The workshop

Fifteen participants [learners and teachers from the medical and nursing professions] volunteered for the poetry workshop at the National Conference on Health Professions Education (NCHPE) hosted at the Himalayan Institute of Medical Sciences (HIMS), Dehradun in October-November 2022.

The resource material comprised of poems curated by the authors beforehand to showcase ethics concepts like autonomy, care-giving, cultural barriers, decisional capacity, dementia, disability, discrimination, paternalism, patient perspectives, structural barriers, surrogate decision making, and triage; and poems brought to the workshop by participants.

Participant experiences were captured *during* the workshop as reactions to the poems (in writing, without identifying