JBIMA Journal of the British Islamic Medical Association

Ethics

Vol. 4 - No. 2 | April 2020 | www.jbima.com

Practical issues for the UK Muslim community facing death and bereavement during the COVID-19 Pandemic

Dr. Nadia Khan, *Consultant in Palliative Medicine, John Taylor Hospital, Birmingham*

Correspondence: *nadia.khan28@nhs.net*

Within the Islamic worldview, death is seen as a very natural part of the fragile human experience. It is a certainty that holds deep meaning and implications for how Muslims value and live their lives, and throws the relationship between Creator and His creation into sharp focus; "and do not call on any other god apart from God. There is no god but He. All things will perish save His magnificence. His is the judgement, and to Him will you be brought back in the end" (Holy Quran; 28:88).

And yet, the fear of death is deeply embedded within the human condition. Arguably, this lies at the heart of a modern Western culture that has been widely characterised as "death denying", as well as driving advances in medical science and technology that have led to a prolongation of life that was previously inconceivable more than 50 years ago. As a result, modern generations have become accustomed to the concealment of death and grief, and where it cannot be concealed, strive to exert a sense of autonomous certainty, choice and control, manifested in its extremity by the assisted dying movement but also in other approaches within modern death-related behaviours, practices and rituals.

The coronavirus pandemic has served to fundamentally challenge this carefully constructed house of cards, both for individuals and in the collective psyche of countries and the global community at large. The 21st century UK Muslim community must now face a highly uncertain situation of unexpected and rapid health deterioration, death, loss and bereavement on an unprecedented scale. Whilst contending with the resultant generated anxiety and fear, there is also a need to understand how we may be able to work with and adapt existing practical, psychological and social frameworks in order to face the particular challenges intrinsic to death and dying in a viral pandemic.

The COVID-19 pandemic will likely strain the UK health care system beyond its capacity, despite the mitigating action being undertaken by the government, and many people are expected to die as a result. It is argued that those people who will be unable to access long-sustaining health care have a right to expect high-quality palliative care[1]. However, several complex challenges exist for this.

The philosophy of palliative care strives to normalise death and promote a shared decision-making approach in planning for the type of care that is most appropriate for the end of life. However, in the context of a pandemic, an individual or collective family's ability to choose treatments or influence details of care, such as location or people present, may be significantly restricted as a result of resource availability, healthcare system logistical constraints and nature of the disease process itself. As the healthcare system becomes more stressed, well-recognised healthcare inequities that affect UK ethnic minority populations may well become more pronounced. Preexisting fears regarding barriers in access to life-sustaining treatments and discrimination in care, are likely to become amplified and impact on engagement with advance care planning measures such as do not resuscitate decisions. The lack of time to form therapeutic relationships and hold complex, nuanced communication with relatives is likely to compound the distress of a community that values collective familial decision-making and the default position of pursuing life-sustaining medical treatment, which is underpinned by a theological Islamic imperative. Muslim physicians may have an important role in bridging this highly consequential gap and drawing awareness of healthcare colleagues to proactively address concerns and issues, before potential breakdowns in trust and care relationships occur.

The requirement to isolate patients affected by COVID-19 is likely to have multiple, significant ramifications that are amplified for the UK Muslim population. Early anecdotal observations suggest that a disproportionately higher number of people from a black and ethnic minority population suffer worse outcomes[2] – biological and social determinants of health including overcrowding, socioeconomic inequalities and cultural behaviours have all been postulated. Communication barriers between elderly Muslim patients and stretched healthcare staff in hospital are likely to be compounded without the lack of family members to serve as translators and advocates. Healthcare staff will need to carefully consider how the

risks to early identification of medical complications, informed decision-making and emotional distress can be mitigated.

Social isolation in hospitals, juxtaposed with the unpredictable and often rapid decline in respiratory function, will unfortunately mean that individuals die alone. Hospital imams and chaplains, usually a source of comfort and spiritual support provision at the end of life, will need to review how such support may be provided in a way that can reach many more people whilst balancing the needs for service continuity. The inability to be present and care for a loved one in the last days of life, and enact the rites and rituals related to anticipated impending death such as Qur'an recitation at the bedside and encouraging final words to be the shahadah, will inevitably cause a great level of distress for younger Muslim family members and caregivers.

Whilst supporting a person deteriorating from COVID-19 to die at home may alleviate the above challenge, there are hurdles to contend with. Families consisting of 2nd or 3rd generations may not have previously cared for, or even experienced, family members approaching end of life. There may be a struggle with internalised, or community-held, perceptions that they are "giving up" or not discharging their duty of care owed by seeking hospital-based treatment. Fears around the use of comfort-care medication to relieve symptom distress remain prevalent- these center around concerns of over-sedation and a hastening of death, despite the established scholarly opinion that medication can be used to palliate symptoms causing harm in terminally unwell patient if given with such an intention and the lack of evidence that appropriately-used medication shortens life. These factors, alongside others, may contribute to the observation that Muslim communities tend to access less end of life care support from hospice services. A divergence in home end of life care uptake, and family satisfaction with support provided, may therefore become apparent between the Muslim ethnic minority communities and counterparts.

Death is, in part, a social construct – how the living make sense of death is a deeply social experience, shaped by cultural beliefs, language and ways of seeing the world, and norms that are interwoven within the interaction with others. Disruption of the collective rituals that form part of the meaning-making, and processing, of grief is in fact a disruption of a deep human connection that provides support, comfort and solace at a time where sadness and vulnerability are an overwhelming experience. The inability to come together for the burial preparation and janazah, and then subsequent gatherings for mourning and collective supplication, compounded by the closure of masaajid risks creating yet another dense layer of loss sensed by the Muslim community.

The practical challenges ahead are great, and many uncertainties lie in the weeks ahead around the consequences of the COVID-19 pandemic. What seems certain however is that Muslims in the UK will face shared loss and grief on an unprecedented level. In addition to high levels of compassion, patience and presence, Muslim healthcare professionals must aim to be emotionally and spiritually prepared for the requirement to give something of themselves above and beyond anything before– from the place where the noblest principles and duties of healer and Mu'min intersect.

References

1. Arya et al. Pandemic palliative care: beyond ventilators and saving lives. CMAJ 2020. doi: 10.1503/cmaj.200465; early-released March 31, 2020

2. ICNARC. Report on 2249 patients critically ill with COVID-19. https://www.icnarc.org/About/Latest-News/2020/04/04/Report-On-2249-Patients-Critically-Ill-With-Covid-19 (last accessed 6th April 2020)