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PERSPECTIVE

Exploring the Ethical Dilemmas in End-of-Life Care and the Concept of a Good Death in Bhutan

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Abstract

Buddhists, including the Bhutanese, value human life as rare and precious, and accept sickness, ageing and death as normal aspects of life. However, death and dying are subjects that evoke deep and disturbing emotions often characterised by denial related to high-tech medicalisation and its inspiring hope. Advanced medical interventions such as cardiopulmonary resuscitation are believed to interfere with the natural process of dying. However, some excessively pursue medical interventions in the hope of prolonging and preserving life, refusing its finitude. Healthcare workers are faced with increasing instances of ethical and moral dilemmas exacerbated by inadequate training and lack of proper understanding of the socio-cultural context on end-of-life care and to facilitate good death in Bhutan. We discuss these ethical dilemmas in providing quality end-of-life care and good death against the backdrop of rapidly changing social values and expectations.

Keywords Death · Palliative care · Elderly and terminally ill · Medical aid in dying · Compassion

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Introduction

Bhutan has a free healthcare system that is delivered through 48 hospitals and 184 primary health centres (Ministry of Health 2021). The country has achieved significant successes in public health indicators with crude death rates reduced from 7.1 in 2005 to 6.7 per 1000 population in 2017 and life expectancy increased from 32.4 in 1960 to 70.2 years in 2017 (Ministry of Health 2021). With economic modernisation, increasing urbanisation and high mobility of the populations, greater demands are placed on the modern health care system with increased hospital visits and a significant proportion of deaths occurring in hospitals. Healthcare workers are faced with increasing instances of ethical, moral and legal dilemmas in providing end-of-life care.

Bhutanese Concept of Life and Death

The concept around life and death in Bhutan is heavily influenced by the principles of Buddhism. Human life is regarded as rare and precious that gives the opportunity to practise Dharma or truths—a gateway to liberation from all sufferings and attain nirvana. Buddhists acknowledge sickness, ageing and death as normal aspects of life, as is suffering from karmic actions (Khyentse 2018). Nonetheless, the experience of death in family and friends continues to trigger a series of emotional, spiritual and social consequences that influence medical practices.

A peaceful death is greatly valued by people especially towards their end-of-life, and Buddhists claim that it is attainable through prior contemplation and practice of death and dying. At the time of death, some prefer extra-corporeal agents such as intravenous catheters, urinary catheters and nasogastric tubes removed while some deny medications. Some read Buddhist texts such as the *Bardo Thodrel*—the liberation in the intermediate state through hearing—to the dying person, believed to heighten his/her awareness and to enable a peaceful journey after death. Some invite Buddhist realised masters into the hospital to perform *phowa* (the transference of consciousness) to the dead to help take rebirth in the better realm (Khyentse 2018). For all these practices, a Buddhist master has an important role to play in times of death in the community and in the hospitals. Every community has a trained Buddhist master (known as *mishi* lama—the master who attends the dead) to guide the dead and the living in times of death. With an increasing number of deaths happening in hospitals, a trained Buddhist master (*menkhang lama*) is now appointed at the National Referral Hospital of Bhutan to cater to the needs of the dead and the dying person. Trained Buddhist masters from the district monastic centres or from the nearest monasteries attend to similar needs in other hospitals in Bhutan.

After the death of a person, the mortal remains are liable for decomposition and Buddhists commonly dispose of it through cremation, while some prefer sky burial. Buddhists view death as a mere transition to the next karmic phase of life through the successful transmigration of consciousness believed to happen within 49 days after the person is dead. Hence, for Buddhists, the period for special rituals and

prayers for the deceased lasts generally 49 days (Smith-Stoner 2005) followed by annual rituals to observe the memory of the deceased.

Ethical Conflicts in the Care of a Dying Patient in the Hospital Settings

With the availability of modern life-saving medical services that often give people an excessive hope for recovery, death once viewed natural has become medicalised, unacceptable, unwelcome, fuelling society's refusal to the finitude of life. The tussle between medical and social issues around health and illnesses, death and dying, often confronts healthcare providers and physicians with ethical dilemmas.

With the improvement in the socio-economic status and accessibility to transportation and ambulances, patients with deteriorating health conditions are referred through roads and airlifts to higher healthcare centres for better management. However, there are instances where patients have been referred from district to regional or national referral hospitals and the patients have died on the way inside the ambulances. The doctors often make such referrals facing the dilemma of holding the patient in a district hospital while the patient and family members expect a better level of care in the referred hospitals.

Besides, patients with irredeemable health conditions such as advanced cancer and terminal illnesses are referred outside the country with curative intentions at the cost of government expenditure instead of providing appropriate palliative care at home. When the government has not funded their medical travel, the families have spent their own money or usually garnered it through public donations. Seeking public donations is increasingly becoming a common strategy to raise money with many people contributing in an act of kindness to saving a person from dying. Millions of ngultrums are collected in a short span of time especially after online facilities for fund transfer have become easily available in the recent past. Nonetheless, there are instances where the patients have expired in hospitals in a foreign country, away from loved ones nearby and not having access to a Buddhist master to perform death rituals at the place of death. The accompanying family members are often faced with challenges in transporting the mortal remains back to Bhutan for the funeral rites.

A significant proportion of patients also perform religious pujas at their homes in hope of recovery via mitigation of karmic debts. This stems from the cultural notion that illness and debt result from past negative karmic actions and that "*rimdro* and *menchoe*" (religious pujas and medical treatment) must go hand in hand (Dorji and Melgaard 2018). However, from our clinical encounters, we find that many patients first perform pujas at home or visit monasteries to perform pujas and then only present the patient to hospitals. Such practices are common in both rural and urban areas. While chronic medical conditions can wait, we have encountered patients with acute appendicitis, bowel perforations, diabetic ketoacidosis, pneumonia, limb cellulitis, urinary tract infections, sepsis and limb paralysis presenting days after the initial onset of symptoms and signs. These social practices contribute to the first delay in presentation to hospitals and have direct connections with preventable deaths. There are other incidences where patients and family members have denied

or delayed life-saving surgeries or procedures as the patient's astrological parameters warrant waiting for an appropriate timing (Gyeltshen et al. 2021).

Concerning the critically ill patients on life support in intensive care units, there are instances where family members seek a second opinion on the options for terminal care and request for transfer of patients to centres outside the country in hope of preserving life. In such instances, family members lose time in trying to contact doctors and hospitals outside the country and put pressure on the critical care teams to preserve life at any cost. On the other hand, some family members opt for "Do Not Resuscitate" orders and deny invasive procedures for the dying patient trying to simulate a peaceful environment during death in a hospital.

To date in Bhutan, there is no policy on how to declare what legally constitutes brain death in cases of patients on life support with absent brainstem reflexes. Physicians perform an apnoea test in front of the patient's relatives to demonstrate a lack of spontaneous breathing and is re-connected to the ventilator. The situation is then discussed with the family members regarding the advance directives on "Do Not Attempt Resuscitation" in an event of a cardiac arrest, withholding or withdrawal of care, terminal weaning of care or removing life support. Often, family members give conflicting decisions exacerbating dilemmas to members of the healthcare team.

The above are some examples of common situations of ethical dilemmas in providing end-of-life care in hospital settings. It is generally accepted that when the patient is nearing end-of-life, it is not necessary to overcompensate by intervening much, and the mere presence with unconditional loving-kindness and caring attitude is enough for the dying person (DeLeo 2019). In most instances, however, the latter is often compromised amidst ethical dilemmas and healthcare professionals and the patient's family having differing views on what is good for the patient. This area of doctor-patient and doctor-patient-family relationship, the ethical dilemmas and its redressal in end-of-life care are not yet studied in Bhutan.

End-of-Life Care in Circumstances outside Healthcare Settings

There are unmet physical and psychological needs of patients and family members providing care for patients with chronic conditions such as cancer, chronic kidney disease, mental illness and dementia. Due to a lack of a robust and accessible palliative care system, civil society organisations such as the Bhutan Cancer Society and Bhutan Kidney Foundation have stepped in to perform social and palliative counselling services. In view of providing a better quality of care to such patients, it is timely for the launch of a palliative care programme to cater to the needs of patients and families including end-of-life care and decisions.

With the population of older adults on a steady rise (4.7% in 2005 and 5.9% in 2017) (National Statistics Bureau 2018), a number of cases of neglected older adults have been reported. Older adults with no family or social support are housed in elderly homes established through the *kidu* welfare system (a prerogative of the King) and is timely for the Elderly Care Programme of the Ministry of Health to address the needs including end-of-life care for older adults in such facilities.

Currently, Bhutan does not have any laws and policies on advance care planning for patients with chronic health conditions. This gap has consequently made end-of-life care an ambiguous area in terms of the immediate and long-term courses of actions to be taken by healthcare workers and the patient's family. The Inheritance Act 1980 covers written and oral wills with regard to properties (National Assembly of Bhutan 1980), but there are no other laws that cover health care issues such as advanced directives regarding making clinical decisions after a patient has become incapable of deciding for himself. There are no laws that specify durable attorney of health care, where a family member or a guardian is designated to make health-related and end-of-life decisions when an individual loses the capacity to decide for himself.

What can Facilitate a Good Death?

Bhutan is undergoing rapid socio-economic development and changes in the socio-cultural context of life and death. As the healthcare infrastructure expands and people have improved physical access to health, more deaths are expected to happen in hospitals than at homes. Religion and culture have a strong influence on people's belief in Bhutan and death is accepted as a part of life and living. However, what would constitute a good death in today's context has not yet been explored. We have provided anecdotal evidence of some of the ethical dilemmas around death and dying in hospitals in Bhutan—what would mean a correct response in one circumstance might not be correct in other settings. In our clinical practice, we have encountered many instances where family members were unhappy with the end-of-life care provided by the healthcare team.

How do healthcare teams respond in such instances of ethical dilemmas? From a cultural perspective, letting go of a precious human life through withholding or withdrawal of care is associated with sin akin to committing murder. For example, withdrawal of life support such as mechanical ventilation is equivalent to taking life away from a person. Performance of cardiopulmonary resuscitation at the time of death is believed to interfere with the natural process of dying that Buddhists care for the successful transmigration of consciousness to life after death. Thus, it is seen as destroying the sanctity of both life and death.

In our clinical experience, we have seen many healthcare professionals unprepared to handle such situations. Often, there are conflicts of views between members of a team or with specialists from other disciplines. There are differences in individual practices that are mostly influenced by the training (or lack of) that they have received. All of the doctors in Bhutan are trained in various colleges outside the country and there are variations in practices, some of which may not be culturally acceptable.

Before deaths became medicalised, deaths used to happen in homes surrounded by family and friends and often in the presence of the village lama or lay monks. Many of these lamas or monks practised Bhutanese Traditional Medicine that has a set of values, concepts and understandings almost all of which are influenced by Buddhist practices. Therefore, an integrated approach of ethical principles of biomedical sciences, socio-cultural influences and Buddhist philosophy can be adopted in providing end-of-life care and facilitating good death in hospitals in Bhutan. We recommend healthcare

professionals, thinkers, social workers, family members and Buddhist scholars to conduct collaborative studies and share their experiences. The Khesar Gyalpo University of Medical Sciences of Bhutan, the only medical university in the country, may adopt educational modules and train the health workers on the identification of ethical issues in patient care and explore a path for solutions.

Conclusion

In Bhutan, although many people value a peaceful and dignified death, patients able to say goodbye to their loved ones and good dying is often undermined in the current healthcare settings and is associated with many ethical dilemmas. It is timely to discuss in public space what constitutes quality end-of-life care and a good death and formulate policies governing such ethical issues. A wider participation of the whole-of-society is required in developing an end-of-life care package that is relevant to the socio-cultural context of Bhutan.

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