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THEME EDITORIAL

Healing and dying with dignity: Where does India stand?

SUNITA V S BANDEWAR, SANJAY NAGRAL

The articles in this special issue have emerged from work towards the sixth National Bioethics Conference entitled "Healing and dying with dignity: Ethical issues in palliative care, end-of-life care and euthanasia". These contributions from physicians and social scientists touch upon three closely linked concepts, and raise complex ethical issues that must be faced by patients and their families, as well as by healthcare providers.

Palliative care is a neglected issue in the Indian healthcare system, with few exceptions. The peer community – individuals, patients and their families, medical professionals, and lawyers – is sharply polarised in the discourse on the ethics of assisted dying or euthanasia in the Indian setting. The diversity of sociocultural contexts, philosophical traditions, and religious and faith systems adds to the complexity of this debate. Individual patients, their families and medical professionals must deal with either poorly equipped public healthcare or exorbitantly priced private healthcare largely driven by profit motives. Both these systems ignore people's palliative care needs. Patients facing end-of-life situations, as well as their providers, are ensnared in a web of ignorance, apathy and helplessness. Clinicians and institutions in such situations often prevaricate under the pretense that there is inadequate "legal" clarity. This leads to prolongation of futile treatment and hospitalisation with the attendant agony and financial burden, undermining the trust of patients and their families in the medical profession.

This issue presents five papers which together offer insights into the complexities of the subject from ethical, legal and medical perspectives against the backdrop of the Indian healthcare system and the entrenched inequities in peoples' access to healthcare.

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The authors of these essays have been part of the processes involved in shaping key policies, programmes and laws on these issues.

Jaywant (1) shares her experiences of interacting with patients during their last days in a private multi-specialty hospital setting. Her account and reflections point to how inadequate human and economic resources constrain the families caring for the terminally ill. The disabilities brought on by illness can force the dying into a position of complete dependence. Their quality of life can be so poor that they might actually prefer to leave this mortal world rather than linger on in a sub-human life, and the family might feel the same way. The helplessness of caregivers, who are generally family members, stems from extreme economic adversity as well as the insensitivity of the healthcare system. Jaywant's compelling narratives are an indictment of healthcare providers who prescribe futile procedures instead of helping families understand that treatment options are exhausted. This is because the legal environment in India has encouraged defensive healthcare practice, but also because of the culture of silence around death. The author underscores the fact that the needs of caregivers and family members feature nowhere in the discussion. She concludes by suggesting simple measures to partially address the appalling condition of palliative and end-of-life care. Will they be sufficient, helpful and implementable? This may be an area for empirical investigation.

Against this backdrop, Rajagopal (2) helps identify the systemic constraints which obstruct access to palliative care. He attributes this to a restrictive legal framework for the medical use of narcotics drugs and psychotropic substances, the paucity of healthcare professionals adequately trained in modern pain management science, and to the fact that "...palliative care is practically unknown in most parts of the country". (2: p 25) Major changes in recent times should improve the situation: morphine is included in the list of essential medicines by the World Health Organisation; the 'right to pain alleviation' is backed by various UN conventions to which India is a signatory; progressive amendments have been made to India's Narcotics, Drugs and Psychotropic Substances Act; and palliative care has been recognised as a medical specialty by the Medical Council of India (MCI). However, Rajagopal argues, more is needed for these changes to have an impact. He points out that palliative care is low cost, and suggests that "... a society which does not provide palliative care to the needy, does not have a moral right to consider euthanasia". (2: p 26) He underscores the role that healthcare professionals must play as advocates of palliative care, and spells out what they must demand from the MCI to ensure people's access to quality palliative care.

Gursahani and Mani (3) centre-stage the notion of dignity and individual autonomy in the context of end-of-life care, arguing that this falls within the very ambit of the Constitution of India. They highlight the fact that all except a small percentage of "sudden deaths" are predictable, giving individuals the opportunity to determine how they should be treated – or not treated – in their last days. However, conversations around death are considered taboo in India, despite the naturalisation of the notion of death in Indian philosophical traditions and various faith systems. Concepts and tools such as advance care planning, "do not resuscitate" orders and "living wills", which have largely been effective in the western world, have remained unexplored in the Indian context. Moreover, there is no legal guidance for healthcare providers regarding withdrawal of care except for persons declared brain dead, and in a persistent vegetative state -- the latter an outcome of public interest litigation motivated by the case of Aruna Shanbaug. They note the Supreme Court of India's recent order revoking the Rajasthan High court judgement making *Santhara*, or voluntary dying, illegal. Indeed, it is difficult to comprehend the contradictions in the judiciary's approach to individuals' right to make healthcare decisions for quality of life during their last days.

Gursahani and Mani argue for the enactment of a sound law in India that "...would enable the good doctor to give morally and ethically sound end-of-life and palliative care without fear of litigation." (3: p 34)

Shukla (4) brings out the ethical conundrums inherent in the notion of "passive euthanasia" which was made legal in India in 2011 in response to the case of Aruna Shanbaug. The author problematises the distinction made by the Supreme Court between active and passive euthanasia. She also notes the failure of the Supreme Court to adequately distinguish between active euthanasia which is viewed as killing and therefore immoral, and passive euthanasia, which is defined as withholding an intervention or withdrawing life support. The moral relevance of the patient's suffering has been neglected in the legal discourse on euthanasia in India. There is a need to look into the practical implications of legalising passive euthanasia. Her work demonstrates the obvious disengagement of the legal discourse on euthanasia from that of ethics.

The last paper (5) is another strong plea for legislative reform in India, locating the Indian scenario in the global context. Kishore, too, notes the restrictions in current laws that permit passive euthanasia and only after approval of the High Court. This precautionary approach is based on the risk that the law can be misused, given the vast vulnerable population in India. However, he stresses the need for better legislation, with safeguards to prevent abuse. The law is essential to honour individuals' right to self-determination and freedom from suffering, and the sanctity of life. Kishore traces discussions on the right to end one's life back to western philosophical traditions, commenting briefly on the core values in arguments for assisted dying, ranging from love and compassion to human dignity, rationality and equity.

The risks of misuse can be reduced if the law draws upon the experiences of other countries with similar legislation. Kishore's insights into the law in the Netherlands and in the state of Oregon in the USA, and his analysis of judicial decisions from around

the world on requests for assisted dying, offer a global perspective on the matter of legislating assisted dying. He touches upon the safeguards that have been enacted to prevent abuse of these laws, which can inform Indian legislative strategies. His list of questions on legislative reforms reminds us to be mindful of specific contexts. The judiciary can offer only temporary solutions; it cannot be a substitute for comprehensive and fine-tuned legislative strategies, he emphasises. In our assessment this fact has been vindicated by the current realities in India.

It may appear premature to focus on a discourse on end-of-life care in a country where the right to life and decent healthcare is still severely compromised. However with the rapid and widespread advance of market medicine and the availability of technology, the growing needs of palliation as well as withdrawal of care come up daily in the real world of clinical medicine. Moreover, the evolution of deceased donation has unfortunately been inextricably linked to the development of an end-of-life care philosophy in intensive care. The linking of organ donation with brain stem death in the Transplantation of Human Organs Act of 1994 has led to a bizarre situation: when families of brain dead patients give consent for organ donation, the organs are removed after which life support systems are withdrawn, but if the family does not consent to donation and asks for the ventilator to be disconnected, the request is turned down (6).

Collectively, these contributions point to the need for systematic empirical research that will inform policies, programmes, and legislative reforms on palliative care, end-of-life care and euthanasia. These enquiries should not only cover medico-legal aspects but also delve into sociocultural and religious perspectives, and the economic dimensions of the matter.

While empirical evidence and experiential knowledge from across the world are critical, they are not sufficient to formulate laws and policies sensitive to the Indian context. For example, it is evident that ignorance and misconceptions about palliative care as a concept and an obligation of the healthcare system are ubiquitous not only amongst the general public but also amongst healthcare professionals. The lack of availability of such care even at otherwise well-equipped hospitals, including cancer specialty centres, reflects the disengagement of healthcare practitioners from advances in medical science that could afford a better quality of life to the terminally ill. We must reflect on why medical and nursing education, healthcare professionals and the system as a whole is so apathetic towards human suffering. This apathy is at odds with the foundational principle, namely compassion, of medical and healthcare ethics. Similarly, the notion of dignity features prominently in discussions on this subject, as is evident in the contributions to this special issue. However, little is known as to what it may mean to people and how it should be translated into healthcare settings in the Indian context.

The situation calls for informed, systematic and sustained public engagement to democratise the processes involved in shaping policies, programmes and laws. When the debate is dominated by medical and legal perspectives, it often ignores the sociocultural, economic and religious backgrounds of the terminally ill and their families as well as those of healthcare professionals. These are critical elements in the ethics discourse. There is also a need to develop conceptual clarity regarding euthanasia, assisted dying and other related terms which are often used interchangeably and without precision. The ethics movement is best positioned to connect these dots.

We have a long way to go before we can have in place a legal framework for end-of-life care and euthanasia or assisted dying that is informed by the Constitution of India and international conventions. We also need wider engagement to ensure that such laws will be effective in a healthcare system dominated by an unregulated private healthcare sector and a resource-constrained public healthcare system, and despite India's poor track record of implementation of laws, vigilance and audit, to prevent their abuse.

We hope this collection of papers will set the stage for further discussions that can influence the agenda for research, advocacy and practice, leading to patient-centred legal reforms towards healing and dying with dignity.

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