EDITORIAL

Death and Dying in India: Circa 2018: What the Conscientious Physician Needs to Know

RD Gursahani[1], SV Khadilkar[2]

The Indian constitution gives us liberty. The concept of liberty has long standing origins and privacy and autonomy are the major personal attributes of liberty. In two recent judgments, the Supreme Court of India has affirmed our constitutional right to both.[1,2] Autonomy here refers to the patient's right and responsibility to choose, refuse or otherwise make their own decisions about their medical treatment. Such autonomy implies that the health care provider's duty is limited to educating them about available choices and their consequences. In the Western tradition, this right to autonomy is absolute and may even supersede the physician's duty of beneficence (do good) and non-maleficience (do no harm) in select situations.[3] The ancient Indian tradition, however, refers to the term 'Swa-dharma' which suggests that our autonomy is conditional or negotiable and factors in the social identity as well.[4] Thus, liberty and patient autonomy are important concepts for physicians to understand, appreciate and incorporate in their practice. As we in India are living longer, the issues of later years of life, particularly of dying and death are assuming importance and in general, the society and physicians find themselves unprepared to tackle them. There in is the importance of the living will and advance care plans.

The reach and implications of living will is important to understand. The very recent Supreme Court judgment[2] of 9 March, 2018 has confirmed the validity and enforceability of duly executed living wills and advanced care plans in India. This concept was first propounded in 1969 by Louis Kutzner, an American human and civil rights advocate.[5] As life support systems prolonged existence and death was 'medicalized' the common man found himself losing control over the decision making process. Increasing awareness of the consumer rights helped the movement to take back the control over one's last days. As the movement gathered pace, state after state in America passed legislation in favour of living will/advance care plan until finally the US Congress passed the US Patient Self-Determination Act. This act requires all federally funded medical facilities to ask patients if they have or would like to complete LW/ACP, at admission. Thus Americans have almost four decades of experience of regularly utilizing these documents.

The scene in India is beginning to change only recently and the concept of 'good death' is gradually taking roots. Last year, the Economist magazine[6] carried this line on its cover: "Dying is inevitable, a bad death is not!" Too many Indians die badly as confirmed by two Quality of Death reports[7] in 2010 and 2015. So, what is Good Death?[8] This concept can be divided into three components. First is the knowledge of when death is approaching and what can be expected. Goodbyes can then be said and a life review completed. This emotional closure is known to lead to a peaceful passing. But the required clarity of communication is not a part of routine in India and the public awareness of these issues is only recently emerging. Too often we are told by families not to tell the patient about their prognosis. While the relatives mean well, this infringes the autonomy of the patient and also is an act of medical omission.[9] Natural variations of length of survival also handicap the medical judgement and this is one more reason why doctors do not initiate the discussion about death issues. However, it is relatively easy to identify the subset of our patients who have a greater than 50% risk of passing away within one year.[10] It is our duty to initiate conversations about death and dying with patients or families in this situation. These discussions will help the family and the patient to handle the eventuality with maturity.

Second component of a good death is to have control over one's last days with dignity and privacy. Worldwide the vast majority of people would prefer to die in their own homes, surrounded by their loved ones.[11] Very few knowingly accept death in a noisy and chaotic hospital ICU, with painful interventions and surrounded by unfamiliar faces and yet that is the reality for most of us today. Since one may not be in a position to communicate coherently towards the end, living wills and advance care plans are required. These may need to be supported by the discretionary power of another person, usually but not necessarily a relative. This individual acts as the Health Care Power-of-Attorney who can interact with the medical team. All of this is now possible for Indian citizens. But it requires the medical practitioner to be aware of his ethical duties in an evolving legal framework. Withholding and withdrawing futile life-sustaining treatments is the norm worldwide. This needs to be systematically incorporated in our country. Doing right can never be illegal and we have adequate constitutional and legal protection for doing so.[12]

Thirdly and above all, a good death requires control of the many symptoms that bedevil the dying process. Their frequency and severity are largely similar regardless of diagnosis. All of us need to be aware of the basic principles of palliative medicine, a new speciality with a minuscule presence in India[13]. Currently it is limited to looking after oncology patients and exists in the large cities only. But it is heartening for physicians to know

[1]Consultant Neurologist and Epileptologist, PD Hinduja National Hospital, Mahim, Mumbai, Maharashtra; [2]Professor and Head, Department of Neurology, Bombay Hospital Institute of Medical Sciences, Mumbai, Maharashtra

that training programs in palliative care are being scaled up in India, with online and clinical components. These are targeted at physicians with clinical experience who are motivated to take up this challenging field. In addition to symptom control, palliative medicine training focusses on communication skills for essential and difficult conversations.

We, the conscientious physicians of India now need to appreciate a very important fact that the Supreme Court has made it possible for all of us to follow our dharma in a legally systematised manner when faced with a dying patient. This dharma includes continuing to care when cure is no longer possible and handing over to the other side with grace and dignity.

References

1. KS Puttuswamy vs Union of India. Supreme Court of India, Civil Original Jurisdiction; Writ Petition (Civil) No 494 of 2012. Accessed from http://supremecourtofindia.nic.in/pdf/LU/ALL%20WP(C)%20No.494%20of%202012%20Right%20to%20Privacy.pdf on 14 March 2018.
2. Common Cause vs Union of India. Supreme Court of India, Civil Original Jurisdiction; Writ Petition (Civil) No 215 of 2005. Accessed from http://supremecourtofindia.nic.in/supremecourt/2005/9123/9123_2005_Judgement_09-Mar-2018.pdf on 14 March 2018.
3. Beauchamp TL, Childress JF. Principles of Biomedical Ethics, 7th Ed, Oxford Univ Press, USA, 2013.
4. Devdutt Pattanaik: Personal communication.
5. Sabatino CP. The Evolution of Health care Advance Planning Law and Policy. Milbank Quarterly 2010; 88: 211-239.
6. The Economist, issue dated April 29th, 2017. . https://www.economist.com/printedition/covers/2017-04-27/ap-e-eu-la-me-na-uk. Accessed 14 March 2018.
7. The Economist Intelligence Unit. The 2015 Quality of Death Index. Ranking palliative care across the world. http://www.lienfoundation.org/sites/default/files/2015%20Quality%20of%20Death%20Report.pdf. Accessed 14 March 2018.
8. Steinhauser KE, Clipp EC, McNeilly M, Christakis NA, McIntyre LM, Tulsky JA. In search of a good death: Observations of patients, families, and providers. *Ann Intern Med* 2000; 132:825-32.
9. Gursahani R. Communicating truth about serious illnesses in the Indian context. *Nat Med J India* 2015; 28:269-70.
10. You JJ, Fowler RA, Heyland DK; Canadian Researchers at the End of Life Network (CARENET). Just ask: discussing goals of care with patients in hospital with serious illnesses. *CMAJ* 2014; 186:425–32.
11. Kulkarni P, Kulkarni P, Anavkar V, Ghooi R. Preference of the place of death among people of Pune. *Indian J Palliat Care* 2014; 20:101–6.
12. Mani RK. Constitutional and legal protection for life support limitation in India. *Indian J Palliat Care* 2015; 21:258-61.
13. Gursahani R, Mani RK. India: not a country to die in. *Indian J Med Ethics* 2016; 13:30-5.