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India: not a country to die in

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Abstract

This commentary addresses the issue of disproportionate medical interventions for end-of-life patients. A complex mix of sociocultural and medical factors, against the backdrop of the legal milieu, has an impact on the quality of death. The barriers to appropriate end-of-life and palliative care in India are multilayered and not easy to dismantle. To raise the level of care for the dying in India, currently rated among the worst in the world, it would require no less than a nationwide movement. This paper attempts to bring into the open the areas of concern for

discussion, and proposes appropriate legislation for a realistic solution.

Yaksha: What is the greatest wonder?

Yudhishtira: Day after day countless creatures reach Yama's abode, yet those who remain behind believe themselves to be immortal. What can be more extraordinary than this? (1)

Dignity in death

Death is not a welcome topic for conversation anywhere in the world. In India, it is “*apshagun*” (inauspicious) to even speak of mortality, even though India's religious traditions emphasise the dignity and spiritual significance of the end of life. Yet, discussions on the end of life are essential when patients, families and medical professionals come face-to-face with the inevitable. Without clear decision-making, the default option is an unnecessarily prolonged death. If one goes about the process the right way, intensive care can overlap

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and segue into palliation and withdrawal/withholding (WD/WH) of futile care. In this regard, it is known that the choices made by medical professionals are somewhat different from those made by the lay public with regard to themselves and their families (2). Anecdotal evidence suggests that “for all the time they spend fending off the deaths of others, they tend to be fairly serene when faced with death themselves”(3). In the questionnaire-based ETHICATT study from Europe (4), physicians and nurses assigned greater value to the quality of life and death than to the length of life. There is now widespread public awareness in the developed world of the futility and burden of intensive care in the last few days of life and jurisprudence is rapidly taking this into account. In the USA, since the early 1970s, legislation and case law have evolved into fairly settled legal positions with respect to limitation of treatment, palliation and living wills (5,6). Canada and the state of California have recently seen the legalisation of physician-assisted dying, building on more than three decades of public acceptance and debate. It is, therefore, not surprising that WD/WH of treatment or “do-not-resuscitate” (DNR) orders were found to precede most intensive care unit (ICU) deaths in North America and Europe (7,8). Both physicians and families now accept such decision-making as routine. Even in the case of neonates and children, 40%–60% of ICU deaths are preceded by limitation of treatment (9,10). The question of managing one’s own death is now also reaching a tipping point in mainstream social media. Death Over Dinner and The Conversation Project (11,12) are two examples of beginning what has been called “the most important and costly discussion America is not having”. India, to the best of our knowledge, has somewhat limited medical literature on this topic (13,14). There is not a semblance of a mention of it in either legislation or public policy, leave aside the private conversations which can then be facilitated.

When the end is near: beginning an essential discussion

The prediction of an individual’s mortality is inexact. In the Indian context, it may not be advisable to depend on western models of prediction, especially because the quality of the data is uncertain. Nevertheless, some trends can be discerned from international literature. In a seminal study from 1993 to 1998, Lunney et al (15) analysed a random sample of United States Medicare beneficiaries and developed a profiling strategy that captured 92% of deaths. Excluding sudden deaths, which accounted for only 7% of deaths, the dying process from the medical point of view was dominated by three distinct trajectories. Malignancy (22%) peaked in the 6th–7th decade of life, initially with functions maintained and followed by a quick but definitive terminal phase. Organ failure (16%) was associated with a slower descent, often punctuated by recurrent acute episodes, and the peak of mortality was in the 7th–8th decades. Beyond the 70s, a good many people (47% of this sample) had an interminably slow decline, with a poor and inexorably deteriorating functional status. In the case of all three scenarios, objective clinical criteria largely developed and used in Europe and North America can identify those with

a greater than 50% risk of dying within a year (16). Even in the case of younger patients, including neonates and children with acute or incurable illnesses, the inevitability of death can be predicted after a period of interventions (9,10). As in the rest of the world, more and more of these deaths are likely to occur in a technology-laden hospital setting. In addition to the evident waste of personal and societal resources, poor quality of life and family stress, this kind of death is actually associated with a lower level of satisfaction with the care received (17). In India, 80% of healthcare is privately financed and in our experience, this often feeds into a narrative of exploitation, especially when futile medical care leaves the family deep in debt. Worldwide, including India (18), home is the preferred place of death for a huge majority of lay people, not just medical professionals (4). To allow patients to make their choice, whether in the acute ICU setting or in the outpatient encounter, it behoves the responsible clinician to openly, honestly and explicitly communicate the prognosis to the capable patient and/or family. The SPIKES (Setting up the interview, assessing patient’s Perception, obtaining patient’s Invitation, giving Knowledge, addressing Emotions, Strategy and Summary) protocol (19) was developed to enhance the content and quality of the communication between the clinician and patient and/or family in a structured fashion. It can be applied in most settings and has been taught successfully to medical students (20). Japanese culture has a major taboo against informing terminally ill patients of their condition and the use of SPIKES has been documented there (21). In Kerala, Narayanan et al have developed and used a simpler version (22), termed BREAKS (Background, Rapport, Explore, Announce, Kindling, Summarise).

Improving the quality of death

Many attempts have been made to define a good death (23, 24) and perhaps it is better to accept a somewhat messy reality (25) as individuals and families come to terms with dying. The basic elements of individual control, dignity, privacy and pain/symptom relief should be available to all as a basic human right, consistent with the first principle of bioethics: the autonomy of the patient. Advance care planning (ACP) is the process by which individuals can align future medical care with their wishes and values, especially if and when they can no longer make decisions or communicate them. It is best seen as a dialogue that allows for an exploration of one’s priorities, especially as these relate to quality of life. These values are then translated into medical care plans and documented in written forms (“living will”) (26), and surrogates are appointed (“medical power of attorney”). The latter assume responsibility for implementing the documents. Optimally done, as the culmination of a series of conversations with the family and clinicians sometime towards the end of life, the ACPs are emotionally satisfying both to patients and caregivers (27). Not everybody is comfortable with the decision-making that this involves. For instance, some individuals are specific about making their own decisions for either altruistic reasons or a felt sense of personal autonomy. Others would prefer to leave the final choice to identified

surrogates by specifically transferring authority or by default (28). Also people's preferences may change over time, although one study found that the preferences are reasonably stable (29). Anecdotally, the will to survive may outlive the will to die with dignity (30). Another issue is that in specific circumstances, the patient's best interests may clash with their previously documented preferences (31). In the absence of a medico-legal framework this is uncharted terrain, even for those Indian physicians who are earnestly engaged in end-of-life care (EOLC). Once legislation is in place, we will probably find that in this regard, too, Indian exceptionalism is just another myth, as the human issues surrounding death are universal. Documentation and legal validity of EOLC would remain unclear without relevant laws.

Understanding medical futility

The related question of medical futility and how to resolve disputes burst into attention in India in 2011 (32). Futility has been defined as excessive (in terms of effort and finances) medical intervention that has little prospect of altering the ultimate clinical outcome (33). The reference is to the case of Aruna Shanbaug, a nurse who was a victim of sexual assault and existed in a persistent vegetative state (PVS), meticulously maintained by the devoted attention of her former colleagues for over 40 years. A public interest litigation (PIL) in the Supreme Court of India (SCI) sought that she stop being fed and be allowed to die. The judges refused the plea and wrote a long judgment including a review of the Indian legal literature. The only definite contribution the judgment made was the explicit decriminalisation of the withdrawal of medical care in the specific circumstances of the PVS, given certain procedural safeguards. There was vague extrapolation to consider all forms of treatment withdrawal as "passive euthanasia", with a cursory reference to the current concepts of bioethics. As a consequence, the judges were led to prescribe an unrealistic pathway of resolving futility questions, whether disputed or not, by involving the local High Court. As expected, in four years, the Aruna Shanbaug case has not influenced even one death, not even her own! In the USA, most EOLC decisions are made at the bedside and disputes are resolved by empowered hospital ethics committees. It is only when local mediation fails that the courts are involved (34). A broad international consensus has evolved in the last decade on the definitions and ethical foundations of EOLC (35, 36). In most cases, the process is now part of standard medical decision-making which occasionally requires legal guidance and only rarely formal authorisation. The case of brain death is even more interesting. The general understanding in India is that brain death can be declared only when organ donation had been planned. Till the Aruna Shanbaug judgment, it was perceived without basis that if the deceased was not an organ donor, disconnecting life support could even attract murder charges. Since there is no case law and no explicit legal recognition of the equivalence of brain and circulatory death, this perception is widespread. The USA promulgated the Uniform Determination of Death Act in the late 1970s to legally recognise declaration of death by neurological criteria

(37). A joint international panel is collaborating with the World Health Organisation to develop a unitary concept that does not distinguish between brain and circulatory death (38). Even in India, the Organ Transplantation Act 1994 (assented to on July 8, 1994, Act No. 42 of 1994, Bill No. LIX-F of 1992) has already recognised the deceased state to be either cessation of brain or cardiac function. However, this fact needs to be made more explicitly known to medical professionals to alter the perceptions that govern our clinical practice.

Keeping in step with change

India is developing and changing rapidly in many ways. The generation that came through Independence believed that their children would see to their end-of-life concerns. Decisions about EOLC are still largely a matter of a family consensus. However, within a few decades, joint families have given way to nuclear families and in the large cities, many people live alone. To understand how the balance between the individual and family/community is likely to change, it is necessary to take a look at some of the unexpected demographic dividends of rapid economic growth in our neighbourhood. East Asians are marrying later and fewer of them are marrying. In Japan and Hong Kong, about 20% of women between the age of 35 and 39 years are single and are expected never to marry. In China, it is projected that in two decades, 10% of men will not find brides as a consequence of the skewed sex ratio (39). Currently, less than 5% of Indians live alone, whereas single-person households already constitute 15% of households in China, 25% in South Korea and 35% in Norway (40). Indian society is deeply uncomfortable with individual choice, or what film-maker Anand Gandhi evocatively calls the "landscape of the individual" (41). To us, this is the fundamental barrier to evolving EOLC legislation. The term passive euthanasia sharpens this conflict with connotations of control outside the individual. The foundation of EOLC is preservation of autonomy irrespective of capacity. As one of us put it, "Animals are euthanised, but sentient human beings take charge of their own deaths." As Gandhi cogently argues, "The individual is the sole owner of the self (and is) entirely responsible for the self. We have to accept and establish that the law has no moral right whatsoever to legally interfere with the lifestyle, sexual, reproductive or death choices of informed, consenting adults, even if they are beyond the understanding of presumably well-intentioned state representatives."

The autonomy of the patient is the first principle of bioethics. Self-determination is fundamental to this autonomy. It cannot be emphasised enough that EOLC and ACP are both the right and the responsibility of the individual, well within the ambit of the Constitution of India. Within the next decade or two, more and more Indians will demand this constitutional right.

Legal and social complexities

The title of this commentary is from an evocative blog by Jo Chopra, who speaks of the difficulties a Dehradun family faced in letting their mother die in peace at home (42). In 2010 and 2015 (43,44), the Quality of Death Report published by the

Economist Intelligence Unit rated India as having amongst the poorest EOLC amongst the major countries that it surveyed. We believe this is because of the lack of any legal framework, government support or community involvement. The only bright spot is the state of Kerala, thanks to the voluntary organisation, Pallium India, and the Neighbourhood Networks in Palliative Care project (43, p24). At the time of the Aruna Shanbaug judgment, one of us had hoped (32) that the Indian judiciary would evolve case law that could perhaps substitute for the lack of suitable legislation. That has not happened and as we have realised in the case of Article 377 (decriminalisation of homosexuality), the judges, too, carry the cultural biases of the Indian establishment. As late as 2012, the 241st Law Commission report (45) concluded that "living wills, whether written or oral, are controversial and can lead to mischief and, therefore, should be made legally ineffective, overriding the common law right of self-determination". This position implies that extraneous considerations would trump the citizen's fundamental right to autonomy and privacy in a decision on something so personal as his/her manner of dying. As in the Aruna Shanbaug case, this document quotes purely legal formulations, most of them dating back to two or even three decades ago. It is oblivious of the varied scenarios in EOLC, published professional guidelines or the existing bioethics literature, and makes no mention of even Beauchamp-Childress! (46). Obviously, checks and balances are in order, but to deny the patient's autonomy in so cavalier a fashion is unacceptable. Elements of this paternalistic attitude can be seen in the Rajasthan High Court judgment on *Santhara*, which has now reached the SCI. Not many are aware that voluntarily stopping eating and drinking is legally valid all across the USA (47). The Indian legal system already accepts the curious concept of "civil death" in the case of someone renouncing the world and taking *sanyasa*, as per Hindu religious tradition (48). Perhaps all that is required is the secularisation of *Santhara*, with safeguards to prevent misuse.

The Indian situation can best be understood as an evolving conceptual continuum in a matrix that incorporates medical capabilities, the legal situation and societal attitudes. At one extreme is a position that emphasises the sanctity of life with no reference to patients' rights. The other limit is a utilitarian argument based entirely on autonomy. To understand how this plays out in a given politico-cultural setting, it is instructive to consider two examples of the bioethics of death in two markedly different nations and political systems. The Netherlands and the People's Republic of China (PRC) are polar opposites. Physician-assisted death has been legal in the former since 2002, but with very strict safeguards. If the conditions are not met, the medical practitioner concerned can be charged with homicide (49). The Dutch are largely Christian Protestants/Lutherans (not Roman Catholics) and the country has been a parliamentary democracy since 1848. At the other extreme, in the last decade, the PRC had the world's highest rates of execution of "criminals" as well as of organ transplants. Supposedly most of those facing execution would offer their organs "as a present to society"! In a sting, a BBC journalist

was offered a liver for transplant from a scheduled execution for about 50,000 GBP (50). As a vigorous democracy under the rule of law, there is little doubt about the direction in which the Indian situation can and will evolve.

Harbingers of reform in India

Some barriers to effective EOLC are obvious (51). Medical training, both here and worldwide (52), is focused on curative therapies and imparts little knowledge of palliative care and when to overlap or switch. The concept of the autonomy of the patient is weak among Indians in general. This is further compounded by the prevalent paternalism and low level of professional accountability. When limiting therapy, physicians here are often wary of being accused of providing suboptimal care and consequent criminal liability. So what is the way forward? Over the past few years, professional societies have filled some of the gaps with detailed guidelines for the responsible practitioner (13, 53). In its new edition, the National Accreditation Board for Hospitals has included proposals for EOLC quality assessment. In its Code of Ethics, the Medical Council of India proscribes euthanasia, but has made it clear that brain death is a valid reason for withdrawal of care, provided due process is followed (54). There is, however, no mention of DNR or WH/WD of treatment in contexts other than brain death. This position needs to be updated to include the current developments in bioethics. However, legal validation must also be aligned and there is thus no alternative to a comprehensive, forward-looking legislation that can serve both doctors and their patients in the coming decades. A PIL requesting such legislation has been pending with the SCI (Common Cause vs. The Union of India, Writ petition civil no. 215 of 2005) for a decade, to which the Indian Society of Critical Care Medicine (ISCCM) has filed an impleadment petition as a party respondent.

The way forward: why we need an EOLC law

Ideally, EOLC legislation should arise out of a wide debate and a felt public need. However, it must also be recognised that India's diversity makes a nationwide conversation next to impossible. For example, it is unrealistic to yoke the self-financed medical choices of an urban, middle-class individual with those of a below-poverty-line rural villager who is often subject to brutal triage in India's grossly underfunded public health system. To us, it is self-evident that the various strands that we have alluded to make for a Gordian knot that can only be cut through by legislation. On August 15, 2015, three medical societies – the Indian Academy of Neurology, the ISCCM and the Indian Association of Palliative Care – came together to try and evolve such a law and to push for having it debated and passed by Parliament. This law would have the following basic components: (i) uniform recognition of death, including death by neurologic criteria; (ii) legal validation of ACP, including living wills and medical power of attorney; and (iii) the establishment of due process for resolving medical futility and WH/WD treatment issues. This law would then allow responsible and willing citizens to take charge of their last days.

The law would have built-in and adequate safeguards against misuse. It would be simple and applicable in all systems, public and private. It would enable the good doctor to give morally and ethically sound end-of-life and palliative care without fear of litigation. The field of palliative medicine would be able to develop India-specific protocols and processes. Far more importantly, the law would help evolve public, professional and personal attitudes to the many choices and shared decision-making that must define medical care at the end of life. Such a law would allow Indians to begin having those necessary conversations with each other about death and dying, well before Yama comes calling!

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Passive euthanasia in India: a critique

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Abstract

Given its preoccupation with the doctor's agency in administering euthanasia, the legal discourse on euthanasia in India has neglected the moral relevance of the patient's suffering in determining the legitimate types of euthanasia. In this paper, I begin by explicating the condition for the possibility of euthanasia in terms of the following moral principle: the doctor ought to give priority to the patient's suffering over the patient's life. I argue that the form of passive euthanasia legally permissible in India is inconsistent with this moral principle, owing to the consequences it entails for the patient.

Inevitably, it is acts of commission on the part of the doctor that can provide the best possible death, which is the moral objective of euthanasia. To meet this objective, doctors must be seen as agents who possess the moral integrity and technical expertise to judge when and how the patient's life ought to be terminated,

depending on the patient's medical condition. They are not bound to save lives and provide care unconditionally.

Introduction

For over 40 years – precisely 41 years and 173 days, for not a moment of suffering ought to be discounted, Aruna Shanbaug remained locked up in ward number 4 of KEM hospital, Parel, Mumbai. Her struggle to die ended on May 18, 2015. The absence of bed sores on Aruna's dying body was celebrated and the nurses' tremendous "attachment" to her was much exalted. All this, despite the bitter fact that Aruna lived a life, to use Peter Singer's words, "so miserable as not to be worth living" (1).

In March 2011, owing to Pinky Virani's indefatigable efforts, the Supreme Court of India deemed passive euthanasia legal. A detailed discussion of the different ways of implementing passive euthanasia is due, given the equivocality of the term in the legal document. I hope to throw some light on several inconsistencies in the verdict's arguments in favour of passive euthanasia (and against active euthanasia). Beyond the legal debates that ensued, euthanasia needs serious moral reflection in India.

We seem to intuitively understand that the pain of aching knees is qualitatively different from the pain of chronic cancer,

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