

Editorial

Making End-of-Life and Palliative Care Viable in India: A blueprint for action

Worldwide, about 85% of all deaths in seniors above 65 years of age are due to cancer, organ failure or old age.¹ Sudden death is uncommon after the age of 50 years. Thus, for the majority of deaths, we can potentially identify patients who are terminally ill, i.e. have a high likelihood of passing away in the next 6 months to a year.² In the USA, >25% of the Medicare budget is spent on individuals in what is identified, usually in retrospect, as the last year of life. Much of it is on intensive care, which is often perceived as inappropriate and futile by healthcare professionals.³ Ideally, discussions by patients and families with doctors and trained counsellors should begin as soon as terminal illness is identified, in anticipation of eventual deterioration. The road ahead is spelt out and discussed with as much clarity as is possible, unless one explicitly chooses not to be informed, so that informed choices can be made well in time. Decisions about future healthcare can be made, and are then formalized, through the process of advance care planning (ACP), which includes instruments such as living wills (LWs)/advance medical directives, healthcare power-of-attorney and physician orders for life-sustaining treatment (LST).⁴ Emotional closures with family and loved ones can then happen, and these permit a peaceful passing. Symptoms such as pain, incontinence and depression are managed by skilled palliative care professionals whose business is to help patients with a serious illness live as well and as long as possible until natural death occurs. When asked, the choice for the majority is for death to occur at home⁵ or in surroundings of one's choice, with minimal or no discomfort. A randomized controlled trial from Australia showed that this process improves both quality of end-of-life care (EoLC) and patient and family satisfaction. It also reduces stress, anxiety and depression in surviving relatives.⁶

Not a country to die in

Quality of death is a term which first appeared in the medical literature in the late 1980s. However, it came to public attention when the Lien Foundation of Singapore commissioned the Economist Intelligence Unit to develop a Quality of Death Index by which entire countries and their healthcare systems could be compared. India is distinctly not a country to die in!⁷⁻⁹ Our failure begins with our underfunded public health system. However, both in the UK and our own Kerala, it has become obvious that public funding is far less effective than voluntary action and philanthropy. Governments' involvement, however, is necessary to enable, mandate and support these efforts by legislative or executive action or both. There is scope for private healthcare as well, as in the USA, where these services, including home or institutional hospice care, are usually funded by medical insurance.

How well a healthcare system manages death seems to depend on some rather simple, low-cost and low-technology factors. Probably, the most important of these is public awareness and the naturalization of death in our daily discourse. The next issue is the availability of morphine and other opioids for the pain and distress that so many suffer from in their last days. This is because of worries about potential misuse. WHO has helped evolve systems that have been put in place by other developing countries such as Mongolia to make these vital but inexpensive drugs available to whoever genuinely needs them. Not so in India¹⁰ where the lack of a legal framework affects the domain of EoLC. In March 2018, the Supreme Court of India¹¹ finally recognized autonomy of healthcare choices as a constitutional right. This includes the right to limit medical care at the end of life and the validity of LWs. As of now, a doctor's duty is still perceived to be to make every attempt to save life even if it means disregarding the patient's clear instructions to allow

natural death. Most Indian healthcare professionals are never trained to recognize and respond to EoLC needs or to provide even basic palliative care. This lack of a systematic approach or of training is seen at all levels: doctors, nurses, counsellors, administrators, etc. Few hospitals invest in these inexpensive services, which could save costs all around while improving the quality of life at the end.

The road ahead

In 2015, the three national medical associations of intensivists (Indian Society of Critical Care Medicine), palliative care physicians (Indian Association of Palliative Care) and neurologists (Indian Academy of Neurology) came together⁹ to form the End of Life Care in India Taskforce (ELICIT). The three authors constitute the Steering Committee of this body. We hope to partner with both public and private agencies to develop the ecosystem of caring for the terminally ill. The tasks ahead include:

1. Creating a legal framework for EoLC decision-making by individuals and institutions
2. Raising public awareness: Normalizing death in day-to-day discourse
3. Creating capacity in the healthcare system for providing adequate EoLC/palliative care services.

Creating a legal framework for EoLC decision-making

Ideally, we should have had a comprehensive all India legislation, adopted after discussion and debate in the Indian Parliament. The ELICIT has prepared a draft through multiple iterative consultations between doctors and lawyers, and this has been submitted to the Ministry of Health and Family Welfare in 2016. Our draft recommends protecting individual autonomy through ACP and provides a framework for medical decision-making. It does not require any financial or budgetary commitments. This draft can be passed by individual state governments because health is a concurrent subject. Nevertheless, even without such a law, much has already been accomplished. The medical use of opioids in EoLC and palliative care is now much easier but not in every state.

The constitutional basis of healthcare decision-making by and for the individual has been addressed by the Supreme Court in three judgments beginning from 1996. The last 'Autonomy' judgment of March 2018¹¹ unequivocally guarantees this mandate, perhaps obviating the need for legislative sanction. However, the Supreme Court out of a concern for abuse went on to prescribe procedures that are impractical and render the judgment unworkable.^{12,13} To our knowledge, this judgment and these processes have never been applied in an actual case. While awaiting clarification either from the Union Government or the Supreme Court, professional initiatives have begun. In 2014, the Indian Society of Critical Care Medicine and the Indian Association of Palliative Care had jointly published guidelines for withholding and withdrawing LST at the end of life.¹⁴

In 2017, the Indian Council of Medical Research, through its Bioethics unit, constituted an EoLC committee which began by preparing a definition of terms.¹⁵ The next phase is an effort to operationalize 'Do-Not-Attempt-Resuscitation' instructions and is being finalized as a white paper. State governments can and should take the initiative and spell out procedures by executive orders. Kerala did so to make brain death declaration and termination of life support mandatory even in the absence of organ donation.¹⁶ The Federation of Indian Chambers of Commerce and Industry (FICCI)-Health and the Manipal Hospital Systems have both prepared documents to guide standard operating procedures (SOPs) for private healthcare.¹⁷ These can well be adopted by all private hospitals on a voluntary basis. The costs of death and dying have been rising rapidly in India,¹⁸ leaving families impoverished and often in debt. We believe this is because decision-making at the end of life is usually a default 'Do everything'.³ When this happens in a private hospital, this futile care and catastrophic medical expenditure at the end of life is often presumed to be a scam. Hence, we believe that private hospitals need to embrace these SOPs in self-interest and for patient satisfaction. Eventually, a more enlightened public discourse will compel governments to make this EoLC decision-making transparent and enforceable, upholding the highest principles of biomedical ethics.

Raising public awareness: Normalizing death in day-to-day discourse

Most Indians are reluctant to speak about death: Considering it an *apshakun* (bad omen). This seems discordant with Indic traditions of our belief in rebirth, and the first mention of this dissonance appears in the Mahabharat.⁹ To normalize death in daily discourse, multiple avenues will need to be explored at different levels of engagement:

1. *Intellectuals, policy-makers:* The first multidisciplinary conference on Death and Dying in India was held at Mathura on 29–30 April 2017, culminating in the Mathura Declaration.¹⁹ This can be made an annual affair to bring together public intellectuals, politicians, economists, judges/lawyers, doctors, etc.
2. *General media campaign:* This is especially important because India has a low demand for EoLC/palliative care services. The general public is completely unaware of the importance of these services in their own lives. One quick option is to build this around LWs, by organizing camps. It should be possible to have a celebrity declare: 'I have made my living will: Have you?'. 'Death over dinner'²⁰ and Death café²¹ are innovative programmes but have yet to take off in a major way in India.
3. *Commercial:* An insurance scheme that speaks about managing the last days will instantly break new ground and become a talking point. It will need expert advertising professionals to figure out how to phrase it and how to pitch it at different stages.

Creating capacity in the healthcare system: To provide adequate EoLC/palliative care services

This field requires skill-sets and attitudes that are somewhat distinct from the rest of medicine. There is a high degree of voluntarism and altruistic behaviour in personnel who devote their professional careers to EoLC/palliative care. Philanthropic and non-governmental organizations can and do provide a yeoman service. Maintaining professional standards and ethics can be a major challenge especially as patients are among the most vulnerable in our society. There is a considerable fit and overlap between these services and those that will need to be provided to senior citizens. Except for physician training for which some facilities do exist, for the rest, organized training programmes will largely have to be set up from scratch.

1. *Medical professionals:* All undergraduate curricula should incorporate the basics of biomedical ethics, communication skills and EoLC decision-making. The Medical Council of India has begun to address this with the Attitude, Ethics and Communication (AETCOM) module.²² Generalist palliative care can be provided by doctors as a supplemental service in addition to their primary speciality (e.g. geriatricians/neurologists/family physicians providing basic palliative care to their own patients). The training for this can be delivered largely online in 3–6 months. Specialist palliative care is meant to train doctors who work exclusively in palliative care, can run hospice services and can provide backup for generalist palliative care providers. This can be through postgraduate courses run as 3-year degree (MD) courses, currently available only at the All India Institute of Medical Sciences (AIIMS), Delhi and Tata Memorial Hospital, Mumbai. To expand this speciality rapidly, it is necessary to create a path for experienced clinicians from other specialties to make a mid-career lateral shift. For this, the existing international standard is a 2–3-year, mainly online, course which culminates in either a diploma or an MSc in palliative care. While the USA has board certification, nothing comparable exists in India, but different organizations do offer certified training of variable durations. These need standardization on a national basis.
2. *Nurses* are the backbone of palliative care services worldwide. The developed skill-sets of experienced senior nurses make them natural providers of palliative care and allow the possibility of reskilling and re-employing nurses retiring from regular service. Younger nurses can enter through a diploma or an MSc in palliative care after the basic nursing graduate degree. Worldwide, nurses can and do run home care services independently, with physicians playing a supportive role.²³
3. *Counsellors and social workers:* Three distinct areas that require specific training are ACP, pastoral (spiritual) care and bereavement support. Personnel trained in these areas can work on a voluntary basis but will also find career opportunities in hospitals.
4. *Supportive care workers:* We propose a cadre of semi-skilled workers who can work with palliative care, elderly patients and those who suffer from dementia. The skills required are simple and can employ individuals with high school education. Currently, individuals providing these services are employed as wardboys and ayahs, with no aptitude testing, training or certification. All of these can be done through the National Skill Development mission. This will provide major employment potential. Well trained with decent employment opportunities and motivation, these individuals could well become equivalent to the accredited social health activist (ASHA) workers, but at the other end of life!
5. *Volunteers:* Students can be encouraged to participate in palliative care programmes

and can then become ambassadors for EoLC and palliative care in their families and communities.²⁴

6. *Provider organizations and physical infrastructure*: Both need accreditation and regular verification. There is a definite complementarity between facilities that will need to be provided for senior citizens at the end of life and hospice care. It should be possible to dovetail this with initiatives for senior living, which currently have an almost exclusive real estate focus.
7. *Hospice care*: All of the above need to come together in the last months of life. Unfortunately, limited services are available in the country at present, and these are almost exclusively limited for cancer care that too only in big cities. In part, this is a legacy issue: Palliative care has been oncology-focused since its origin. However, it also makes economic sense. When run as not-for-profit ventures, it becomes obvious that only cancer offers a definite prognosis of months or less and budgets can be matched to individual outcomes and palliative care needs. For organ failure, neurological disease or geriatrics, the best prediction may just be 'this is probably the last year', even after the need for palliative care has been established. When palliative care is offered as a community and home-based service, cancer patients are in a minority. As care has to be offered to whoever needs it, it cannot be restricted by diagnosis. Hence, the economics of this needs to be addressed as a sustainable service and not just as charity! In the USA, this service is paid for by Medicare for those who cannot afford it. In India, this is where government and insurance will need to do the heavy lifting. We envision an insurance product that fills this gap. This is one space where recognition and planning is desperately needed.

Conclusion

The challenges and opportunities in EoLC/palliative care are immense. Most of the work will have to be done through philanthropic initiatives and involvement of the government. However, given the size of the market, there is also large scope for the private sector to provide quality, commercially viable services.

Conflicts of interest. None declared

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