Legislation for End-of-Life Care in India: Reflections on 5 Years of the End-of-Life Care in India Taskforce Journey

Independence Day 2015 was a Saturday and the weekend saw the coming together of three national medical associations: The Indian Academy of Neurology (IAN), the Indian Association of Palliative Care (IAPC), and the Indian Society of Critical Care Medicine (ISCCM). The three societies were represented by senior office bearers and concerned members and the meeting was facilitated by Dr Gagandeep Singh, secretary of the IAN. The purpose was to review the state of End-of-Life Care (EOLC) in India and the way ahead. We heard lectures from legal and constitutional experts among others as we brainstormed possibilities. It was resolved to form a standing joint committee and this was christened EOLC in India Taskforce (ELICIT) by Dr. U Meenakshisundaram, neurologist, Chennai. The other attendees included Drs. J Divatia (ISCCM, Mumbai), V Goyal (IAN, Delhi), R Gursahani (IAN Delhi), S Iyer (ISCCM, Pune), RK Mani (ISCCM, Delhi), M Mehndiratta (IAN, Delhi), M Muckaden (IAPC, Mumbai), A Pauranik (IAN, Indore), SN Simha (IAPC, Bengaluru), and N Surya (IAN, Mumbai). The authors of this piece are members of the Steering Committee of ELICIT. On the fifth anniversary of that meeting, it is appropriate to reflect on the journey so far and the road ahead.

As an Economist cover put it "Dying is inevitable, a good death is not" and Indians seem to die very badly. EOLC impacts and is affected by ethics, legislation, and the politics and economics of health care. Complex decision making in illness is combined with individual and family suffering. It is everyone's responsibility: Government, the medical and legal professions, civil society, and ultimately all of us as individuals. Making a "good death" possible for everyone requires personal and public conversations about death and dying as well as strengthening services in Palliative Care (PC). However, it also requires enabling laws, judicial rulings and professional medical guidelines. This piece looks at the current legal landscape, the various actors and their roles.

Government

India has only one legislation concerned with the end of life: The Human Organ Transplant Act (1994 and 2011) which validated the concept of brain death for the limited purposes of organ donation. The next frontier in transplantation is Donation after Cardiac Death but that needs substantial evolution of the whole field. In the 5 years since ELICIT was formed we were able to prepare and discuss two drafts of an EOLC legislation. The process involved extensive discussions between doctors from the three associations and lawyers, in an iterative process. We would like to place on record our gratitude to G Gokhale, N Shah and N Kohli of DSK Legal and D Mehta of Vidhi. Three components were defined: (i) Validation of patient autonomy and advance care planning (ACP); (ii) establishment of due process for resolving issues of medical futility, including foregoing life support; and (iii) uniform recognition of death, including death by neurologic criteria. All three can be accomplished with due safeguards and more importantly, without any budgetary allocation. We believe that a single overarching central legislation is the quickest route to EOLC reform. However this requires convincing the political and administrative leadership. The only movement so far has been a Kerala government order in late 2019, that spelt out due process for declaring brain death in patients who were not organ donors. Perhaps the way forward is for different components or perhaps the whole legislation to be passed by individual state legislatures through focused advocacy since health is a concurrent constitutional issue.

Judiciary

India is a common law country and a major route for reform is through case law. As the state High Courts and the Supreme Court answer issues brought to them, they may go on "make law," especially if there is no corresponding Act of Parliament. The views of the Supreme Court of India on EOLC have evolved as enunciated through three major judgments, the last of which was delivered in 2018. In the Common Cause judgment, SCI confirmed the constitutional right to regulate one's own treatment, including refusing it even if it were to cause one's death. They affirmed the validity of advance medical directives (AMD) and withdrawal of life sustaining treatment. However, they were unable to bring themselves to trust in the good sense and integrity of ordinary citizens and doctors. They prescribed an impractical procedure, as a result of which this path breaking judgment became unimplementable. Attempts are being made to rectify this situation.

Medical Profession

Over the past decade, guidelines have been put out by professional bodies (ISCCM, IAPC) and hospital systems (AIIMS Delhi, Manipal Hospitals). The most recent is the Do-Not-Attempt-Resuscitation guideline from the Indian Council of Medical Research (ICMR). Both the AIIMS and ICMR documents focus on empowering and educating the patient and family to withhold inappropriate life support treatments at the end of life. Quality EOLC has also been mandated by the National Accreditation Board for Hospitals and Healthcare. However, there has been hardly any investment

in PC either by private providers or by the public health system. Hence, implementing these guidelines depends mainly on awareness of the individual doctor. The medical community as a whole has yet to realize the importance of providing appropriate EOLC. Inappropriate and excessive treatment at the end of life fuels conflict. Doctors need to realize that if this provokes litigation, judges are likely to ask if acceptable medical standards were followed and will look to published professional guidelines. Worldwide, the bulk of cases against doctors for EOLC are for unwanted treatment.

Civil Society

There needs to be a concerted effort to bring discussion of death and dying into the mainstream media. We believe the best way to do that will be by advocacy for ACP and wide use of the Advance Medical Directive and the PC community needs to take this on as our responsibility. Although the mandated procedure for AMD is cumbersome, it is now constitutionally valid and legal. The West, especially the USA has five decades of experience with these instruments and there are very few instances of misuse that have come to light. As more and more people make the effort to discuss their own wishes within their families and then put their plans down on record, this will become a virtuous circle. Eventually, the government and judiciary will see the logic of making ACP/AMD easy to document and implement.

In the future, we can aspire to a quality of death that matches the best in the world. This would include free home PC, hospice admission when required, actionable AMD and a system that targets a death as free as possible of pain and other distressful symptoms. A comprehensive EOLC legislation has to enable this and can do so while simultaneously reducing medical expenditure.

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