COMMENTARY

Simplified Legal Procedure for End-of-life Decisions in India: A New Dawn in the Care of the Dying?

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Abstract

Recent amendments to the onerous legal procedure laid down in the Landmark Supreme Court Judgment Common Cause vs The Union of India have aroused widespread interest. The new procedural guidelines of January 2023 appear workable and should ease ethical decision-making toward the end-of-life in India. This commentary provides the backdrop to the evolution of legal provisions for advance directives, withdrawal, and withholding decisions in terminal care.

Keywords: Advance care planning, Comfort care, End-of-life care, End-of-life care foregoing of life support, Intensive care unit, Medical ethics, Medico legal issues, Palliative care, Withdrawal and withholding ethics.

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Background

The culture in Indian intensive care units (ICUs) has long been skewed toward aggressive life support till the very end, no matter the disease trajectory or the prospects for meaningful outcomes.[1] Excessive treatment in both ICU and general healthcare settings is rife, resulting in intolerable burdens to the patient and the family and adverse consequences to the healthcare environment.[2,3] For the caregiver, moral distress, compassion fatigue, burnout, and a propensity to leave their jobs result from impaired ethical climate in ICUs.[4] The overwhelming focus on technological advances in organ support contrasts sharply with the declining priority accorded to human-centricity in health care.[5] End-of-life (EOL) practices vary across national, cultural and religious diversity, and even within nations.[6] Curtis et al. described how the ecosystem of culture, law, public policy, institutional policy, physician attitudes, and societal beliefs impact EOL decision-making.[7] This construct has proved to be true for India where legal guidelines and institutional policies were identified by ICU physicians as the most important stumbling blocks in administering quality end-of-life-care (EOLC).[8,9] The first ethical position statement for limiting life support and applying palliative care for the Indian Society of Critical Care Medicine (ISCCM) was published as early as 2005.[10]

Legal Evolution Enabling Limitation of Life Support in India

In 2006, the Law Commission of India published its 196th report titled "Medical Treatment of Terminally ill Patients," unequivocally separating foregoing of life-sustaining treatments (FLST) from euthanasia or abetting suicide.[11] In the same breath, the report cautioned against legalizing advance directives (AD) as the judge feared potential "misuse" of the provision by colluding families and physicians for secondary gains. Subject to such risks of misinterpretation and distrust, it was daunting for doctors to take EOL decisions without fearing potential legal liability. Together with the legal ambiguities, there were societal and cultural unawareness of the needs of the dying that seemed to place insurmountable obstacles to treatment-limiting decisions in the ICU. Iterations of the guidelines in 2012 and 2014[12,13] further tweaked the clinical pathway, with in-built checks and balances through a patient-centered shared decision-making process, but the core apprehensions precluding its widespread utilization remained.

The "Aruna Shanbaug" judgment queered the pitch further. They continued with the reservations articulated in the 196th report in letting the physicians and families together decide for the incapacitated patient.[14] Though the Supreme Court (SC) accepted "passive euthanasia," a procedure mandating validation by a high court was prescribed. It proved to be unworkable on the ground, leading to, paradoxically, less confidence among physicians in making these decisions than earlier. In fact, Left Against Medical Advice (LAMA)/Terminal Discharge rates rose, as revealed by two large point prevalence studies, INDICAPS I and II, conducted 8 years apart, before and after the judgment.[15] The 241st report by the law commission in 2012 only reiterated the Aruna Shanbaug procedural requirements and continued to disallow AD.[16] This was unfortunate

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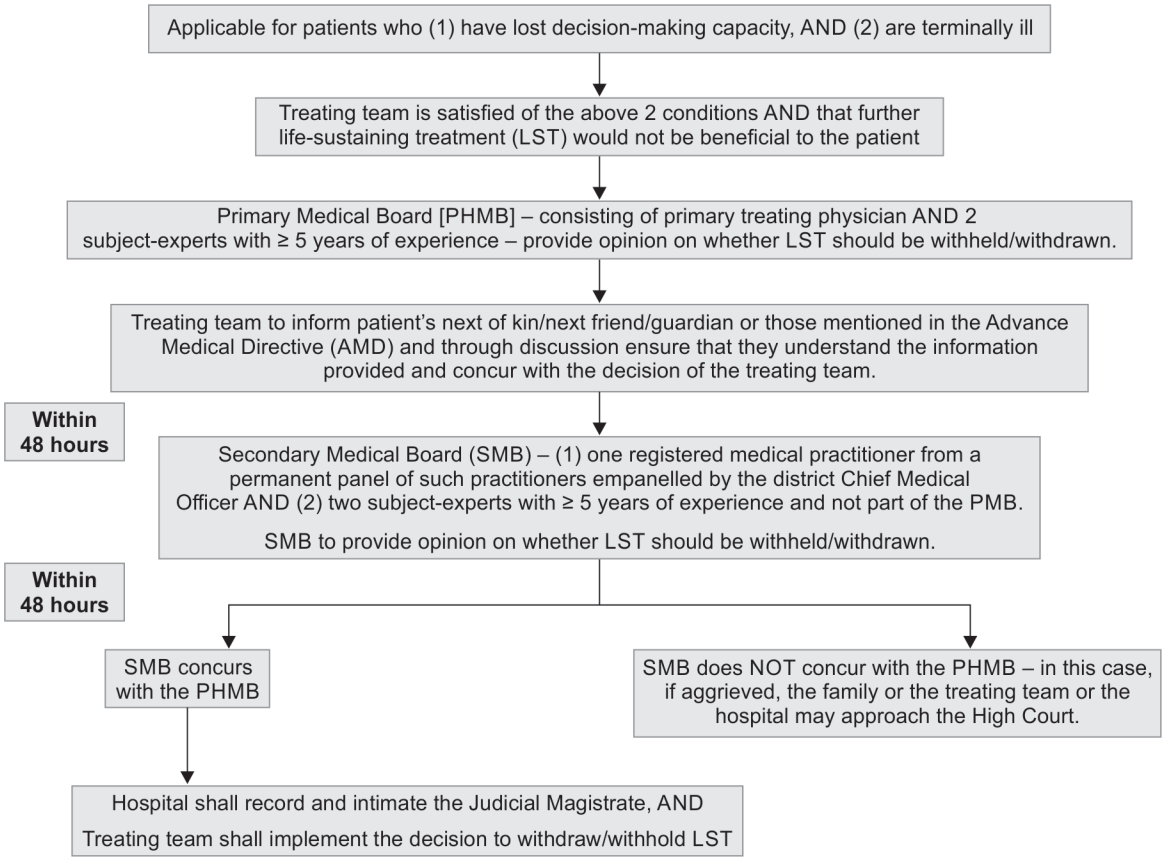
Flowchart 1: Summary of the SC's legal guidelines for decisions to forgo life-sustaining treatment



since best practices involve open discussions around prognosis to set goals of care toward advance care planning (ACP). Advance care planning is crucial to improving the quality of dying and mitigating patient and family suffering. According to Sudore et al., ACP aims "to help ensure that people receive medical care that is consistent with their values, goals, and preferences during serious and chronic illness."[17] Ethical decisions continued to take place informally based on the ISCCM-IAPC guidelines, but were few and far between. The AD has been, until recently, largely unknown even in professional circles.

A brace of landmark SC judgments in 2017 and 2018 enabled a paradigm shift in the legal provisions for AD and withdrawal (WD) and withholding (WH) decisions.[18,19] Article 21 or the "Right to Life" enshrined in the Constitution of India was expanded to identify privacy and autonomy as inalienable rights. The progressive Mental Healthcare Act of 2017 also validated AD.[20] The most important of these judgments for EOLC, the Common Cause vs The Union of India, explicitly established the right to execute an AD and to refuse life-sustaining treatments. When it came to voluntary decisions, there was no procedural complexity. However, with respect to decisions made for the incapacitated patient, the procedure laid down was complicated. The mandated three-tier process involving the district collector and the Jurisdictional Magistrate of the First Class (JMFC) had few takers. Simplification was necessary to actualize the principles of patient autonomy and physician beneficence and nonmaleficence in everyday practice. To simplify the procedure, an appeal was submitted to the SC by the ISCCM, represented legally by the Vidhi Center for Legal Policy and supported by End-of-Life Care in India Task Force (ELICIT), a multi-disciplinary advocacy group.[21]

In a momentous development, a 5-judge constitutional bench allowed a simplification acceptable to both the appellant and the Government of India. In its amended form, the AD need not be attested by the JMFC- either notarization or attestation by a gazetted officer will do. A two-, not three-tier process, for WD/WH finally emerged, whether or not an AD/appointed proxy was in place. Accordingly, now two medical boards need to be set up by the hospital/institution. The District Magistrate, in contrast to the previous ruling, needs only to be "intimated" (informed) of the decision, not requiring his/her authorization (Flowchart 1).

Utilizing the Provisions by the Bedside

What do these amendments mean on the ground? Will doctors more readily embrace this procedure and find it easier to implement ethical decisions? For one thing, based on a recent questionnaire-based survey of randomly selected 91 ICU physicians, there appears to be a general acceptance of compassionate care in the terminally ill, especially in non-teaching and teaching private hospitals.[22] A workable legal procedure would reassure physicians of the validity of ethical decisions when the prescribed legal procedure is followed.

The primary medical board comprises the admitting physician, the intensivist, and any other specialist involved in the case. The secondary medical board of three other physicians requires one member to be empaneled by the District Chief Medical Officer (CMO). The empaneled physician can be from within or outside the institution. A permanent set of empaneled doctors can be constituted by the CMO much like that for a hospital Brain Death committee. Of note, it is stipulated by the SC that the secondary board shall provide its opinion within 48 hours, covering for the

time-sensitive nature of these decisions in an ICU. All physicians need to hold only 5 or more years of experience (unlike the 20 or more years stipulated by the 2018 judgment).

The Way Forward

We can take heart from improved physician- and nurse-assessed Quality of Death and Dying (QODD) scores in South Korea following its recent promulgation of the "well-dying law."[23] Since now in India the procedure is simplified for both AD and WD/WH, we can likewise expect a wider utilization of these provisions than hitherto. Yet, sustained advocacy to promote death literacy and discourse among both the public and physicians is the need of the hour. Training curricula in EOLC for physicians must begin early, including bioethics, standard clinical pathways, and legal provisions for FLST. The push for improving the quality of dying at the policy level and later for definitive legislation must be pursued with renewed vigor. After a long night of waiting for path-breaking reform in the care of the dying, we can look forward to a new dawn.

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References

1. Mani RK. Coming together to care for the dying in India. Indian J Crit Care Med 2014;18:560–562. DOI: 10.4103/0972-5229.140139.
2. Piers RD, Azoulay E, Ricou B, Ganz DF, Decruyenaere J, Max A, et al. APPROPRICUS Study Group of the Ethics Section of the ESICM. Perceptions of appropriateness of care among European and Israeli intensive care unit nurses and physicians. JAMA 2011;306:2694–2703. DOI: 10.1001/jama.2011.1888.
3. Sallnow L, Smith R, Ahmedzai SH, Bhadelia A, Chamberlain C, Cong Y, et al. Report of the Lancet Commission on the Value of Death: Bringing death back into life. Lancet 2022;399:837–884. DOI: 10.1016/S0140-6736(21)02314-X.
4. Benoit DD, Jensen HI, Malmgren J, Metaxa V, Reyners AK, Darmon M. DISPROPRICUS study group of the Ethics Section of the European Society of Intensive Care Medicine. Outcome in patients perceived as receiving excessive care across different ethical climates: A prospective study in 68 intensive care units in Europe and the USA. Intensive Care Med 2018;44(7):1039–1049. DOI: 10.1007/s00134-018-5231-8.
5. Nin Vaeza N, Martin Delgado MC, Heras La Calle G. Humanizing intensive care: Toward a Human-Centered Care ICU Model. Crit Care Med 2020;48:385–390. DOI: 10.1097/CCM.0000000000004191.
6. Mark NM, Rayner SG, Lee NJ, Curtis JR. Global variability in withholding and withdrawal of life-sustaining treatment in the intensive care unit: a systematic review. Intensive Care Med 2015; 41:1572–1585. DOI: 10.1007/s00134-015-3810-5.
7. Dzeng E, Bein T, Curtis JR. The role of policy and law in shaping the ethics and quality of end-of-life care in intensive care. Intensive Care Med 2022;48:352–354. DOI: 10.1007/s00134-022-06623-2.
8. Barnett VT, Aurora VK. Physician beliefs and practice regarding end-of-life care in India. Indian J Crit Care Med 2008;12(3):109–115. DOI: 10.4103/0972-5229.43679.
9. Phua J, Joynt GM, Nishimura M, Deng Y, Myatra SN, Chan YH, et al. ACME Study Investigators and the Asian Critical Care Clinical Trials Group. Withholding and withdrawal of life-sustaining treatments in intensive care units in Asia. JAMA Intern Med 2015;175:363–371. DOI: 10.1001/jamainternmed.2014.7386.
10. Mani RK, Amin P, Chawla R, Divatia JV, Kapadia F, Khilnani P, et al ISCCM position statement: limiting life-prolonging interventions and providing palliative care towards the end of life in Indian intensive care units. Indian J Crit Care Med 2005:9;96–107. DOI: 10.4103/0972-5229.17097.
11. Law Commission of India. 196th report (2006). Medical treatment of terminally ill patients (for the protection of patients and Medical practitioners). Available from: http://lawcommissionofindia.nic.in/reports/rep196.pdf. (accessed on April 18, 2023).
12. Mani RK, Amin P, Chawla R, Divatia JV, Kapadia F, Khilnani P, et al. Guidelines for end-of-life and palliative care in Indian ICUs: ISCCM consensus ethical position statement. Indian J Crit Care Med 2012;16(3):166–181. Doi: 10.4103/0972-5229.102112.
13. Myatra SN, Salins N, Iyer S, Macaden SC, Divatia JV, Muckaden M, et al. End-of-life care policy: An integrated care plan for the dying. Ind J Crit Care Med 2014;18:615–635. DOI: 10.4103/0972-5229.140155.
14. Aruna Shanbaug vs Union of India [2011]2SCR869.
15. Divatia JV, Mehta Y, Govil D, Zirpe K, Amin PR, Ramakrishnan N, et al. the INDICAPS-II investigators. Intensive Care in India in 2018–2019: The Second Indian Intensive Care Case Mix and Practice Patterns Study. Indian J Crit Care Med 2021;25(10):1093–1107. DOI: 10.5005/jp-journals-10071-23965.
16. The Law Commission of India. 241st report. Passive Euthanasia: A relook (2012). Available from: https://indiankanoon.org/docfragment/133438875/?formInput=law%20commission (accessed April 18, 2023).
17. Sudore RL, Lum HD, You JJ, Hanson LC, Meier DE, Pantilat SZ, et al. Defining advance care planning for adults: A consensus definition from a multidisciplinary Delphi panel. J Pain Symptom Manage 2017;53(5):821–832. DOI: 10.1016/j.jpainsymman.2016.12.331.
18. Reportable In The Supreme Court of India Civil Original Jurisdiction (Civil No 494 0f 2012. Justice KS Puttaswamy (Retd.) vs. The Union of India. AIR 2017 SC 4161.
19. Reportable In The Supreme Court of India Civil Original Jurisdiction. Common Cause Vs The Union of India. Writ Petition (Civil) no. 215 of 2005.
20. Mental Healthcare Act 2017. Available from: https://egazette.nic.in/WriteReadData/2017/175248.pdf.
21. Miscellaneous Application No. 1699/2019. Available from: https://isccm.org:9001/static/Highlighted-25360_2019_3_504_41295_Judgement_24-Jan-2023.pdf [cited 18th April 2023].
22. Kapoor I, Prabhakar H, Mahajan C, Zirpe KG, Tripathy S, Wanchoo J, et al. A nationwide survey on the practice of end-of-life care issues in critical care units in India. Indian J Crit Care Med 2023; 27(5):305–314.
23. Lee YJ, Ahn S, Cho JY, Park TY, Yun SY, Kim J, et al. Change in perception of the quality of death in the intensive care unit by healthcare workers associated with the implementation of the "well-dying law". Intensive Care Med 2022;48:281–289. DOI: 10.1007/s00134-021-06597-7.