

Who Cares About Me? The Need of the Hour is to Improve Awareness and Quality of End-of-life Care Practices in Indian Intensive Care Units

Umadri Singh¹, Indubala Maurya², Mohan Gurjar³

Keywords: Awareness, Educational program, End-of-life care, Ethical issues, Legal issues, Practice, Quality care, Terminal care.
Indian Journal of Critical Care Medicine (2023); 10.5005/jp-journals-10071-24512

In real-world practice, critical care physicians often encounter situations in the intensive care unit (ICU) where continuing invasive life-sustaining therapies appears to be potentially non-beneficial, further increasing the suffering of the patient and caregivers. The “end-of-life care” (EOLC) in these clinical conditions poses a unique challenge to critical care physicians due to its practical, ethical, moral, and legal issues. Though few countries and academic societies have prepared EOLC policies, they are still not uniform and many inconclusive aspects have not been addressed.^{1–4}

The Indian Council of Medical Research (ICMR) has defined EOLC as “An approach to a terminally ill patient that shifts the focus of care to symptom control, comfort, dignity, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life.” The concept resides on the foundations of the right to a dignified death under Article 21 of the Indian Constitution.⁵ Despite the better awareness and acceptance of EOLC in the socio-political context in terminally ill conditions, there are marked differences when EOLC comes into the picture for ICU patients who are most of the time already on life-sustaining supportive therapies. In 2005, the Indian Society of Critical Care Medicine (ISCCM) published the first Indian document summarizing existing legal solutions that physicians can use for their defense; which they later (2009) formulated into a guideline providing rationale and advisory regarding several EOLC situations.^{6,7} After the historic Aruna Shanbaug judgment in 2011, ISCCM published (2012) a position statement reemphasizing further the previous guidelines and including the proceedings of the landmark case.⁸ Recently in 2020, ICMR described the principles of “Do not attempt resuscitation (DNAR)” and provided guidelines.⁹

The primary goal of EOLC in any condition is to ensure patients’ comfort, dignity, and respect during their final stages of life. The EOLC approaches for ICU patients vary based on cultural, ethical, and legal considerations. Some common approaches and terminologies are (A) “Comfort Care,” which focuses on providing comfort and relieving suffering for the patient. The emphasis is on pain management, symptom control, and psychological support; (B) “Withholding or withdrawing life-sustaining treatment” where ongoing treatment is no longer beneficial, and the decision may be made to withhold or withdraw life-sustaining interventions. This might include an approach of not escalating, adding, or starting any new life-supportive therapies or considering discontinuing new life-supportive therapies, or considering to discontinue any or all treatments like mechanical ventilation, dialysis, or medications to prolong life. The focus shifts toward providing palliative care and

^{1,3}Department of Critical Care Medicine, Sanjay Gandhi Postgraduate Institute of Medical Sciences, Lucknow, Uttar Pradesh, India

²Department of Anaesthesiology, Kalyan Singh Super Speciality Cancer Institute, Lucknow, Uttar Pradesh, India

Corresponding Author: Mohan Gurjar, Department of Critical Care Medicine, Sanjay Gandhi Postgraduate Institute of Medical Sciences (SGPGIMS), Lucknow, Uttar Pradesh, India, Phone: +91 9918386530, e-mail: m.gurjar@rediffmail.com

How to cite this article: Singh U, Maurya I, Gurjar M. Who Cares About Me? The Need of the Hour is to Improve Awareness and Quality of End-of-life Care Practices in Indian Intensive Care Units. *Indian J Crit Care Med* 2023;27(8):523–525.

Source of support: Nil

Conflict of interest: None

ensuring a peaceful and dignified death; (C) “Do-not-resuscitate (DNR)” approach is a medical directive that indicates a decision taken well in advance to forego cardiopulmonary resuscitation (CPR), including “Do-not-intubate (DNI)” in the event of the clinical condition requiring resuscitation. The DNR orders can be implemented when the benefits of resuscitation are deemed unlikely to result in a meaningful recovery; (D) “Passive euthanasia” is often used interchangeably with “withholding and withdrawing treatment,” while some describe passive euthanasia which involves intentionally causing death by withholding or withdrawing treatment with the explicit purpose of ending the patient’s life.

A recently published largest study on EOLC practices in ICUs across 36 countries (Ethicus-2) revealed that limitations of life-sustaining therapies in ICU patients are commonly practiced worldwide with regional variability.¹⁰ Withholding life-sustaining treatment (44.1%) and withdrawing life-sustaining treatment (36.4%) was the most common practice for EOLC. More withdrawal treatment was standard in Northern Europe and Australia/New Zealand than in Latin America and Africa. Geographic location, age, diagnoses (acute and chronic), and the local legislation in the respective countries influenced the variation of EOLC globally.

The current issue of the *Indian Journal of Critical Care Medicine* publishes a survey-based study by Kumar et al. on assessing practical aspects of EOLC practices across Indian ICUs.¹¹ Their study had a web-based survey on 16 multiple-choice questions. Most respondents practice “Do not intubate” (91%) and “Do not

resuscitate" (86%). Withhold or withdrawn renal support (84%) was also common practice. One-fifth (18%) of respondents do terminal extubation; while palliative sedation by two-thirds (62%) only. The primary reason for avoiding the EOL decision was a moral dilemma and fear of litigation. However, the major concern of this study is a smaller number of respondents (only 200) in a country where the national professional society of critical care physicians (ISCCM) has more than 15,000 active members. The study finding does not cover the response rate and participants' experiences, which could influence their findings and limit generalizability. The authors used only closed-ended survey questions, thus not allowing participants' unrestricted opinions. Adding a few semi-closed questions would have allowed participants to express themselves. Out of 16, 10 questions have only two options, "yes" and "No," which is not always possible to answer explicitly. Besides this, inherent drawbacks of any survey-based cannot be ignored, such as response bias, interpretation bias, etc.

A similar cross-sectional online survey, performed with a small number of 91 clinicians found a varied practice pattern of EOLC in Indian ICUs depending upon hospital settings (government/private), location (urban/suburban/rural), and years of work experience.¹² Respondents working in urban setup frequently provided sedation as palliation, but imposed limitations on the number of relatives or loved ones of the patients who had come to meet them. Critical care physicians working in private non-teaching settings discussed more the care plan with relatives of the patient (95.45%), followed by private teaching centers (86.79%), and government institutes (50%). They also observed that respondents from private non-teaching institutes often consider withholding or withdrawing of care in terminally ill patients (50%) followed by private teaching centers (41.51%) and government centers (6.25%).

Another survey from different ICUs at a tertiary care center in India found that limited knowledge and lack of formal training was the main barrier to EOLC practice.¹³ The comfort and proficiency of doctors regarding managing and discussing EOLC differed, with some specialties showing more cognizance and comfort than others. Most respondents had not counseled more than five families regarding EOLC over 1 month. The majority of the respondents (81.7%) had heard of EOLC; mainly through their work in the concerned specialty. Only 20.3% of the respondents were aware of Indian guidelines about EOLC. One-third of respondents found discussing EOLC issues with the families troublesome.

In India, EOLC practices might be influenced not only by wide variation in the social and financial background of the family, their cultural beliefs, and traditions toward death but also by healthcare setups and critical care physicians' understanding of EOLC, their communication skills, availability of time to discuss with family members. Family plays an essential role in ICU patients because of the incapability of patients to take decisions for them; therefore, familial discordance regarding treatment choices can hinder appropriate and timely decision-making. The more awareness and understanding about EOLC among critical care physicians, more time and engagement with family members, and proper documentation might improve the very purpose of EOLC. The EOLC practice for the ICU patient is expected to be better in a few aspects than in other areas of hospital settings because clinicians can have an easy approach for better alleviation of symptoms such as pain, anxiety, and respiratory distress.

In the process of EOLC practice, there remained an important unanswered question "How to ascertain the quality of EOLC practice

within the frame of existing available policies and guidelines for country specific as well as ICU and non-ICU settings?" In a large retrospective cross-sectional study from US, done at 146 inpatient facilities (including acute care, long-term care, and inpatient hospice), the quality of EOLC provided to patients with different serious illnesses was assessed by the family members.¹⁴ The rates of excellent EOLC quality reported by 34,005 decedents' families were similar for cancer and dementia patients, but lower for patients with end-stage renal disease, cardiopulmonary failure, or frailty.

A recently implemented procedural guideline by the Supreme Court of India on 24 January 2023 offers a practical approach expected to facilitate ethical decision-making during the end-of-life stage in India.¹⁵ Once the treating physician finds futility in continuing life-sustaining therapy in a patient who is terminally ill and incapacitated; the two separate medical boards, one primary and the other review (secondary) are required to assess the patient's medical condition. The hospital has to constitute both boards, including a nominee doctor from the district medical officer (for the secondary board). Each medical board is expected to decide on such cases within 48 hours. These guidelines mark a significant step in developing legal provisions concerning advance directives and decisions related to withdrawing and withholding treatment in terminal care.

In India, it is the need of the hour to have well-framed programs like continuing medical education, workshops, etc. through professional societies to improve awareness about EOLC policies among clinicians who deal with terminally ill patients, including critical care physicians. Further, involving palliative care physicians, allowing family members to spend more time with their patients, having quiet and private surroundings, empathetic care, and effective communication by medical and nursing team members might improve the quality of EOLC in the ICU.

ORCID

Umadri Singh  <https://orcid.org/0000-0002-6379-9628>

Indubala maurya  <https://orcid.org/0000-0002-3593-2313>

Mohan Gurjar  <https://orcid.org/0000-0002-8489-0324>

REFERENCES

1. Bloomer MJ, Ranse K, Butler A, Brooks L. A national position statement on adult end-of-life care in critical care. *Aust Crit Care* 2022;35(4): 480–487. DOI: 10.1016/j.aucc.2021.06.006.
2. 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: A Joint Position Statement of the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC). *Indian J Crit Care Med* 2014;18(9):615. DOI: 10.4103/0972-5229.140155.
3. Bhatnagar S, Biswas S, Kumar A, Gupta R, Sarma R, Yadav HP, et al. Institutional end-of-life care policy for inpatients at a tertiary care centre in India: A way forward to provide a system for a dignified death. *Indian J Med Res* 2022;155(2):232–242. DOI: 10.4103/ijmr.IJMR_902_21.
4. Kumar A, Psirides A, Maheshwari N, Chawla V, Mandal AK. Framework for decision-making and management of end-of-life decisions in intensive care units: A modified protocol. *Indian J Crit Care Med* 2015;19(11):655–660. DOI: 10.4103/0972-5229.169339.
5. Salins N, Gursahani R, Mathur R, Iyer S, Macaden S, Simha N, et al. Definition of terms used in limitation of treatment and providing palliative care at the end of life: The Indian Council of Medical Research Commission Report. *Indian J Crit Care Med* 2018;22(4): 249–262. DOI: 10.4103/ijccm.IJCCM_165_18.

6. Mani RK, Balakrishnan S. The constitutional and legal provisions in Indian law for limiting life support. *Indian J Crit Care Med* 2005;9: 108–114. DOI: 10.4103/0972-5229.17098.
7. Mani RK, Mandal AK, Bal S, Javeri Y, Kumar R, Nama DK, et al. End-of-life decisions in an Indian intensive care unit. *Intensive Care Med* 2009;35:1713–1719. DOI: 10.1007/s00134-009-1561-x.
8. Mani RK, Amin P, Chawla R, Divatia JV, Kapadia F, Khilnani P, et al. Guidelines for end-of-life and palliative care in Indian intensive care units: ISCCM consensus Ethical Position Statement. *Indian J Crit Care Med* 2012;16(3):166–181. DOI: 10.4103/0972-5229.102112.
9. Mathur R. ICMR Consensus Guidelines on “Do Not Attempt Resuscitation”. *Indian J Med Res* 2020;151(4):303–310. DOI: 10.4103/ijmr.IJMR_395_20.
10. Avidan A, Sprung CL, Schefold JC, Ricou B, Hartog CS, Nates JL, et al. Variations in end-of-life practices in intensive care units worldwide (Ethicus-2): A prospective observational study. *Lancet Resp Med* 2021;9(10):1101–1110. DOI: 10.1016/S2213-2600(21)00261-7.
11. Kumar A, Sinha S, Mani RK. A survey for assessment of practical aspects of end-of-life practices across Indian intensive care units. *Indian J Crit Care Med* 2023;27(8):531–536.
12. 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;7(5):305–314. DOI: 10.5005/jp-journals-10071-24446.
13. Agrawal K, Garg R, Bhatnagar S. Knowledge and awareness of end-of-life care among doctors working in intensive care units at a tertiary care center: A questionnaire-based study. *Indian J Crit Care Med* 2019;23(12):568–573. DOI: 10.5005/jp-journals-10071-23293.
14. Wachterman MW, Pilver C, Smith D, Ersek M, Lipsitz SR, Keating NL. Quality of end-of-life care provided to patients with different serious illnesses. *JAMA Intern Med* 2016;176(8):1095–1102. DOI: 10.1001/jamainternmed.2016.1200.
15. Supreme Court of India. Common Cause (A Regd. Society) ... vs Union of India (A) Ministry of ... on 24 January, 2023. Available at: <https://indiankanoon.org/doc/55919876/>. Accessed on: 23 July 2023.