ORIGINAL ARTICLE

A Survey for Assessment of Practical Aspects of End-of-life Practices across Indian Intensive Care Units

Arun Kumar[1], Sharmili Sinha[2], Raj Kumar Mani[3]

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Abstract

Background: The end-of-life (EOL) decisions continue to be debated for their moral and legal standing. The acceptance of these decisions varies, based upon the perceptions and personal choices of the intensivists.

Materials and methods: An online questionnaire-based survey was designed and circulated among the practicing intensivists via Indian Society of Critical Care Medicine (ISCCM) e-mail.

Results: Out of 200 responses, 165 (82.5%) affirmed that EOL decisions are routinely undertaken in their intensive care units. The most prevalent reasons expressed for avoidance of EOL decisions are moral and ethical dilemmas and fear of litigation. There is notable variability in the practice of withholding (47.7%) vs withdrawal (3.5%) of therapies. A good proportion of intensivists follow do-not-intubate (91%) and do-not-resuscitate (86%) orders, whereas only 18% affirmed to be practicing terminal extubation. About 93% of the respondents acknowledged the use of monitoring toward the EOL, and 49% reported the use of preformatted documents. A meager 2% admitted to facing a medicolegal issue after taking an EOL decision.

Conclusion: The survey establishes a general acceptance among the Indian intensivists regarding providing compassionate care to terminally ill patients, especially toward the EOL. The pattern of responses, however, indicates significant dilemmas and hesitancy with regard to the decision-making process.

Keywords: Decision-making, End-of-life care, India, Intensive care units, Surveys and questionnaires.

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Highlights

- The article discusses the perceptions and dilemma of Indian intensivists regarding the practical aspects of the end-of-life (EOL) decisions, especially the decision-making process.
- The survey presents an objective sneak peek at the current end-of-life practices, identifies the gaps in the knowledge, and adds to the pool of limited data available regarding such practices in India.

Introduction

End-of-life decisions have long been debated for their moral and legal standing among the practicing physicians. The acceptance of these decisions varies, depending upon the perceptions and personal choices of the intensivists. The past two decades have been a witness to greater approval of such decisions by our professional societies, judiciary, and legislature.[1–5] The Indian Society of Critical Care Medicine (ISCCM) has been at the helm of affairs both as an advocate and a guiding force to influence and pursue the judiciary and the legislature regarding the rights of terminally ill patients. The legal protocols and the professional regulatory guidelines, however, have acted more as a deterrent and limited the accessibility of these decisions. The current survey was designed with an intent to understand the practical aspects of EOL practices across Indian ICUs, identify the gaps in the knowledge, and thereby establish the avenues to improve the perceptions and practices regarding end-of-life care.

[1]Department of Intensive Care, Medical Intensive Care Unit, Fortis Healthcare Ltd., Mohali, Punjab, India

[2]Department of Critical Care Medicine, Apollo Hospitals, Bhubaneswar, Odisha, India

[3]Department of Critical Care and Pulmonology, Yashoda Super Specialty Hospital, Ghaziabad, Uttar Pradesh, India

Corresponding Author: Arun Kumar, Department of Intensive Care, Medical Intensive Care Unit, Fortis Healthcare Ltd., Mohali, Punjab, India, Phone: +91 9872828779, e-mail: arun.udhv@gmail.com

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Materials and Methods

A total of 16 multiple-choice structured questions were formatted using Microsoft Forms (Appendix 1). An initial draft of the questionnaire was deliberated by the authors regarding the content, clarity, and its relevance to the intended aim of the survey. Judicious care was taken to identify potential issues such as ambiguous or confusing questions, response options, and formatting problems.

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Table 1: Baselines responses to survey questions

	Responses (percentage)		
Survey questions	*Yes*	*No*	*Seldom*
Practicing EOL decisions	165 (82.5%)	35 (17.5%)	
Offering do-not-intubate (DNI)	182 (91%)	18 (9%)	
Offering do-not-resuscitate (DNR)	171 (86%)	29 (14%)	
Offering noninvasive ventilation to patients on DNI pathway	66 (33%)	57 (28.5%)	77 (38.5%)
Withhold/withdrawing renal support (HD/SLEDD/CRRT) when shifting to EOL pathway	167 (84%)	31 (16%)	
Practice terminal extubation (TE)	36 (18%)	163 (82%)	
Practice terminal weaning (TW)	76 (38%)	123 (62%)	
Practice palliative sedation	120 (62%)	40 (21%)	35 (18%)
Monitoring in patients on EOL pathway	185 (93%)	14 (7%)	
Explain legal position of our country on EOL	148 (74%)	51 (26%)	
Use of pre-formatted documents for documentation	97 (49%)	102 (51%)	
Faced medicolegal issue for EOL decision	4 (2%)	195 (98%)	
Hospital/healthcare center's name revealed (optional)	103 (51.5%)	97 (48.5%)	

Table 2: Responses to questions with options to select multiple choices

Survey questions	*Responses (percentage)*			
Reasons for avoiding EOL decisions	Moral or ethical dilemma 91 (35%)	Fear of litigations 88 (33%)	Lack of support from peers 41 (15.5%)	Organizational policy 43 (16.5%)
EOL options offered to the families	Withholding 95 (47.7%)	Withdrawal 7 (3.5%)	Both withholding and withdrawal 88 (44.2%)	None 9 (5%)
Plan regarding inotropic support for a patient shifted to EOL pathway	Do not initiate inotropic support 62 (23%)	Do not further escalate the doses if the inotropes are already on flow, but do not stop 163 (60.6%)	Stop all inotropes once EOL pathway is adopted 44 (16.3%)	

A random group of intensivists was requested to fill the survey, and their opinions were amalgamated to design the final version of the questionnaire. The intention to conduct the survey was communicated to the ISCCM-organizing committee. After the necessary approvals, the survey was circulated by the ISCCM office to the registered members vide official mail (isccm@isccm.org) on 29.11.2022. Most of the questions required a single-option response, whereas responders could choose multiple choices in three questions (Q2, Q3, and Q7). The responders were given the option to keep themselves anonymous, hence, the option of identifying the institute of the participant was kept as optional (Q16).

Results

A total of 200 responses were obtained over a 2-week period after floating the survey via ISCCM mail. A few participants of the survey did not provide answers to all the questions. The responses for the direct questions (yes/no/seldom) are presented in Table 1. The response to questions regarding the avoidance of EOL decisions, the modality of EOL care offered to families, and plans regarding the utilization of inotropic support toward the EOL pathway have been presented in Table 2.

Discussion

The EOL decisions in an intensive care setting continue to be widely debated for their legal and ethical ramifications. The practices vary, more so guided by the local hospital policy, physician biases, and family preferences. The "Good Death" journey of our country began with the first ISCCM position paper by Mani et al., which was followed by 17th Law commission's 196th report on "Medical Treatment to Terminally ill patients (Protection of Patients and Medical practitioners Bill) 2006".[1,2] The Aruna Shanbaug case became the first Indian case law (2011) directly addressing the issue of withdrawal of artificial life support.[3] The principle of "Parens Patriae" was invoked, which held that the judiciary is the ultimate decider of what is best for the patient. A significant development to bring in the reforms was the position paper on the care of the dying, published by the Indian Society of Critical Care Medicine (ISCCM) and the Indian Association of Palliative Care (IAPC).[4] The Common Cause vs Union of India, a historic judgment by Supreme Court of India (2018), upheld the right to die with dignity as an inextricable facet of Article 21 of the Constitution of India.[5] The draft "End-of-Life care" policy (2020) developed by a team of experts at the All India Institute of Medical Sciences (AIIMS, New Delhi) offered terminal patients and their family members the options of withholding life-sustaining care.[6] Despite the above developments in the last two decades, the EOL decisions continue to be mired by ethico-legal debates. The recently proposed amendment to the "Common cause" judgment is a reflection to the fact that our judiciary does acknowledge the impractical nature of the current procedural safeguards.[7]

While the legal aspects on the practice of good death continue to evolve, we planned a survey to understand the current

acceptance of EOL decisions and to identify the gaps and challenges regarding such decisions in Indian ICUs.

As per our survey, 82.5% of the total participants affirmed that EOL are routinely being taken in their ICU. The recently published Ethicus-2 study has investigated the global disparity in the EOL practices in ICUs worldwide. The limitations of life-sustaining treatment occurred in 11.8% of the ICU admissions and 80.9% of the study population.[8] A study by Kapadia et al. way back in 2005, had revealed limitations of therapy in 19% of deaths in public hospital ICUs vs. 40–50% of deaths in private hospitals and cancer hospitals in Mumbai.[9]

Another retrospective observational study by Mani et al. in a medical–surgical ICU of a private hospital had revealed decision to limit therapy (mostly withholding or DNAR) in nearly half of the dying patients in the ICU.[10]

The moral or ethical dilemma and fear of litigations were chosen as the major deterrents to the practice of EOL decisions followed by organizational policy and lack of support from peers. The results of our survey are in sync with the global perception among the intensivists. Syrous et al. published the results of in-depth thematic analysis of semistructured interviews of Swedish critical care specialists, highlighting the reasons for physician-related variability in EOL decision-making. The study found that such variability was based on intensivist's personality, experience, values, avoidance of criticism and conflicts, and individual strategies for emotional coping.[11] A systemic review by Visser et al. too indicated lack of communication skills among physicians, gaps in prognostic estimation, and lack of knowledge about the relevant legal framework as the important barriers to the provision of good EOL care in the ICU.[12]

As per our survey, withholding (nonescalation) continues to be a more favorable EOL option. Since the respondents were given the option to choose multiple answers, those opting for withholding treatments appear to be equally comfortable with withdrawal (de-escalation). However, isolated withdrawal was reported only by a miniscule 4% of the respondents. Melltorp and Nilstun, in an article published in intensive care Medicine, had identified the problem as withdrawing been seen as an "action" rather than the passive "omission" of withholding.[13] A similar observation has been noticed in various surveys and questionnaires where withdrawal was considered more difficult than withholding.[14,15] Vincent, in an article published in critical care, way back in 1995, had argued that both withdrawal and withholding are indeed ethically equivalent and that withdrawing life-sustaining therapy may in fact be preferable to withholding. He further contended that, "although, emotionally it may be easier to withhold treatment than to withdraw that which has been started, there are no legal, or necessary morally relevant, differences between the two actions".[16]

The ANZICS statement on care and decision-making at the EOL clearly suggests that there is a certain amount of benefit to withdrawal as it allows assessment of the patient's response to treatment and provides more time for the family to witness that the patient has not improved despite the interventions.[17]

In our survey, we found a good proportion of respondents with acceptance of do-not-intubate (91%)/do-not-resuscitate (86%) as a modality of EOL care. Wilson et al. had conducted a systemic review and meta-analysis of the do-not-intubate orders in patients with acute respiratory failure. As per their study findings, there is an increase in the rates of DNI orders over the past two decades, which is reflective of a greater focus on the utility of EOL care, changing ethical climates, and increased utilization of noninvasive ventilation (NIV), especially in patients who are deemed to not benefit from intubation.[18] Do-not-attempt resuscitation (DNAR) is increasingly being practiced in cases where cardiopulmonary resuscitation (CPR) is considered futile and to maintain dignity in dying. The recently published consensus guidelines by ICMR have extended the scope of DNAR to a patient with progressive debilitating, incurable, and/or terminal illness where medically meaningful survival is not expected.[19] A greater acceptance of DNI/DNR as per our survey may be a reflection of these modalities being perceived as withholding rather than withdrawal.

Noninvasive ventilation (NIV) is increasingly being used for dyspneic patients with acute respiratory failure, especially after a "do-not-intubate" orders. As per our survey, the results project a divided house regarding the perception of the role of NIV toward the EOL. About 33% of the respondents were in favor, whereas 28% were against and 39% indecisive about its use. The intention to use NIV in the current context is solely for symptom relief. The opponents to the role of NIV in patients with DNI orders believe that it is discomforting and results in medicalization and prolongation of dying process. They further argue that NIV once initiated creates an ambiguity in terms of the aim of treatment, particularly around when to discontinue NIV and when to introduce sedatives and opiates.[20] Curtis et al. have formulated that NIV should be applied after careful discussions of the goals of care, with explicit parameters for success and failure and defined endpoints weighing the benefits vs the burden of life support interventions.[21]

The perceptions regarding the use of inotropes similarly echo the general preference toward not escalating (60.6%) the already-on-flow infusion doses any further, followed by not initiating the inotropic support (23%). The least-favored response (16.3%) is to withdraw the ongoing inotropic support. A possible explanation is the apprehension or guilt among the intensivists that acute withdrawal may result in sudden demise of the patient. As per the ANZICS statement, cessation of inotropic support does not result in any discomfort to the patient, and therefore staged de-escalation is unnecessary.[17]

There appears to be a greater consensus regarding the utilization of renal support for a patient being shifted to comfort care pathway. About 84% of the respondents agreed to practice withholding or withdrawal of renal support.

The question regarding terminal extubation (TE) and terminal weaning (TW) revealed that TE is practiced only by 18%, while TW found acceptance among 38% of respondents. Our results are in sync with the nearly two-decade-old survey of SCCM physicians, where preference for TE and TW was 13% and 33%, respectively.[22] A greater acceptance of TW is probably due to lesser moral burden on the physician and the family, as it is considered less intrusive than TE. Furthermore, the patient remains comfortable without any possibility of acute air hunger or distress related to secretions.[23] As per the article published in Chest (1994), TE has limited acceptance as it is often equated to an act of commission. The authors, however, expressed that TE has the advantage of allowing the patient to be free from an unnatural endotracheal tube and does not prolong the process of dying.[22]

Palliative sedation is an intervention aimed at alleviation of intolerable suffering resulting from one or a combination of symptoms.[24] A total of 195 participants responded to this query. About 62% of the respondents admitted to practicing palliative sedation, whereas 21% clearly denied it. Another 18% answered that

they seldom consider using the palliative sedation. The practice has its share of controversy in clinical practice, with one argument that it is used as a covert form of euthanasia.[25] Despite the data suggesting that palliative sedation does not hasten the death of patients, there still is a concern for abuse where clinicians may administer doses with a potential to hasten demise.[26,27]

The recent William Husel controversy, where he was tried for 14 counts of murder for administering excessive doses of fentanyl prior to TE, exposes the professionals to risks associated with the use of palliative sedation. He was found not guilty as the juror accepted the defense plea that the patient died after being taken off the ventilator rather than the fentanyl he prescribed.[28] A strong recommendation is to use the level of sedation, which is the lowest necessary to provide comfort and relieve suffering, while continuing with humane and dignified treatments and routine monitoring and evaluation.[29]

The monitoring of vital parameters is continued for most of the patients even after shifting to comfort pathway. As per our survey, 93% of the respondents acknowledged use of monitoring toward the EOL. We have, however, realized that the use of monitors results in the mere medicalization of death. The families who are allowed at the bedside have their gaze fixed on the monitors and one can easily perceive their distress with every change in vital parameters. This aspect too needs to be addressed when conversations are held regarding the transition to comfort care pathway and consensus decisions being taken toward modalities to be discontinued. The ANZICS guidelines recommend optimization of ICU settings in terms of privacy, lighting, and removal of monitoring devices and unnecessary tubes and infusions.[17]

There is a general belief that EOL decisions are fraught with legal implications, and this becomes a major barrier to taking these decisions in the ICU. In response to our survey question, 74% of the respondents reported informing the family regarding the legal framework of our country with regard to EOL decision. In our opinion, the moral fabric of the EOL decisions is based on honest and open discussions and trust. A judicious explanation to the families about the legalities would only bring more transparency to the entire decision-making process. In the event of an impasse from any of the stakeholders (treating team/family), the option of involving the court must also be discussed and explained.

A thorough and accurate documentation is fundamental to safeguard the patient, the surrogates, and the physician interest. As applied to EOL decisions, meticulous documentation ensures that healthcare professionals fulfill their professional and legal obligations and are less likely to have the processes questioned in the event of litigation.[17]

As per our survey, 49% of the respondents have reported use of preformatted document for EOL decision. The annexures included in the AIIMS draft policy on EOL and a EOL checklist developed by Kumar et al., are suggested to aid the intensivists in decision-making and formulation of care plan.[6,30] The APT documentation must include details of communication, discussion, and final decision regarding the modalities of comfort care pathway.[1,4]

Out of the total responses, only 2% (4/199) admitted to having faced litigation after taking an EOL decision. The details of the litigation were not captured.

The response to the final question regarding the affiliated institute was kept as optional. Nearly 50% of the responders kept their replies as anonymous. Among the responders who identified their hospitals, nearly 40% were from the southern parts of India, 25% from the north, 10% from central India, 8% from west, and 6% from the eastern part of our country.

Conclusion

This survey reflects the general perception of the intensivists across India, regarding the practical aspects of EOL decision-making process. The findings of our study echo a general acceptance of EOL care pathways. The moral and ethical dilemma along with the risk of litigations appears to be the predominant barrier toward such decisions. The pattern of responses indicates conflict and hesitancy with regard to the concept of withholding and withdrawal. The variability in perceptions and practices needs to be acknowledged and addressed. A future survey with in-depth questionnaire is warranted to identify the reasons for variation in practices. The authors wish to use the gathered information to design a pilot study with a better design for future research.

Limitations and Suggestions for Future Research

This is just a questionnaire-based survey, and the actual documentation of the EOL decisions was not verified. A greater response rate would have provided deeper insights regarding the perceptions regarding EOL care. The survey, being a preliminary attempt to understand the perceptions of intensivists, did not endeavor to evaluate the difference in practices between the public–private sectors, the categorization of terminally ill patients, and type of drugs used for palliative sedation.

Orcid

Arun Kumar https://orcid.org/0000-0001-6522-007X

Sharmili Sinha https://orcid.org/0000-0001-5242-9405

Raj Kumar Mani https://orcid.org/0000-0003-4759-8233

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Appendix 1: Questionnaire for the survey

1. Do you take end-of-life decisions in your unit?
   a) Yes
   b) No
2. If EOL decisions are avoided in your unit, the possible reasons are? (more than one option allowed)
   a) Fear of litigations
   b) Moral or ethical dilemma
   c) Organizational policy
   d) Lack of support from peers
3. Select the EOL options offered to the family of terminally ill patients?
   a) Withholding treatment (non-escalation)
   b) Withdrawal (de-escalation)
   c) Both of the above
   d) None of the above
4. Do you offer option of do-not-intubate (DNI)?
   a) Yes
   b) No
5. Do you offer option of do-not-resuscitate (DNR)?
   a) Yes
   b) No
6. Do you believe that noninvasive ventilation (NIV) must be offered to all patients opting for do-not-intubate (DNI) pathway?
   a) Yes
   b) No
   c) Maybe
7. What is your plan regarding inotropic support once the terminally ill patient is shifted to EOL pathway? (more than one option allowed)
   a) Do not initiate inotropic support
   b) Do not further escalate the doses if the inotropes are already on flow, but do not stop
   c) Stop all inotropes once EOL pathway is adopted
8. Do you withhold/withdraw renal support (HD/SLEDD/CRRT) when shifting to EOL pathway?
   a) Yes
   b) No
9. Do you practice terminal extubation (removal of endotracheal tube and discontinuation of mechanical ventilation)?
   a) Yes
   b) No
10. Do you practice terminal weaning (reduction in tidal volume, oxygen support, and PEEP without removal of artificial airway)?
   a) Yes
   b) No
11. Do you practice palliative sedation (defined as intentional reduction of alertness, up to loss of consciousness, by pharmacological means to reduce or abolish the perception of a symptom that is otherwise intolerable for the patient, despite the most adequate means having been put into practice to control of symptoms, which is therefore refractory). *SICP recommendations.
   a) Yes
   b) No
   c) Seldom
12. What do you do with monitoring once the terminally ill patient is placed on EOL pathway?
   a) Continue monitoring
   b) Switch off monitors
13. Do you explain the family regarding the legal position of our country while taking a EOL decision?
   a) Yes
   b) No
14. Do you use any pre-formatted document for the documentation?
   a) Yes
   b) No
15. Have you ever faced any medico-legal issues after shifting a patient on EOL pathway?
   a) Yes
   b) No
16. Hospital/healthcare center's name (optional)
   - Enter your answer