EDITORIAL

# Evaluating Determinants of End-of-life Care Provision in Indian Intensive Care Units

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In this editorial commentary, we would like to reflect on the determinants of palliative and end-of-life care (EOLC) provision in intensive care units (ICUs) in India. This commentary accompanies a survey study published in the current issue of this journal on EOLC practices by clinicians in a critical care setting in India.[1]

In this survey, Kapoor et al. found that a higher number of years as an ICU physician and urban, non-academic, private critical care settings facilitated better EOLC in Indian ICUs.[1] The study is unique, exploring the determinants of EOLC provision in Indian ICUs. A scoping title search on the SCOPUS database in April 2023 showed less than 50 published articles on EOLC in Indian ICUs. Of these, only a handful were empirical studies, making this survey a novel area of research inquiry.[2]

Despite the interesting findings of this survey, it is worthwhile to consider its limitations. Although 91 clinicians participated in this web-based survey, the number of physicians who received the web link and were disinclined to participate is not known. Therefore, the survey response rate cannot be determined. It is possible that critical care physicians with a positive view of ICU palliative care participated in this survey, which may have skewed the results. Moreover, it is also unclear from this manuscript how many critical care units participated in this survey. It is also possible that a set of clinicians with a similar approach practicing in the same ICU participated in this survey, potentially skewing the results. The binary distinction of experience as 15 years and more is arbitrary, and the three-point Likert scale used to measure response may be inadequate.[1] Further, discordance between physicians' perceptions and actual practices is a well-known phenomenon. A study compared perceived versus actual adherence to interventions recommended for the treatment of severe sepsis in 214 German ICUs. ICU directors perceived adherence to be higher than it actually was; for example, perceived adherence to ventilation using low tidal volume was 79.9%, but in reality, only 2.6% of patients received this.[3] Thus the opinions given by physicians in the current survey may not reflect real-life practices. An inherent limitation of these surveys is that one cannot ensure the reliability of individual responses.

In two large cross-sectional observational studies in Indian ICUs (INDICAPS with 4032 patients and INDICAPS-II with 4669 patients), terminal discharges accounted for 25.1% and 32.5% of all non-survivors (patients who died in ICU or were terminally discharged). Withholding and withdrawal of care in the ICU occurred in about of 8% patients in both studies.[4,5] A systematically constructed scoping review on EOLC in the ICUs was recently conducted by a team of palliative care professionals from India and the United Kingdom (UK) low and middle-income countries.[2] Legal issues surrounding withholding and withdrawing, conflicts around professional role identity, lack of palliative care training and knowledge, unrealistic expectations and inappropriate requests by the families, cultural and religious concerns, and high treatment costs were the key factors that determined the EOLC provision in ICUs. Out of 19 included studies in this systematic scoping review, nine studies were from India. A recent study from India used a theory of change approach to evaluate the role of stakeholder engagement as a strategy to facilitate the EOLC in Indian ICUs. The study conducted by a group of palliative care and critical care professionals from India and the UK, identified 12 determinants to facilitate EOLC provision in Indian ICUs. In summary, they were mitigation of legal concerns, written policy, palliative care and communication skills training for ICU physicians, improving public awareness, discussion on the goals of care, shared decision making, and enhancing recognition of medical futility.[6]

A study that explored the factors leading to delayed initiation of EOLC in terminally ill patients in Indian ICUs, found challenges associated with prognostication, hesitancy among ICU physicians, and family member reluctance to be the critical determinants of delayed EOLC.[7] A study conducted at AIIMS New Delhi in 2019 showed that ICU physicians felt uncomfortable discussing the EOLC issues. This was attributed to their lack of training. Similar to the finding in INDICAPS and INDICAPS-II, they preferred terminally ill patients to be discharged home than EOLC provided in the ICU.[8]

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The ETHICUS-2 is an important study that focuses on EOLC practices worldwide.[9] Two critical care centers and 1,402 patients from India were included in this study. Concerns surrounding withholding and withdrawing treatment and the reluctance of families to limit treatment were the significant factors determining EOLC ICU treatment in the ICUs.[9] The ACME Study was conducted to assess physicians' attitudes toward withholding and withdrawal of life-supporting treatments during EOLC and to evaluate factors associated with the observed attitudes in ICUs in Asia.[10] Physicians in Asian ICUs reported that they seldom withdrew but often withheld life-supporting treatments at the end of life, practice and attitudes varied widely across countries. There were many factors related to country and region, including legal differences, economic, religious, cultural, and personal attitudes, associated with these variations. Of the 176 physicians who participated from India, 76% reported that they almost always withheld rather than withdrew treatment during EOLC.[10] A sub-study of the ACME study found significant differences in ICU physician-reported practices of limiting life-supporting treatments, the role of families and surrogates, financial considerations and perception of legal risk between low-middle-income, and high-income Asian countries.[11]

Interestingly, the findings from this survey study[1] on factors determining EOLC in ICUs differ significantly from the studies discussed. It needs further exploration. Furthermore, the authors of this survey have not discussed and interpreted their work in relation to the contemporary literature on EOLC in the Indian ICU setting, which is discussed above. Perhaps the authors are a bit over-enthusiastic in making overarching conclusions, not fully supported by the study findings.

The 2023 Supreme Court Judgement on treatment limitation and EOLC is a welcome move towards better integration of Indian ICUs. India faces a considerable burden of health-related suffering due to unhelpful medical therapies offered at the end of life to people with serious and terminal illnesses when there is almost no chance for recovery. The quality of EOLC in India has been rated dismally low by the Quality of Death Index reports published by the Economic Intelligence Unit. Experts have been concerned about the country's slow progress in improving EOLC. Much of the delay was due to a lack of legal clarity on withdrawal, withholding of inappropriate medical interventions, and limitation of life-sustaining treatments. Previous law commission reports and Supreme Court judgments could not provide legal clarity. Moreover, the lengthy procedure requirements in the 2018 Supreme Court Judgement complicated these issues.[12] Therefore, a writ petition was filed by the Indian Society of Critical Care Medicine to seek clarification on the judgment reported in Common Cause (A Registered Society) vs Union of India and Another (2018) 5 SCC 1. In the 2023 Judgement, judges felt that it was essential to put at ease the minds of the doctors and enable them to act in the best interest of the patient when they are managing people with serious illnesses with no hope for recovery and when intensive care therapies are deemed to be unhelpful.[13] Therefore, it is prudent to generate evidence on EOLC in the Indian ICU setting. The current studies from India on ICU palliative care lack methodological rigor and are insufficient to advance this cause. It is an important area of research inquiry requiring well-conducted robust studies from India to justify integrating EOLC in the Indian ICU setting. Such studies are a step in this direction.

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