EDITORIAL

Physician Perspectives on the Quality of Dying in Indian ICUs: A Call to Attention

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Quality of dying (QoD) as a metric has at long last come into focus in India. In the last quality of death ranking India remained low calling for urgent reform.[1] There are several barriers to improving QoD in India. In this issue of the *IJCCM*, Iyer et al. study the Indian clinicians' perspectives using a qualitative research methodology that is relatively new for evaluating end of life care (EOLC).[2] We have, for long discussed the difficulties in practicing quality EOLC in India as compared with the high-income countries.[3] The alarming frequency of Left Against Medical Advice (LAMA) reflects the inadequacy of EOLC in Indian ICUs. INDICAPS I and II have revealed a high prevalence of "terminal discharges" with undocumented and unplanned treatment limitations across Indian ICUs.[4,5] Curtis et al. have shown that the Nation's culture, healthcare policy, institutional culture, physician attitudes and beliefs, and the patient/family predilections all impact EOL decision-making.[6] Another recent study in three US hospitals revealed that treatment limitations are fewer in settings where aggressive treatments are the default culture.[7] Against this background, the present study is a valuable addition to the Indian literature on physician attitudes toward EOLC in ICUs.

The study uses semiotics or the language of codes to systematically analyze semi-structured interviews.[2] Instead of using a large enough sample to achieve saturation of themes, the study employs an in-depth interview of carefully selected candidates having what is considered adequate training and experience. The interviewer, an experienced intensivist himself, uses his own subjectivity-the so-called reflexive thematic analysis. This gives a full play of the interviewer's perceptions in processing the information generated from the participants. However, in so doing, there exists an inevitable bias which is itself sought to be employed as an analytical tool in this approach. It may, therefore, be the viewpoints of this group of experts giving a snapshot of the realities on the ground that may not be generalizable to the ICUs across the country. Nevertheless, the findings are interesting as they crystallize the physician perceptions that, while appearing familiar, are being subjected to a methodical process.

Using the semiotic theory, the "signified" was identified as the idealized quality of dying and the "signifiers" are the standard operative procedures that are used to realize these objectives. Additional broad themes are the sociocultural and legal context in which EOLC is practiced and the possible strategies for the future derived from these discussions.

The subthemes of what defines quality of death and dignity (the signified) are well described by the participants of this study. These are (a) choices of patients and families are respected (b) their needs are addressed (c) their requests are met (d) care is continued toward families beyond death of the patient, (e) ensuring family satisfaction. These are among the 11 evidence-based determinants of good death recognized in a meta-analysis of systematic reviews.[8] Physician paternalism is increasingly giving way to autonomy in the Indian setting as well.[9] Respecting choices implies eliciting patient's values and preferences from the family or from Advance Directives since most patients are incapacitated in critical illness. Patient- and family-centricity are being regarded as central to EOL decision-making in Indian professional statements[10] as well as globally.[11] It is heartening to note that the participants generally acknowledged these established values.

Needs of patients can be at several levels—physical, emotional, psychosocial, and spiritual. It is now well recognized that all of this forms the standard of care.[10] Control of pain, dyspnea and distress is of utmost importance to the patient and to the family who are witness to their suffering. Additionally, spiritual/existential suffering also should be recognized and addressed. The physician role in spiritual support is now well studied, in addition to employing religious rituals and counselling by priests.[12]

Meeting the patient's preferred place of death is also important. If the preference for dying at home this must be planned and facilitated not leaving the patients and family to fend for themselves through a LAMA process. Bereavement and grief support to the family is an important metric of quality of care in the ICU as post-traumatic stress disorder and complicated grief among families are widely recognized.[13] Family satisfaction is the composite result of attention to the above. None of the participants seem to have described the use of any of the standard tools, such as Quality of Death and Dying for measuring family satisfaction.

The "signifiers," that is, the components of the delivery of care in this study included the following: (a) timely determination of appropriateness of care (b) family communication, (c) guidelines on treatment limitation, (d) liberalizing visitation. Each of these

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components of care identified in the interviews are essential to end of life decision-making. A recent consensus position statement also describes these steps in detail.[10] Timely determination of appropriateness of proposed interventions is crucially pegged on reflective prognostication. This is best accomplished by combining subjective and objective evaluation of the disease trajectory and realistic treatment options.[10] Once there is consensus of such assessment within the treating team, the next step is communication. This is the definitive intervention in EOL decision-making. Multidisciplinary family meetings serve to build trust, elicit patient's values and preferences, ensure prognostic awareness, and set appropriate goals of care.[14] Such communication must begin early during ICU care and repeated as needed. Guidelines on treatment limitation are essential to provide decision support in these challenging situations. Ethical position statements have been available earlier but have been recently updated following legal guidelines by the Supreme Court of India.[15,16] Combined clinical, ethical, and legal norms have been formulated in this consensus and evidence-based statement are summarized in a flow chart.[10]

Once the decision to forego aggressive care and to transition to palliative care has been made, physicians must implement these decisions expeditiously, following the due process described in the position statement.[10] The participants of the present study realize the value of liberalizing visitation by families to facilitate a good death. This is essential for the emotional health of patients as well as the family that can be beset with anxiety, depression, insecurity, and loneliness. A medicalized death should be avoided. Care should be taken to reduce the burden of medication and monitoring since curative intent is no longer valid.

The theme addressing the sociocultural and legal contexts is useful. The societal, legal, and institutional barriers have been reviewed earlier.[3] Despite nearly two decades of legal evolution, the Indian intensivist perceives legal vulnerabilities related to taking ethical decisions. The recent simplification of the procedures for withdrawal and withholding laid down in the Common Cause Judgment[15] should serve to allay these apprehensions. The position statement has clarified the legal provisions and requirements for these decisions. Societal awareness is expected to rise with the ease of procedure for executing an Advance Directive and with increasing public discourse related to appropriate care of the dying. In the professional domain, having clear institutional policy and standard operative procedures for EOLC as well as staff training is recommended by expert professional groups.[10] The improved patient- and family-centricity and communication should generate the atmosphere of trust that many study participants have noted to be deficient in the prevailing ICU ethical climate. Improved ethical climate has been shown to result in better physician–patient relationship and staff emotional health.[17]

Practices such as "slow codes" were alluded to by the participants. These are not ethically acceptable. Presently, Do Not Attempt Resuscitation (DNAR) has been validated by ICMR[18] and by the Supreme Court since it is a form of withholding. Indian intensivists need not worry over its legal status if these decisions are taken in the prescribed manner and duly documented.

The concerns articulated by the participants on the enormous cost burdens are germane. It is obvious that timely setting of goals of care and transitioning to palliative care-only option would reduce heavy costs related to aggressive treatments. Palliative options are relatively less expensive and resource-consuming.

In sum, EOLC calls for reform at several levels of the healthcare ecosystem and has the potential to not only improve the way patients die in the ICUs, but also enable voices to be heard, prioritize holistic care, build public trust, improve communication and professionalism, mitigate suffering imposed by techno-intensive care, optimize resource utilization, and reduce economic burdens. This paper could serve as a pilot study to generate and explore ideas to improve EOLC practices on the ground.

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