Semiotics of ICU Physicians' Views on End-of-life Care and Quality of Dying in a Critical Care Setting: A Qualitative Study

Shivakumar Iyer[1], Rutula N Sonawane[2], Jignesh Shah[3], Naveen Salins[4]

Abstract

Background and aim: While intensive care unit (ICU) mortality rates in India are higher when compared to countries with more resources, fewer patients with clinically futile conditions are subjected to limitation of life-sustaining treatments or given access to palliative care. Although a few surveys and audits have been conducted exploring this phenomenon, the qualitative perspectives of ICU physicians regarding end-of-life care (EOLC) and the quality of dying are yet to be explored.

Methods: There are 22 eligible consultant-level ICU physicians working in multidisciplinary ICUs were purposively recruited and interviewed. The study data was analyzed using reflexive thematic analysis (RTA) with a critical realist perspective, and the study findings were interpreted using the lens of the semiotic theory that facilitated the development of themes.

Results: About four themes were generated. Intensive care unit physicians perceived the quality of dying as respecting patients' and families' choices, fulfilling their needs, providing continued care beyond death, and ensuring family satisfaction. To achieve this, the EOLC process must encompass timely decision-making, communication, treatment guidelines, visitation rights, and trust-building. The contextual challenges were legal concerns, decision-making complexities, cost-related issues, and managing expectations. To improve care, ICU physicians suggested amplifying patient and family voices, building therapeutic relationships, mitigating conflicts, enhancing palliative care services, and training ICU providers in EOLC.

Conclusion: Effective management of critically ill patients with life-limiting illnesses in ICUs requires a holistic approach that considers the complex interplay between the EOLC process, its desired outcome, the quality of dying, care context, and the process of meaning-making by ICU physicians.

Keywords: End-of-life care, Good death, Intensive care unit, Physician, Quality of dying, Views.

Indian Journal of Critical Care Medicine (2024): 10.5005/jp-journals-10071-24696

Highlights

- Despite the high death rates in intensive care units (ICUs) of low-resource countries, the limitation of treatment, referral to palliative care, and access to end-of-life care (EOLC) is significantly less.
- A few qualitative studies conducted worldwide, none from India, have delved into ICU physicians' perspectives concerning the quality of dying and EOLC within the critical care milieu.
- The present study has identified gaps in the provision of EOLC in ICUs and has proposed several effective strategies to address these gaps. The insights obtained highlight the need for improved EOLC provision in ICUs. They might serve as a resource for healthcare providers (HCPs) and policymakers seeking to enhance palliative care delivery in these settings.

Introduction

The disparity in ICU bed capacity between high-income and low-income countries is striking, with 33–240 intensive care beds per million population in the former and only 1 per million in the latter.[1,2] Even though patients who are most likely to benefit from ICU admission are from low-income countries, the death rates in ICUs in these countries are considerably higher (46%) than in high-income countries (8–18%).[3] Limiting support in ICU is more prevalent in high-resource countries than in low-income countries, with more than two-thirds of patients in a UK study and up to

[1-3]Department of Critical Care Medicine, Bharati Vidyapeeth Deemed University Medical College, Pune, Maharashtra, India

[4]Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, India

Corresponding Author: Naveen Salins, Department of Palliative Medicine and Supportive Care, Kasturba Medical College, Manipal Academy of Higher Education, Manipal, Karnataka, India, Phone: +91 9969683669, e-mail: naveen.salins@manipal.edu

Patient consent statement: The authors have obtained written informed consent from the patient for publication of the case report details.

89% in European research undergoing limitation of support.[4,5] In contrast, the limitation of support was only 22–49% in three Indian studies.[6–8] A recent survey found withdrawal rare in Asian countries, including India.[8] Most of the limitations of support decisions in India culminated in a terminal discharge against medical advice (DAMA)

Table 1: Eligibility criteria

Inclusion criteria	Exclusion criteria
1. Intensivists practicing at a consultant level.	1. Intensive care trainees.
2. Intensivists working full-time in a critical care setting.	2. Healthcare providers providing care in ICUs other than intensivists.
3. Formally qualified in critical care or have received at least two years of on-the-job training in critical care medicine.	
4. Adult critical care setting.	

or left against medical advice (LAMA), as suggested by the point prevalence Indian study INDICAPS II.[9]

A survey of chest physicians in India identified a lack of hospital policy, social constraints, and a fear of litigation as the primary factors hindering appropriate EOLC decisions.[10] Another study suggests that the paternalistic attitudes of physicians and a lack of clear legal guidance may be responsible for the delay in appropriate EOLC decisions.[11] In a survey of ICU physicians in India on EOLC practices, lack of law and fear of law was the most commonly cited reasons for not practicing appropriate EOLC.[12] Many participants also reported that the inability to afford treatment influenced EOLC decisions.[12] An Indian mixed-methods study exploring EOLC perspectives among patients and healthcare professionals (HCPs) found significant discordance between patients and HCPs' views of what is essential in EOLC.[13]

A study conducted in India on providing palliative care for ICU patients with COVID-19 found low referral rates to palliative care.[14] A scoping review on palliative and EOLC in ICUs from low and middle-income countries had no qualitative studies that explicated the views of ICU physicians on EOLC in the critical care setting, necessitating the conduct of this study. Intensive care unit physicians gate keep palliative care referrals, and understanding their views may facilitate appropriate care for critically ill patients in ICUs.[15] Therefore, in this study, we explored the views of ICU physicians on EOLC and the quality of dying in a critical care setting.

METHODS

Aim and Study Setting

The research question was: What are the views of ICU physicians on EOLC and quality of dying in a critical care setting? The sites for the ICU physician qualitative interview were selected based on: (A) presence of a full-time consultant-level ICU physician, (B) a multidisciplinary ICU with a minimum of 10 critical care beds, (C) ICU is situated in a public or private multispecialty hospital. All ICUs selected for this interview were in tier 1 and 2 (urban and semiurban) cities.

Participant Recruitment and Study Sample

The eligibility criteria for selecting study participants are provided in Table 1. We identified and invited ICU physicians deemed suitable for delivering detailed, insightful, and reliable information about the phenomenon. Therefore, we used the purposive sampling method.[16] Moreover, we employed the reflexive thematic analysis (RTA) method for qualitative data analysis.[17] Consequently, we did not adopt data saturation as the standard quality marker for sample size determination.[18]

Qualitative Interviews

After obtaining consent, data for the study were collected through individual, face-to-face, semistructured qualitative interviews. The semistructured interview topic guide was formulated using a critical realist perspective.[19] It is provided as a supplementary file 1. The researcher who conducted the interviews, an ICU physician, designed the interview topic guide. It was further developed after conducting two pilot interviews. Using a critical realist perspective enabled the researcher to be reflexive and draw upon his experience in dealing with EOLC and quality of dying in the ICU, which was essential for conducting the interviews and analyzing the findings. Interviews lasted between 45 and 70 minutes.[20] Automated transcripts were generated using the Otter.ai transcription service. After that, the researcher thoroughly listened to all the audio recordings and corrected the transcripts. A palliative medicine consultant and a researcher colleague also reviewed the audio recordings and checked the transcripts to ensure accuracy. Any comments made in vernacular languages were translated using standard dictionaries and cross-checked with the participants to confirm their meaning in English. All interview transcripts were coded using NVivo (12.6. for Mac). A sample-coded transcript is provided as a supplementary file 2.

Qualitative Data Analysis

The research data was analyzed using Braun and Clarke's RTA method, which follows a systematic six-step approach.[17] This approach incorporates the researcher's subjectivity as a valuable resource during data analysis.[17] The researcher conceptualized and analyzed the resulting themes, providing a deeper understanding beyond a mere data summary.[17] A critical engagement with the dataset is fundamental to this approach, allowing the researcher to interpret the data based on their scholarly information, sociocultural outlook, beliefs, and theoretical assumptions.[21] The study's findings were analyzed using the semiotic theory framework, which allowed for constructing sub-themes and themes.[22]

RESULTS

The qualitative study involved 22 participants, out of which 17 were men. All the participants had training in the subspecialty of Critical Care Medicine, with three of them being trained overseas. The consultant experience of the participants varied from 1 to 30 years. The study included participants from 20 public or private multispecialty hospital ICUs traversing 18 cities in India. A detailed description of the participants is provided in Table 2.

The semiotics model is built upon three essential concepts.[23,24] Firstly, the sign comprises two elements: the physical form it takes (also known as the signifier) and how it is perceived by the viewer (the signified). Secondly, the concept of context encompasses the various aspects of discourse that provide pertinent and precise meaning to the phenomenon. Finally, the third concept is meaning-making. It is the individual's experience as they comprehend and engage with the sign by connecting it with their surrounding reality.[23,24] In our study, the quality of dying is the signifier, and the process of EOLC is the signifier. Sociocultural, legal, and political discourse forms the context, and ICU physicians'

Table 2: Description of the study participants

Participant	Age	Sex	Primary qualification	Intensive care qualification	Years of experience post qualification
1	25–30	F	MD (A)	IDCCM	1–5 years
2	55–60	M	MD (A)	Trained abroad FRCA	>10 years
3	25–30	F	DNB (M)	FNB (CCM)	1–5 years
4	40–45	M	DNB (Chest)	FNB (CCM)	>10 years
5	50–55	M	MD (Med)	FNB (CCM)	>10 years
6	45–50	F	MD (A)	Lateral entry	>10 years
7	45–50	M	MD (Med)	EDIC (Abroad)	>10 years
8	45–50	M	MD (Med)	Lateral entry	>10 years
9	40–45	F	MD (A)	IDCCM	>10 years
10	60–65	M	MD (Med)	Trained abroad FRCP	>10 years
11	30–35	F	MD (A)	DM (CCM)	1–5 years
12	30–35	M	MD (A)	DM (CCM)	1–5 years
13	30–35	M	DNB (A)	FNB (CCM)	1–5 years
14	30–35	M	DNB (A)	FNB (CCM)	1–5 years
15	30–35	M	MD (A)	FNB (CCM)	1–5 years
16	30–35	M	MD (A)	Lateral entry	5–10 years
17	30–35	M	MD (A)	FNB (CCM)	5–10 years
18	45–50	M	MD (A)	PDCC	>10 years
19	40–45	M	MD (A)	FNB (CCM)	>10 years
20	35–40	M	MD (Med)	DM (CCM)	1–5 years
21	40–45	M	AB (Med)	AB (CCM)	>10 years
22	60–65	M	MD (A)	Lateral entry	>10 years

presuppositions and perceptions of the value of palliative care engagement contribute to meaning-making. These are the four themes informing this study.

Theme 1: Signified – The Quality of Dying for Patients with Critical Illness

The signified refers to the conceptual ideal form, an abstract idea of the phenomenon.[23,24] In this theme, the quality of dying refers to the signified, which is often aspirational, individual, contextual, and fallibilistic.[20] According to the ICU physicians, when the choices of patients and families are respected, needs are addressed, requests are facilitated, continued care is provided beyond death, and families are satisfied, it signifies the quality of dying. These were the subthemes informing this theme. The participant excerpts supporting the subthemes are provided in Table 3.

Subtheme 1.1. The Choices of Patients and Families are Respected

Most participants agreed that the choice of care made by the patient is of utmost importance and should be respected. A few participants shared their own experiences of caring for their loved ones. They believed respecting their preferences meant allowing them to die with dignity and without depending on others. They also emphasized the need to discuss the available care options, including life-sustaining measures and adhering to the patient's care preferences. The ICU physicians believed respecting the family's choices is essential if patients cannot express their views on care. The family's preferences can be known by conducting a joint family meeting to reach a consensus. Letting family members speak about their patients' views of care is also essential. Respecting the family's choice means allowing them to act in the patient's best interest, especially when continuing care is deemed potentially inappropriate. It also included facilitating the patient's preferred place of death.

Subtheme 1.2. Needs are Addressed

During qualitative interviews, several intensivists emphasized the needs of patients and families. The top priority was controlling pain and agitation with opioids and benzodiazepines, as well as addressing physical symptoms like constipation. Only one participant stressed the importance of preserving privacy and dignity. Some participants expressed caution about using opioids, fearing respiratory depression and hastening death. The consensus was that psychological and emotional support is crucial but challenging in the ICU. Intensive care unit physicians in private hospitals felt that hospital counselors are rarely involved in dying patients' care, and management of physical symptoms often takes precedence over psychological ones. Families also face significant financial and emotional stress, adding to their burden. Many participants highlighted the importance of allowing families to be present with their loved ones during the last moments, allowing them to fulfill patient's wishes or religious practices. Some noted that oncology patients tend to express these desires more openly. Intensive care unit physicians mentioned several spiritual practices, including providing holy water, playing sacred music, following customs, or calling a religious priest.

Subtheme 1.3. Requests are Facilitated

According to the participants' views, patients and their families usually visit hospitals with the hope of preventing death and

Table 3: Theme 1-subthemes and select participant quotes

Subthemes	Select participant quotes
1.1. Choices of patients and families are respected.	"He had a bad chest … didn't want to be intubated, we didn't as per his wishes" (P05).
	"If it is my close relative with a chronic illness … I would prefer to discuss with (the patient) … about options available" (P09).
	"My friend's father with advanced malignancy did not want any tube down his throat and when he deteriorated the family agreed" (P17).
1.2. Needs are addressed.	"We used to call the priests or Maulanas from the mosque … to give the prayers to the family … they also helped us explain it to the family" (P07).
	"We provide supportive care in terms of opioids, benzodiazepines and maintenance fluid … along with weaning ventilatory support" (P13).
	"We've got our psychiatry team and counsellor team … they counsel the family; we also have nurse counsellors who talk to the family" (P19).
1.3. Requests are facilitated.	"If we could, in some way, recreate the home atmosphere in ICU … the dying patient and family will be served better" (P17).
	"If we want to improve the quality of death and you're only looking at ICU, I think we're missing a whole big sphere" (P10).
	"We should find a way so that patients who have been discharged from the hospital ICU can be in the comfort of their home" (P12).
1.4. Continued care is provided beyond death.	"The families need transparency, and if you tell them what exactly happened … they will listen to your perspective … important to have some sort of closure" (P21).
	"During COVID … a very sick young husband for whom withholding decision was taken … family couldn't visit due to restrictions … wife did not get any explanation … she was not accepting the fact that he's died" (P02).
1.5. Satisfied families.	"The patient died eventually, and they invited us to his last rites … there was a family connection … despite a negative outcome" (P12).
	"The family, along with the obituary message, has put a thank you note … all these doctors have taken care and made sure that my loved one has passed peacefully" (P08).
	"We could get her out with a tracheostomy but she developed sepsis and died — despite a poor outcome, the family are still thankful … we tried to respect all the wishes of the family members" (P04).

avoiding suffering. In the past, older adults or those with incurable illnesses used to die at home. However, participants pointed out that in India, many deaths occur at home or outside of the hospital due to a lack of access, while most deaths of patients who come to the hospital happen in the ICU, especially in private hospitals. Many participants believe that families prefer death at home when there is no hope of recovery and a peaceful death at home, with acceptance, and without pain, which is preferable to an ICU death.

Subtheme 1.4. Continued Care is Provided Beyond Death

According to several participants, junior doctors, nurses, and support staff at hospitals should provide immediate logistic support after a person's death. Such support helps ease the emotional and psychological distress that grieving families face. Some hospitals also have designated areas where families can grieve in private. However, a few participants shared their experiences of prolonged grief and lack of closure with some families. Participants felt that their ability to provide support in such cases was limited. They suggested that following up with families could help provide closure and assist them in coping better with prolonged grief.

Subtheme 1.5. Satisfied Families

Most participants felt fulfilled and happy when families returned to thank the HCPs, even if they lost their loved ones. In some cases, families were satisfied because they believed that everything possible was done for their loved ones despite losing them after a prolonged acute illness. Participants emphasized the significance of continuity of care and good symptom management in preventing families from altering their perception of comfort care and the quality of dying.

Theme 2: Signifier – The Process of End-of-Life Care in ICUs

The signifier often entails fundamental and modifiable components that might enable the signified.[23,24] In this theme, the process of EOLC delivery underpins the quality of dying, and these processes could be identified, defined, and improved.[25] The ICU physicians felt that timely determination of the appropriateness of care, family communication, guidelines on treatment limitation, and relaxing ICU visitation rights are the EOLC processes that might facilitate the quality of dying in the ICU. These were the subthemes informing this theme. The participant excerpts supporting the subthemes are provided in Table 4.

Subtheme 2.1. Timely Determination of the Appropriateness of Care

During the interviews, several participants emphasized the importance of identifying reversible factors in managing acutely ill patients before deeming the situation irreversible. Some participants noted that they provide aggressive care as a trial for non-responsive patients for 48–72 hours before considering limiting therapy. One senior participant explained that all care in the ICU should be viewed as a time-limited trial (TLT). Intensivists working in government or army hospitals mentioned that informal principles of triage aim to provide ICU support to patients with acute illnesses who are most likely to benefit. In general, participants felt that discussions about transitioning to palliative

Table 4: Theme 2-subthemes and select participant quotes

Subthemes	Select participant quotes
2.1. Timely determination of the appropriateness of care.	"I look for correctable causes … but if it is not going to … benefit the patient … we counsel the relatives … this is the maximum" (P01).
	"If a patient (is going to have) a very restricted life, after whatever insult (traumatic brain injury) he has suffered … patient is in septic shock … just adding another vasopressor is of no help … but the primary (the neurosurgery team) may think it is not appropriate" (P07).
	"End-of-life decisions require a deep work … it should be a sort of a collegial decision involving not just physicians, but also nurses and other caregivers" (P10).
2.2. Family communication.	"We communicate with the families within 24 hours of admission … you get to know the family … the family gets to trust because they think that you care" (P15).
	"You should be the first to pick that something is going wrong (won't improve) … you go to the family … tell them each thing … make them understand in layman's language" (P03).
	"One of the most important needs seen across cultures is … the family … wants accurate, reliable information" (P09).
2.3. Guidelines on treatment limitation.	"The new BLUE MAPLE pathway … brought out in 2019 for limiting treatment … along with the palliative medicine team is helpful" (P06).
	"There are some guidelines at their hospitals, but there is not enough consensus among all stakeholders" (P17).
	"My hospital policies allow no escalation and withholding but not de-escalation or withdrawal" (P04).
2.4. Relaxing ICU visitation rights.	"This patient, we shifted to cabin … she was calm with pain meds … her daughters used to be with her in between … you're surrounded with your loved ones in ICU premises" (P11).
	"Those patients staying in ICUs without family by their side did not have a good death" (P03).

care are initiated by intensivists, sometimes by primary care providers, and rarely by families. The exploration of goals of care and transitions in government and private hospitals usually comes from the intensivists, and balancing the benefit vs cost is usually their responsibility. Participants noted that primary physicians may not be well-equipped to prognosticate in critical illness and may fear legal prosecution, leading to delayed or premature transitions. Financial interests may also come into play. Nonetheless, participants agreed that resolving conflict within the treating team before talking to families is crucial for developing trust. Collaborative decision-making that involves a multidisciplinary and multi-professional approach can help avoid conflict.

Subtheme 2.2. Family Communication

Several senior participants stressed the importance of building trust with families. Most participants believed that after families overcome their initial feelings of being overwhelmed, they seek honest and reliable information communicated clearly and understandably. Additionally, they thought that trust and effective communication are built through experience.

Subtheme 2.3. Guidelines on Treatment Limitation

While some participants were knowledgeable about the Indian guidelines on EOLC, only certain hospitals had implemented these guidelines to create local policies and standard operating procedures. Several participants noted that their hospital policies allowed for non-escalation and withholding but not de-escalation or withdrawal. Many participants practiced withholding or non-escalation but did not withdraw. A select few felt that EOLC should adhere to guidelines and that all stakeholders should document and sign off on all discussions. A hospital committee could also review and endorse the decision, improving EOLC. However, most felt there needed to be more consensus among stakeholders regarding guidelines. Building consensus with hospital authorities would likely be the next step. Many participants agreed that palliative physicians would be beneficial and could play a vital role as facilitators in

promoting good EOL practices in the ICU. However, only a few participants had reported palliative care support at their hospitals.

Subtheme 2.4. Relaxing ICU Visitation Rights

During interviews, it became clear that many participants believed that end-of-life patient visitations should be open and accessible. Some individuals wanted to allow as much time as possible with the patient. In contrast, others highlighted concerns regarding care issues for patients in the ICU, such as isolation and ICU psychosis. Although many participants would like to allow greater visitation and time to families in the ICU, they find it difficult to do so. A few expressed concerns that patients staying in ICUs without families may not experience a good death. Others provided poignant descriptions of how being with family and allowing them to participate in care in the ICU is crucial. However, some participants felt that constant presence with the patient might distress relatives and disrupt care for other patients.

Theme 3: Context – Sociocultural, Legal and Societal Discourse Influencing End-of-life Care in ICUs

The context refers to the situation in which the phenomenon is embedded and how it might influence it.[23,24] Sociocultural, legal, and societal discourse can influence EOLC delivery, especially in ICU settings.[26] Legal fears, mistrust, managing expectations of self and families, complexities and dilemmas in decision-making and costs and affordability contributed to these discourses that formed the context in which EOLC is provided in the ICUs. These were the subthemes informing this theme. The participant excerpts supporting the subthemes are provided in Table 5.

Subtheme 3.1. Legal Fears

Most participants expressed concern over the absence of established legal guidelines, local policies, and standard operating procedures (SOPs) in India regarding the limitation of treatment and EOLC. The apprehension of being held accountable by families, a lack of support from hospital administration and colleagues, and

Table 5: Theme 3-subthemes and select participant quotes

Subthemes	Select participant quotes
3.1. Legal fears.	"The Supreme Court allows withdrawal of life support … but it is a bit complex; it is not so easy" (P22).
	"The rules are not set properly, even the passive euthanasia rules, so you might need to go to court. It's a cumbersome process" (P15).
	"Even among our colleagues (intensive care community), there is a misunderstanding of what the Indian legal system says" (P17).
3.2. Mistrust.	"They are ventilating a brain dead; are they harvesting organs illegally?" (P13).
	"The lack of trust and the previous hospital admissions were responsible for the current conflict" (P01).
3.3. Managing expectations of self and families.	"You mean you're asking me about giving up? - That I will not choose so easily" (P09).
	"Some families who have been struggling young patients' acute deterioration, … it becomes difficult to explain … how things have suddenly changed" (P20).
	"Once they know that the patient is suffering from cancer — they agree, but for all other diseases they (families and primary physicians) want to keep on trying" (P12).
3.4. Complexities and dilemmas in decision-making.	"Withdrawing is a slippery slope, I don't know, at which point are we crossing over and, playing god" (P02).
	"We take a do not escalate consent … if it prolongs, we just slow code ourselves" (P11).
	"One big undesirable practice is DAMA, where you do not want to address the stark realities of disproportionate treatment. You absolve yourself of responsibility by getting a refusal of consent document signed (by family)" (P10).
3.5. Costs and affordability.	"We have to honor the will of the family (if they want to take the patient away). The financial status of the family plays a big role in making these decisions; those who could not afford were sent away only if they wanted to go to a government hospital (not home)" (P22).
	"Not suffering, they don't mention ever about suffering. If they have signed, do not escalate because of financial reasons; they would want the patient to die the same day. They don't want to pay for the next day" (P11).
	"Because finances are not involved in care, they (family) will not take the decision to stop the treatment" (P19).

the fear of legal consequences all appear to impede intensivists from making informed decisions regarding EOLC and providing timely palliative care.

Subtheme 3.2. Mistrust

Most participants felt that a lack of trust within families is a common issue that often causes conflicts with the treating team. Additionally, some participants have noted that this lack of confidence can lead to unnecessary treatment and a lower quality of EOLC. In some cases, family members have refused to provide consent for ICU care due to their lack of trust. This lack of trust may stem from inadequate counseling from the primary physician regarding chronic illnesses, previous hospital admission, and a lack of improvement in clinical conditions. A few ICU physicians felt that initiating palliative care referral could be a potential source of mistrust where families have sought the opinions of other physicians.

Subtheme 3.3. Managing Expectations of Self and Families

Participants expressed the difficulty that many intensivists face in accepting the possibility of death as an outcome. They felt that it is often due to a prevailing medical culture that regards recovery as a victory. Consequently, ICU patients who are not recovering may be kept alive for long periods, raising unrealistic expectations among families and causing stress for HCPs. Some participants suggested that intensivists may be more inclined to consider transitioning to palliative care earlier, particularly in cases of cancer where medical professionals and patients alike better understand irreversibility. Others noted that patients admitted to the ICU often lack a precise diagnosis, making prognosis challenging and leading

to extended ICU stays. Additionally, some participants observed that patients with children living overseas may experience feelings of guilt for not being present when their parents fall ill, resulting in prolonged transitions and aggressive treatment. In some cases, family members may be in denial or have many questions, leading them to pursue aggressive treatment until the end.

Subtheme 3.4. Complexities and Dilemmas in Decision-making

Many participants in the study expressed their reluctance to withdraw treatment, citing legal concerns, disagreement from the administration, or disapproval from the primary consultant. For most, withdrawal is seen as a definitive "no." Some participants believed that families might feel guilty if treatment is withdrawn, while others pointed out that families are often unwilling to consider this option. Interestingly, participants who received international training reported feeling comfortable removing the ventilator and extubating. However, they noted that this is rarely done in India, possibly due to cultural factors or reluctance from families and doctors. Additionally, hospital authorities may be hesitant to withdraw treatment, fearing negative publicity if a family member later accuses the hospital of being responsible for the patient's death.

Few participants emphatically said that withdrawal is ethically the same as withholding and pointed to the abysmally low withdrawal rates in our country. Declaration of brain death is legal under Indian law if families opt for organ donation. However, in a non-organ donation setting, it is seldom practiced. The term slow code is used to describe giving slow or sham CPR or going slow

Table 6: Theme 4-subthemes and select participant quotes

Subthemes	Select participant quotes
4.1. Patient and family voices must be heard.	"He was born Hindu … he wanted to die a Buddhist … my friend arranged for a monk, who gave the oath (to change his religion)" (P08).
	"He was more afraid of the symptoms … if he would have any pain – (if) he would die of breathlessness … he was not worried about other things" (P01).
	"He knows what he wants … he doesn't want to suffer" (P16).
4.2. Building a trustworthy therapeutic relationship.	"My goal is to keep them comfortable, at the same time, not prolong. But I also don't want the family to carry that burden for the rest of their … life that they have not done everything" (P21).
	"Designating an appropriate family member for communication and calling for a family meeting when required" (P16).
	"It is important for the senior clinician to meet the family early and meet them repeatedly to establish trust and maintain rapport. It facilitates the difficult transition to palliative care" (P14).
4.3. Mitigating conflicts and crises.	"I had to call a psychiatrist for help … it took us 4–5 hours to convince he has passed away … she had agreed for withholding … when the patient died it was difficult" (P07).
	"We have a critical care review board … any patient staying beyond one week, we discuss … we decide whether it is appropriate to continue … whether to give a time-limited trial whether to refer to palliative care … then we discuss with the family" (P06).
	if we need to make a major decision … we organize a family meeting (and all stakeholders) … they can air the doubts and discuss" (P21).
4.4. Enhancing palliative care capacity.	"With the palliative care department … we can identify patients (for palliative care) early" (P07).
	"We could have a separate area for end-of-life care with privacy to the patient (and family) and care and dignity for whatever suffering they may be facing" (P12).
4.5. Orienting ICU providers towards end-of-life care.	"As intensivists, we make our effort, but many times we never explain the limitations of science — it requires a lot of effort (to explain) … dying is a natural process" (P18).
	"There is no intensive care without its due component of palliative care" (P10).
	"I think we should — have a workshop on ethical and end-of-life issues and communication about that … and the key principles of what needs to be done" (P21).

on other therapies (without explicit consent) when we know that it is not going to benefit the patient. Few participants said they practiced it even though it may not be strictly ethical and creates distress in them. Some participants felt that the combination of not being able to afford expensive ICU care and the reluctance of HCPs to limit inappropriate therapy in deteriorating acute illness leads to undesirable practices like LAMA or DAMA. Legal fears and hospital policy often lead to DAMA. They felt these patients suffer, which is stressful for the family and the treating doctors.

Subtheme 3.5. Costs and Affordability

A few participants expressed concern that specific expensive treatments routinely offered in ICUs may lack evidence-based support. One participant noted that private healthcare-predominant countries like India often use a profit-oriented approach that incentivizes treatment escalation over limitation. Another participant shared that limited government reimbursement schemes offer initial promises, but families are often left to make out-of-pocket payments, leading to conflicts. Some participants believed that financial reasons are the root cause of conflicts in the ICU, with families unable to sustain costly life support measures. Ultimately, families may refuse consent due to financial constraints and may be discharged against medical advice. Some participants pointed out that government reimbursement schemes offer options for acute care to the lower middle class and poor. Still, patients may be forced to shift to government hospitals or return home once these schemes are exhausted or if they are deemed non-salvageable. Several participants also noted that affordability or reimbursement delays the transition from curative to palliative care.

Theme 4: Meaning-making – Strategies to Enhance Palliative Care Engagement in ICUs

Meaning-making refers to how a phenomenon is socially constructed and the relationships between the signifier, signified, and the context in which they are comprehended.[23,24] Intensive care unit physicians felt that strategies like making patient and family voices heard, building a trustworthy therapeutic relationship, mitigating conflicts and crises, enhancing palliative care capacity, and orienting ICU providers towards EOLC meant a way forward for enhanced EOLC in the ICU. These were the subthemes informing this theme. The participant excerpts supporting the subthemes are provided in Table 6.

Subtheme 4.1. Patient and Family Voices must be Heard

Participants agreed that it is crucial to communicate with patients about their illness, especially when they are less sick or have had time to reflect on their chronic disease. However, they noted that this often does not happen. They suggested that physicians who know the patient well could recognize their perspective and work to fulfill their wishes. In cases where a patient has partially recovered from a prolonged ICU stay and still requires ventilator support but wishes to stop life-sustaining therapy, they recommended repeated counseling of the family to help them appreciate the patient's perspective. Several participants emphasized the importance of treating patients with dignity, which begins with respecting their wishes. They shared that they would want their perspectives on EOLC to be explored for themselves and their loved ones. To implement this, they recommended that physicians elicit patient

wishes through living wills or advance directives, not only in the face of chronic illness but even before, if possible.

Subtheme 4.2. Building a Trustworthy Therapeutic Relationship

The shift from curative to palliative care for patients with irreversible illness in the ICU is a complex transition, according to most participants. Effective communication and trust-building with the family are essential, which may require multiple meetings over time. Intensivists must navigate various family relationships and may need to designate a specific family member for communication and arrange meetings as required. Participants emphasized the importance of senior clinicians meeting with the family early and frequently to establish trust and ease the transition to palliative care. Families may require additional explanations and emotional support to cope with the guilt of stopping therapy. Misunderstandings surrounding treatments such as ventilation can lead to distrust of HCPs, making it crucial to correct any misperceptions and build trust to prevent conflicts.

Subtheme 4.3. Mitigating Conflicts and Crises

Most participants believed joint counseling with an empathetic approach effectively mitigated conflicts and crises. Other methods suggested included appointing a responsible family member who is well-informed and known to all stakeholders, involving a doctor within the family, and holding regular family meetings with key stakeholders such as intensivists, primary physicians, surgeons, and senior consultants. If conflicts remain unresolved, participants recommended referring the matter to the hospital's Clinical Ethics Committee. In some cases, financial support was provided to salvageable patients with longer stays using available government schemes, and guided transfers were facilitated from private centers to government facilities. For non-salvageable patients, participants attempted to provide a second opinion, convince the family to transition to comfort care, and involve palliative care physicians. Discharging them against medical advice was the last option. Even when sending patients home, arrangements were made for comfort care at home or a nearby nursing home, as some participants shared.

Subtheme 4.4. Enhancing Palliative Care Capacity

Most intensivists have raised concerns regarding the insufficiency of palliative care services available at their medical facility. They believe that the presence of palliative care specialists can assist in facilitating the transition. Some physicians also suggest having a dedicated space for ICU palliative care may be beneficial. This approach could result in lower costs, decreased nurse-to-patient ratios, the ability to allow one family member to remain with the patient at all times, and a reduction in the intensity of monitoring and treatment.

Subtheme 4.5. Orienting ICU Providers towards End-of-life Care

The participants emphasized fostering team cohesiveness to provide appropriate EOLC. It involves maintaining continuity of care during handovers, not only for medical considerations but also for communication with the patient's family. Interacting with clinicians from other specialties and establishing a consensus before discussing transitions was also crucial. Effective communication between senior treating physicians is a skill that must be practiced and taught. The participants preferred a shift in focus towards the medical and ethical aspects of decision-making in EOLC rather than legal considerations, which they believed to be unique to India. Younger ICU physicians were found to be less familiar with current best practices and legal aspects of EOLC. While some participants felt that their primary duty was to focus on ethical care of the patient and family within the scope of good medical practice and the law, others noted that the presence of a palliative care team could add value to the care of dying patients. However, they believed this care could not be outsourced in the ICU. A well-rounded intensivist must manage pain and other distressing symptoms and communicate well. Finally, some participants expressed the need for training in palliative care skills.

DISCUSSION

While the direct experience of death may only be known to the dying patient, the process of dying and the factors that influence it can be better understood through the experiences of intensivists who regularly work with patients and their families in a critical care setting.[27] The authors in this qualitative study explored the perspectives of ICU physicians on EOLC and the quality of dying in a critical care setting.

The findings concerning respecting patients' and families' choices, addressing their primarily physical needs, facilitating requests for a place of death, providing adequate aftercare and closure, and ensuring family satisfaction with care were comparable to recent systematic reviews and a qualitative Australian study exploring ICU physicians' perspectives.[28–31] However, other dimensions that support the quality of dying, such as patient autonomy, relief from psychological distress, and avoiding unnecessary prolongation of life in Indian ICUs, need further exploration in future studies. The quality of death and dying (QODD) instrument is widely used to measure quality care in the United States and ICUs of high-resource countries.[32] However, there is a lack of formal studies examining the quality of EOLC in Indian ICUs. A study conducted in India on end-of-life perspectives revealed that patients placed equal importance on emotional, psychological, and social support, pain, and symptom control.[33] In this study, ICU physicians felt that families expressed a greater need for artificial prolongation of life than physicians.[33] It highlights the need for clear explanations regarding inappropriate care at EOLC. The study found that ICU physicians emphasized the importance of psychological support, but it needed to be explored or provided sufficiently in their ICUs.[33] Fulfilling the religious wishes of patients and families was also deemed necessary by ICU physicians, as previously reported in systematic reviews.[30] However, religious beliefs did not significantly influence the quality of dying in this study. It was observed that the examples provided by ICU physicians regarding respecting patient choices mostly involved friends or relatives of HCPs, indicating a possible discordance between the participants' personal views and those of patients and families. Some ICU physicians were hesitant to use opioids and preferred smaller doses. Additionally, opioids were not readily available in specific settings like public hospitals, mirroring findings from a previous study conducted in a cancer setting in India.[34]

Most EOLC guidelines and pathways in India and internationally prioritize correcting modifiable factors and assessing the irreversibility of acute illness, as reported by the ICU physicians in the present study.[11,35] In situations where uncertainty or conflict arises, published literature suggests a TLT of aggressive therapy should follow.[36] Some ICU physicians also mentioned that informal

hospital triage rules may exclude patients unlikely to benefit from ICU care and aggressive therapy. It is consistent with ICU triage rules implemented during the COVID-19 pandemic to maximize benefit.[37] Palliative care needs assessment at admission can prevent unnecessary ICU care for patients unlikely to benefit.[14,38] A few participants felt that communication with the family was the next step. Establishing trust as early as possible after admission was recommended by one participant as it helps with communication regarding the transition from curative to palliative care. Another participant emphasized the need to give accurate information and check understanding with the family. A recent nursing study from Australia proposed a model for meeting the needs of families with a relative in ICU, building on previous work on meeting family needs in ICU.[39,40] Despite several EOLC guidelines in the literature, most participants in this study reported that only a few hospitals had developed comprehensive SOPs and policies. Many ICU physicians reported that they relax visitation policies for families with a patient in the ICU. Restrictive visitation policies were found to negatively affect family satisfaction in a review of ICU deaths in India.[41]

The study highlights a significant challenge most intensivists face while transitioning from curative to palliative care. Predictive models incorporating the surprise question are now being developed to predict 6-month mortality in critical illness, which could assist in making the transition to palliative care easier.[42] However, studies suggest that transitioning to palliative care is comparatively more challenging in chronic organ system failure than cancer for both doctors and families.[43] One of the significant challenges that primary physicians and intensivists face is reluctance from families to discuss the transition.[43] This reluctance often leads to a lack of trust and requests for second opinions. However, having this difficult conversation at the right time is essential, and preparation for it should start early in the course of worsening critical illness.[44] The Lancet Commission report suggests that such discussions should be termed the "essential conversation" for prognostication and breaking bad news.[45]

The balance of beneficence and non-maleficence in critical illness is a crucial aspect that clinicians struggle with. Published studies show that medical professionals often prioritize prolonging life and saving lives, making it difficult to decide when to shift away from causing harm and prolonging the patient's suffering.[46,47] Young patients with no comorbidities or those with a diagnostic dilemma or prolonged acute illness were more susceptible to this struggle.[46,47] The study also highlights the need for more laws and legal guidance for EOLC in India. Lack of it leads to ambiguity in hospital policies and the continuation of inappropriate therapy. The fear of litigation and adverse publicity significantly contributes to the administration's reluctance to implement appropriate EOLC.

Due to a scarcity of ICU beds and costs, the lack of access to ICU care for the vast majority of patients in India is a significant issue.[48] Private ICU care in India is often more expensive, leading to a tendency to prolong inappropriate therapy, resulting in over-treatment at the end of life.[49] Moreover, catastrophic health expenses due to severe illness leading to impoverishment or bankruptcy have been reported in India, the US, and China.[50,51] Decisions regarding withholding and withdrawing therapy are often challenging, and the study suggests that withholding therapy or non-escalation of therapy is more accessible than withdrawing therapy, especially the ventilator. Withdrawal of therapy is less common in the Indian (and Asian) setting as compared to the West.[6–8] The reluctance to withdraw therapy is attributed to various reasons, including lack of acceptance from families, ethical objections, and no support from the law or administration.[52] The study highlights that reluctance to limit inappropriate therapy and inability to afford continuing ICU care often led to LAMA and DAMA decisions. Left against medical advice and DAMA decisions have been previously reported in Indian studies.[6,9] Slow code or sham CPR is sometimes performed in non-salvageable situations, causing ethical distress to HCPs.[53] Informed non-dissent may be an ethical alternative to slow code.[54] There is a possibility of underreporting and discussing the limitation of life support in this study, especially when it takes the form of slow code.

Solving conflicts and crises during EOLC is crucial for facilitating a positive outcome. To this end, several international societies have jointly published guidelines for conflict resolution in EOLC in the ICU.[55] A recent review has suggested the inclusion of a palliative care consult as part of the algorithm for resolving such conflicts.[56] Communication skills and training in EOLC have been identified as core competencies in critical care by the CoBaTrICE task force of the ESICM and have been endorsed by National Critical Care Societies in various countries, including India.[57] However, some participants expressed concern about the need for such training. One participant suggested conducting workshops focusing on communication skills, palliative care, and EOLC for practicing consultants and intensive care trainees.

Healthcare professionals delivering EOLC often experience stress and burnout due to non-beneficial treatment in the ICU. Several participants in a recent study have described the stress they experience in delivering EOLC.[58] In this study, factors such as dealing with dying patients and their families, the varying perceptions of other treating doctors, conflicts, insensitive administration, and their own inner uncertainty and ethical dilemmas regarding death and dying have contributed to this stress. Therefore, strategies need to be developed to mitigate this stress.

A recent qualitative study in the United States explored the sociology of limits of finitude with EOLC as a specific example.[59] The study found three regimes of valuation that helped define limits in EOLC: a medical professional regime led by the palliative care specialty that promoted the concept of limiting inappropriate life-sustaining treatment to facilitate a good death, a monetary regime that would help hospitals, insurers, and policymakers consider capping unnecessary expenses on disproportionate EOLC, and a patient-focused regime designating individual patients or their families as the actual authorities for deciding EOLC.

Strengths and Limitations

This first-of-its-kind qualitative study from India explored intensivists' detailed perspectives regarding the QODD and EOLC in a critical care setting. The researcher who conducted the interviews is an intensivist with two years of training in palliative medicine and has played an active role in EOLC within Indian ICUs. He explored this phenomenon in detail during qualitative interviews and analysis. Moreover, the in-depth information analysis from the homogenous group of 22 ICU physicians answered the research question satisfactorily. The study had a few limitations, such as it solely reflects the opinions of ICU physicians. The perspectives of patients, their families, and other HCPs were not included. Additionally, insights from hospital administrators, ethicists, and legal and religious experts might have offered more depth to the context of EOLC in ICUs.

Conclusion

The study identified that while there was a moderate degree of awareness about the concept of the quality of dying, the focus was on providing physical symptom support and fulfilling the religious wishes of patients and families. However, the study highlighted the other dimensions of the quality of dying that may require more attention. Prior exploration of care goals for patients with acute or chronic illness was uncommon, and living wills, advance directives, or exploration of patients' wishes were also rare. Emotional and psychological support, though considered necessary, could be provided only in certain hospitals. The transition from curative to palliative care was frequently delayed, which was attributed to several factors, including the internal conviction of intensivists to prolong life and save lives, difficulty in prognostication, legal fears, lack of hospital policies, and lack of trust in families. The study found broad awareness of the EOLC pathways, but translation into local SOPs and hospital policy was lacking. Consensus in the treating team regarding the transition to palliative care was usually not a problem, and conflict was resolved by mutual discussion or occasionally by referring to a second-level review or ethics committee in some hospitals. However, most hospitals did not have such committees. Families lacked trust in hospitals, which frequently led to delays in the transition to palliative care. Common reasons for mistrust were unrealistic expectations, emotional attachment, inadequate communication, and financial issues, often resulting in conflict. Financial issues often result in premature limitation of therapy, more commonly and earlier in private hospitals. Withdrawing therapy, especially the ventilator in non-salvageable patients, even in brain-dead patients, was uncommon. The reasons cited were that withdrawal is a slippery slope and akin to killing a patient, families would not accept, they would have bad memories and later blame the doctors, and lack of support from hospital administration who fear litigation and adverse publicity. Overall, the study highlights the importance of providing holistic EOLC and addressing the gaps in the current practices.

Authors' Contributions

SI, RS, JS, and NS: Contributed to formulating the research question and developing the research protocol and interview topic guide; SI: Conducted all the research interviews and coded the transcripts; SI, RS, JS and NS: Contributed towards data analysis and theme generation; All authors contributed equally towards manuscript writing. The manuscript has been read and approved by all the authors, and all the authors meet ICJME requirements for authorship.

Clinical Trial Registry Number

The study was registered with the Clinical Trials Registry of India (REF/2021/12/049746). Both are provided as Supplementary Files 3 and 4.

Availability of Data and Materials

This published article and its supplementary information files include all data generated or analyzed during this study.

Ethical Approval

The institution's ethics committee approved the study (BVDUMC/IEC/32/21).

Supplementary Materials

All the supplementary materials are available online on the website of www.IJCCM.org.

Orcid

Shivakumar Iyer ● https://orcid.org/0000-0001-5814-2691
Rutula N Sonawane ● https://orcid.org/0009-0006-9769-234X
Jignesh Shah ● https://orcid.org/0000-0002-8812-8791
Naveen Salins ● https://orcid.org/0000-0001-5237-9874

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