



AN INTENSIVE CARE UNIT TEAM REFLECTS ON END-OF-LIFE EXPERIENCES WITH PATIENTS AND FAMILIES IN CHILE

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Background Deaths in the intensive care unit (ICU) represent an experience of suffering for patients, their families, and professionals. End-of-life (EOL) care has been added to the responsibilities of the ICU team, but the evidence supporting EOL care is scarce, and there are many barriers to implementing the clinical recommendations that do exist.

Objectives To explore the experiences and perspectives of the various members of an ICU care team in Chile regarding the EOL care of their patients.

Methods A qualitative study was performed in the ICU of a high-complexity academic urban hospital. The study used purposive sampling with focus groups as a data collection method. A narrative analysis based on grounded theory was done.

Results Four discipline-specific focus groups were conducted; participants included 8 nurses, 6 nursing assistants, 8 junior physicians, and 6 senior physicians. The main themes that emerged in the analysis were emotional impact and barriers to carrying out EOL care. The main barriers identified were cultural difficulties related to decision-making, lack of interprofessional clinical practice, and lack of effective communication. Communication difficulties within the team were described along with lack of self-efficacy for family-centered communication.

Conclusion These qualitative findings expose gaps in care that must be filled to achieve high-quality EOL care in the ICU. Significant emotional impact, barriers related to EOL decision-making, limited interprofessional clinical practice, and communication difficulties were the main findings cross-referenced. (*American Journal of Critical Care*. 2022;31:24-32)

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Currently, a significant proportion of the US population dies in intensive care units (ICUs), which represent the most advanced hospital technology available.¹ A study of Medicare decedents showed that in 2015, 29% of deaths in the United States took place in an ICU and almost 1 in 3 had been admitted to an ICU during their last month of life.²

Deaths in the ICU often represent an experience of suffering. Patients may have experienced numerous severe symptoms in the days leading up to their deaths.³ Family members report psychological repercussions after the death of a loved one in the ICU, such as mood problems and posttraumatic stress disorder.^{4,5} Likewise, ICU physicians and nurses report high levels of stress and moral distress.⁶ In this complex clinical context, end-of-life (EOL) care has been added to the responsibilities of the ICU team. Numerous clinical guidelines have been published with recommendations for the EOL care of critically ill patients.⁷⁻¹³ However, the evidence supporting these suggestions is scarce,^{14,15} and few data exist regarding the application of EOL interventions in the real world.¹⁶ Furthermore, many barriers exist to implementing the clinical recommendations offered by scientific societies in the ICU setting.¹⁷

Changing practices associated with health care is complex, and success depends on organizational culture and personal self-efficacy.^{18,19} Confidence is principally individual and develops according to the experiences of each professional in his or her specific environment.²⁰ Therefore, improving EOL care requires strategies compatible with the realities and motivations of the individuals involved. Understanding the perspective of those who work in the ICU is necessary to implement strategies to improve EOL care.

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In this study, we explored the experiences and perspectives of various members of an ICU team regarding the EOL care of their patients.

Methods

We conducted a qualitative exploratory-descriptive study and applied the Consolidated Criteria for Reporting Qualitative Research (COREQ) checklist.²¹ We chose a grounded theory approach because it incorporates guidelines for simultaneous data collection and analysis for developing theories about social processes grounded in real-life experiences.^{22,23} The study was performed in the ICU of Hospital Clínico Universidad de Chile, a high-complexity academic urban hospital. This medical-surgical ICU has 12 beds and predominantly cares for medical patients. The mean length of stay of the patients in this ICU is 7 days, and the mean mortality rate is 13%. The research team consisted of a physician and palliative care specialist (A.P.), a psychologist (L.B.), and a physical therapist (V.A.C.), the last 2 of whom had postgraduate training in qualitative research.

Participant Selection and Sampling

We used a purposive sampling method²⁴ to collect data from 4 discipline-specific focus groups within the ICU team:^{25,26} (1) senior physicians, (2) junior physicians, (3) nurses, and (4) nursing assistants. Senior physicians were attending critical care specialists, and junior physicians were internal medicine specialists who worked shifts in the ICU. Nursing assistants had nonuniversity technical degrees and performed tasks such as bathing and oral drug administration. The only inclusion criterion was having completed at least 1 year of active ICU work.

A.P. disseminated the study among the ICU medical and nursing coordinators. Afterward, we sent an individual invitation by institutional email to all potential participants (N = 72). Interested participants enrolled voluntarily in the study and gave

Improving EOL care requires strategies compatible with the realities and motivations of the individuals involved.

Table 1
Focus group participants

Focus group	Health occupation	No. of participants	Sex	Age, mean (range), y
1	Nurses	8	2 female/6 male	33.0 (30-37)
2	Nursing assistants	6	3 female/3 male	33.6 (23-49)
3	Junior physicians	8	4 female/4 male	34.7 (29-41)
4	Senior physicians	6	2 female/4 male	45.5 (36-50)

their informed consent. Each focus group comprised 6 to 12 participants.

L.B. and V.A.C., neither of whom was related to the hospital, conducted the focus groups in an external office of the Faculty of Medicine. Therefore, no relationship with participants was established before the start of the study. We encouraged participants to openly express their opinions. We defined broad, prespecified themes related to the EOL by literature review and researchers' deliberation; these themes included roles, challenges, and successes. The interview guide included open-ended questions and was pilot-tested with ICU professionals from other hospitals (see Supplemental Table, available online only, at ajconline.org). Focus groups lasted a mean of 90 minutes, were audio recorded, and were transcribed literally. Field notes were taken during and after data collection. L.B. and V.A.C. continued data collection until theoretical saturation was reached.²⁷

Data Analysis

A narrative analysis of content was performed.^{22,23} L.B. and V.A.C performed a deductive process of codification and posterior thematic categorization of the data. For purposes of rigor, a continuous process of reflexivity and researcher triangulation was carried out.²⁸ The anonymity of the participants and the confidentiality of the data were protected throughout the analysis process.

This study was approved by the institutional research ethics committee in May 2019.

Results

The focus groups were conducted between May 2019 and January 2020. The participants' characteristics are summarized in Table 1. We present the emergent themes in the same general order as used in the interviews.

Roles

The participants expressed priorities that aligned with their roles on the team. The physicians prioritized opportune decision-making and communication

with family members. Nurses emphasized daily communication and satisfying the needs of family members. Nursing assistants placed priorities on providing comfort and physical care for patients as well as emotional support for family members.

Nurses and nursing assistants agreed that physicians have the legal and technical responsibility to make EOL decisions and communicate these decisions to families. The physicians agreed that the nurses and nursing assistants spent more time with the patients and therefore played a fundamental role in bedside care. However, physicians did not report that nurses and nursing assistants played roles in providing information or emotional support to family members as part of their regular work duties. In general, the professionals reported that communication roles were divided according to discipline, rather than integrated as elements of an interprofessional communication process (Figure 1).

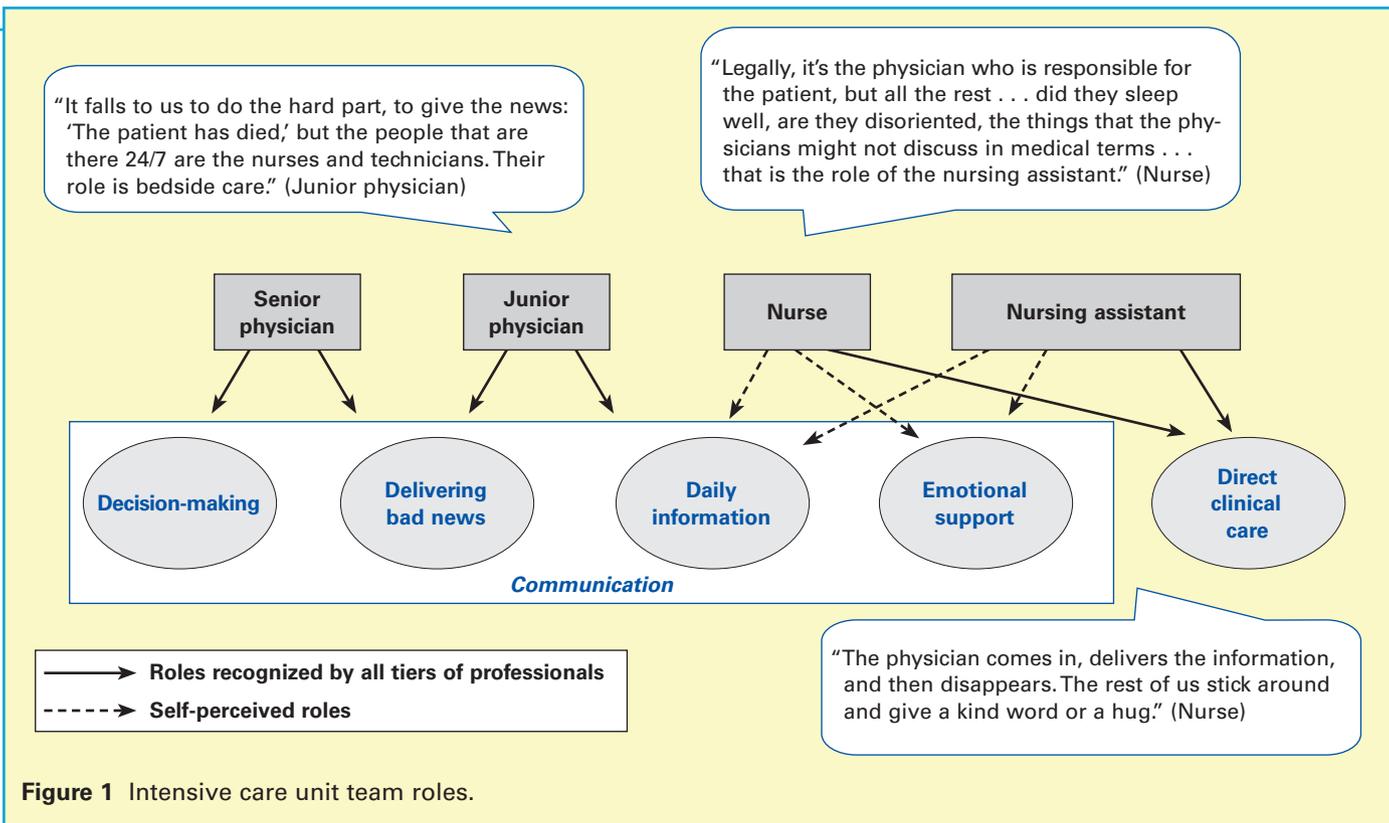
Challenges

Challenges were concentrated in 3 main areas: decision-making, communication, and emotional impact.

Decision-making. Physicians expressed difficulty in making EOL decisions from various perspectives, emphasizing the role of cultural elements and uncertainty. These professionals perceived cultural resistance on the part of families to talk about death and a lack of norms and standards to define limits for life-support therapies in advance. On an individual level, these difficulties were reflected in difficulty discussing preferences or behaviors related to EOL.

It falls to us to talk about things that nobody wants to talk about, sometimes not even the family and perhaps not the patient. We have to tell them something they haven't been told before, not by the oncologist or the geriatrician. (Junior physician)

The main problem is that the concept of death, as a process related to life, isn't discussed on a cultural level in our country. People who are facing a complex disease do not have the necessary conversations about advance directives. As a critical care unit, we are a support unit. It falls to us to deal with complex situations in which the patient's primary physician, who presumably has the best doctor-patient relationship with the person, has never discussed the issue with the patient or the family. (Senior physician)



Professionals emphasized the uncertainty surrounding the care of critically ill patients, including the impossibility of precisely predicting prognosis. At the same time, those interviewed felt responsible for suspending life-support therapies as a prelude to death.

Declaring that the patient is not going to improve, making the decision to initiate end-of-life care, that point-of-no-return is hard for us. Sometimes we delay making the decision, doing everything possible. (Senior physician)

If they are on total life support and we withdraw care, what will happen to the patient? They will most likely die. I try to reassure myself that it is an a priori decision. You have the elements that you have and you don't know what the consequence will be. To know the consequence, you would have to live backwards. (Senior physician)

Perhaps now, patients die less than before, but it is still a situation of great uncertainty. You can try to look at all of the objective data, but the patient's situation changes from day to day, so even looking at the data is difficult. (Senior physician)

Communication. All groups mentioned communication as one of the most challenging aspects of EOL care, both within the team and with patients'

families. The interviewees felt that communication difficulties within the team manifested as tension among the ICU team members. Lack of communication regarding the criteria used by the physicians for EOL decisions sometimes led other team members to question the decisions to either prolong a life with "excessive" or "cruel" treatment, or, conversely, to end a life by withdrawing care "prematurely" or "giving up on" the patient. Some participants interpreted this tension as the result of elements the other discipline failed to perceive, which they described as "blind spots" (Table 2).

All interviewees agreed on the importance of continual, close communication with the patient and the patient's family. However, they also reported significant barriers to achieving this level of interchange, such as excessive workloads and the constant need to respond to urgent situations. Because patients at the EOL remain in the same physical space as other patients, the teams felt that they needed to prioritize patients under active medical management. Nurses and nursing assistants reported that communication with family members was not part of their daily duties because of a lack of time and physical space to carry out this task (Table 3).

Participants also identified internal barriers, such as emotional unease and feeling they did not have adequate communication skills for the task. They described witnessing a death as an intimate and painful experience—a moment of tension that

Table 2
Communication problems within the intensive care unit team:
questioning the decisions of physicians

Theme	Sample quotations
Excessive or "cruel" treatment	<p>Where we work is a clinical hospital so . . . they do studies, studies that I don't know, that you notice they are suddenly alienated from the patient. (Nursing assistant)</p> <p>I can say that on two occasions I have told the physician to please stop. I don't know . . . that they take the biomedical model and say, "Okay, is this right or wrong?" When you realize that all of the medical treatments you are doing are just cruel, then say, "Okay, stop," or "Maybe it would be right to stop?" or "is it right to keep doing this?" (Nurse)</p> <p>And then the nurse comes in and says, "Hey, doctor, are we going to keep doing this to this patient? For how long? Because the gentleman . . ." and then of course I try to at least . . . I think that we are lacking a bit there, including more of the team, not in terms of expressing their opinion, because they do that, but in terms of us explaining why we are doing what we are doing. (Senior physician)</p>
Premature withdrawal of treatment or "giving up on the patient"	<p>He was struggling to breathe and didn't have anything for that, and I asked the nurse, "Listen, why is he like that?" "Because he's about to die." "But we could put an oxygen mask on him or something, I don't know." (Nursing assistant)</p> <p>The other thing that we've started to do is to make sure that the rest of the team has been given information, the nursing assistants and the nurses, because sometimes you say, "We are going to remove the tube," and the nurse looks at you like, "What?" "Yes, we are going to suspend tube feedings." "But how can you just stop feeding him?" . . . and then they look at you like you're a murderer. Then the sense of being questioned can get pretty harsh. (Junior physician)</p> <p>There are emotional demands on the family, but also on the team, or when you have a colleague who is upset about what happened to a patient, dealing with all of that takes skill, which you have to learn. We learn as we go, and we need to learn more, but we also have to include more people, because it's easy to be critical from the outside and say that the doctor is doing too much or too little, but internally you have a little voice whispering in your ear about what you're doing and what you're not doing. (Senior physician)</p>
Individual aspects of care or "blind spots"	<p>And the surgeon was there at a moment when the patient happened to be doing well, but otherwise the patient was the same or getting worse. The family member is left with the idea that the patient is recovering because of what the surgeon tells them—that the patient is better—but it's not true. So, in terms of the specialists, I think that sometimes they don't have the complete information, and the family is given false hope. (Nurse)</p> <p>The team members have different backgrounds and blind spots for these situations, not just between the different types of professionals, like physical therapists, nurses, pharmacists, therapists, and physicians, but even among the physicians, depending on their specialty, or, for instance, cases in which a certain type of specialist doesn't understand the purpose of a treatment because they have a blind spot for the patient's actual situation. (Senior physician)</p>

Table 3
Communication problems between the
intensive care unit team and patients' families

Theme	Sample quotations
External barriers: work conditions	<p>As nurses, we don't have time to provide information, and there are no official channels of communication with the family. So, when we are free, or when we make time, we talk to them. Or when we go in to change the IV or give a medication, if the family happens to be there, we'll talk to them if they ask us something. (Nurse)</p> <p>We aren't authorized to give out information. And often right when they are asking, everyone is busy, but it's not because we don't want to . . . it's hard to tell them that we can't say anything. (Nursing assistant)</p> <p>In the unit, we are overloaded with work all the time. So, you try to be present for a family, for this person who is suffering. But it's always very hard because you are just overwhelmed with work. (Junior physician)</p>
Internal barriers: lack of self-efficacy	<p>Because a lot of times, when you are confronted with the pain, the weeping, the breakdown of a family member, you don't know what to say. You have to go into the room to do something, and it's as silent as the tomb. No one is talking, and everyone is looking at you. What am I supposed to say? (Nurse)</p> <p>You have to stand there, with a family who is dealing with the death of someone they love . . . you have to stand there without really knowing them, without having experienced the process of the illness. It's very hard. And we have to do it on our own, because you just learn as you go . . . (Junior physician)</p> <p>The patient was about to die, and everyone else literally went and hid. You had to deal with the situation alone and without much training. We don't get a lot of guidance on communication skills or delivering bad news. (Senior physician)</p>

Abbreviation: IV, intravenous catheter.

Constant exposure to pain and death

- Emotional ties
- Personal identification

- “For me it’s a question of attachment, how much time that you’ve spent with the family members of that patient. It has to do with how long they are in the hospital, and . . . there are patients that stay for 2, 3 months, and then end up dying from something acute. So, with that type of patient, yes, it hurts. In those specific cases I have cried . . . by myself, and then I wash my face, go out, and get back to work.” (Nurse)
- “Sometimes (the patient) is your own age, so it’s like . . . it’s impossible not think about it more in those cases, to think about how they must feel, and their family, and then trying to explain why . . . they are going to die.” (Junior physician)

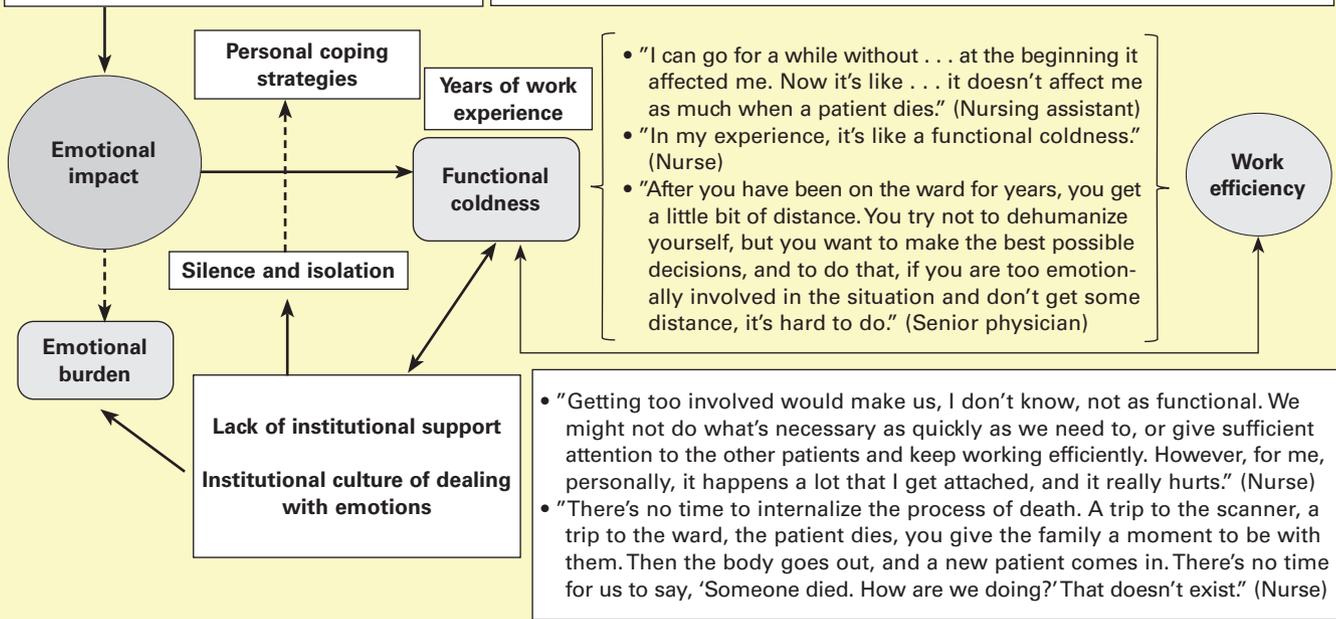


Figure 2 Emotional impact.

engenders compassion but also fear and frustration because of not knowing what to say or how to provide emotional comfort (Table 3).

Emotional Impact. All participants recognized the emotional energy consumed by working with people who are severely ill and dying, exacerbated by the simultaneous and intense demand for critical care of potentially recoverable, severely ill patients. The emotional impact was even greater when the professional identified with the patient or established affective ties, especially during prolonged hospitalizations. Interviewees reported a diminishing sensitivity to the death of patients, referring to “insensitivity” or “coldness.” This change was perceived as an undesirable consequence, albeit one that was necessary for a person working in an ICU. The participants remarked on the lack of personal tools and institutional support available to foster self-care and prevent burnout. Nurses and nursing assistants, for example, noted that they needed at least time for a break after having witnessed the death of a patient (Figure 2).

Successes

Participants related few successful experiences, reflecting the difficulty of associating death with job satisfaction. All interviewees, however, reported that

they were gratified by demonstrations of appreciation by family members and the self-perception of a job well done.

When the family sees that we did everything we could, and the person is peaceful, the family is grateful. (Junior physician)

Doing your job well and making the patient comfortable. (Nursing assistant)

Sometimes you are able to get the family there in time and do what is necessary and right. Those are the most thankful families, often even more than families of those you save. (Senior physician)

Discussion

This study identified important qualitative information about the experiences and perspectives of various members of an ICU team in Chile regarding EOL care. We document that carrying out EOL care in the ICU had a significant emotional impact on the team. We highlight several barriers to effective EOL care related to difficulties in decision-making, a lack of interprofessional clinical practice, and a lack of effective communication strategies.

Communication difficulties within the team manifested as tension among the ICU team members.

The psychological stress experienced by critical care professionals represents a high risk for burnout syndrome, the prevalence of which in the ICU is reported to be between 6% and 47%.²⁹ Research has identified various organizational and individual risk factors for burnout syndrome, including caring for dying patients, participating in ethical decision-making regarding EOL, and the perception of delivering inappropriate care.³⁰ Our qualitative data show that

the ICU team can suffer emotionally from providing EOL care. Notably, we found that the close emotional ties of the ICU team with dying patients and families, the tension inherent in caring simultaneously for dying and recoverable patients, the experience of isolation, and the scarcity of institutional measures to support the emotional well-being of health care staff all contributed to the emotional challenges of providing EOL care.

Recently, critical care societies published a statement with recommendations to prevent and manage burnout syndrome in the ICU.³¹ Our results support this call to action, highlighting the need to comprehensively address the emotional impact of providing EOL care in the ICU.

Since the 1960s, many countries have developed the concept and legal framework of advance care directives,³² which allow patients to discuss and express their preferences for EOL care.³³ Unfortunately, only a handful of countries in Latin America have integrated advance care directives into their legal framework. Chile specifically does not currently have laws pertaining to these directives.³⁴ The literature also indicates that many incapacitated patients have never had conversations regarding their preferences in specific clinical scenarios, and if they had such conversations, the outcomes were often insufficient for defining EOL decisions.^{35,36} Accordingly, the ICU physicians in this study experienced difficulty in identifying when to transition to EOL care and identified several cultural factors as potential barriers to this transition. These barriers included a lack of norms and standards that define limits for life-support therapies and a frequent resistance by patients and relatives to engage in EOL discussions.

How ICU clinicians address EOL decisions is determined by personal and cultural factors, including experience, personality, hierarchical role, religious beliefs, and nationality, which introduce biases that can have significant effects on patient care.³⁷⁻⁴⁴ In this study, physicians reported prognostic uncertainty as

a barrier to EOL decision-making. They felt responsible for suspending life-support therapies as a prelude to death. Decisions related to withdrawal of life-support therapies could be especially challenging when relatives of dying patients emphasize as a priority the sense that all potentially beneficial treatments be attempted.⁴⁵ In this context, shared decision-making has emerged as the framework to allow patients or their surrogates to collaborate with clinicians to make decisions regarding the limitation of life-support therapies consistent with the patient's values, goals, and preferences.⁴⁶⁻⁵⁰ Physicians should discuss key domains of prognosis, which may include certainties and uncertainties related to mortality or functional or cognitive impairment, but aim to tailor the decision-making process according to the patient's preferences. If ICU physicians have ethical conflicts that hamper the shared decision-making process, these difficulties must be recognized in a timely manner. Professionals must become aware of their own biases related to EOL issues, not only to remain open to patients' values and preferences, but also to ask for clinical, ethical, or emotional support if needed.

Interprofessional collaboration in EOL care in the ICU has been reported as an exigent challenge. Jensen et al⁵¹ underscored the need to improve EOL decision-making with interprofessional collaboration. Brooks and colleagues⁵² noted a lack of timely discussions and multidisciplinary acceptance of EOL plans. Ozga et al⁵³ reported a lack of professional collaboration and limitations of hospital managers as the main barriers to implementing EOL care in the ICU. Flannery and colleagues⁵⁴ reported role ambiguity and lack of opportune discussions about EOL care as great clinical challenges.⁵⁴ Similarly, our findings reflect tension among ICU team members, criticism of medical decisions, and a lack of appropriate team coordination to carry out EOL tasks. Participants described different and valuable EOL tasks, but these tasks were divided up according to disciplines rather than integrated as teamwork. Accordingly, scientific societies endorse the need to develop interprofessional EOL care planning, integrating different members of the team from the beginning of the transition to the EOL.^{55,56}

There is a known positive relationship between effective EOL communication and family satisfaction in ICU settings.⁵⁷ Family-centered guidelines recommend communication training for ICU professionals and the use of structured communication approaches, such as the VALUE mnemonic, including active listening, expressions of empathy, and making supportive statements about nonabandonment.¹⁰

Participants in this study stressed the need for continuous communication with patients and families during EOL processes, but simultaneously described feeling a lack of self-efficacy to achieve the task.^{18,19} This finding reflects a relevant gap in professional education on EOL.

Strengths and Limitations

This study provides an interdisciplinary approach to research on EOL care in the ICU, including wide purposive sampling across the care team to analyze different and simultaneous points of view. Our use of focus groups separated by disciplines allowed the participants to freely express themselves regardless of their roles or place in the team hierarchy. This study also contributes data on EOL care in the ICU in Latin American settings, a previously underexplored but much needed area of discussion.

The sample of participants was drawn from a single ICU in an urban academic hospital; therefore, the ideas may not necessarily represent the perspective of professionals in other national or international clinical settings. Because all interviews were conducted in Spanish and translated into English, some nuances in responses may have been lost. Finally, because participation was open and voluntary, those interviewed may have had a particular interest in EOL topics.

Conclusion

This study identified relevant qualitative information about the experiences and perspectives of the various members of a Chilean ICU care team regarding EOL care. Our main findings were of significant emotional impact, barriers related to EOL decision-making, limited interprofessional clinical practice, and difficulties in communication. The information provided by this study allows us to visualize gaps to be explored and filled to achieve high-quality EOL care in ICU settings.

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Supplemental Table

Guide to focus group questions

General question	Purpose
<p>Opening question: How was your experience with patients who have died in the unit where you work? What was your experience with the families of those patients like?</p>	To collect spontaneous reactions
<p>In your personal experience, what are the main difficulties or challenges you have experienced within the framework of patients who have died in the intensive care unit (ICU)? In your personal experience, what are the main satisfactions or successes you have experienced within the framework of patients who have died in the ICU?</p>	To identify types of difficulties and successes
<p>How do you define a “good quality” end-of-life (EOL) or death process in the ICU? If we create a definition ourselves, what name would we give to this process and which elements would be central?</p>	To identify differences or an emphasis on different elements and variables related to EOL
<p>Which would be the main aspects of a patient’s care for a good-quality EOL or death process in an ICU?</p>	To identify facilitators and barriers to EOL care
<p>During the EOL process, what would be your individual role? During the EOL process, what would be the role of other members of the ICU team (technician, nurse, physician)?</p>	To describe professional-occupational roles vs roles of other health professionals and workers How they perform/want to perform
<p>Regarding the role of the family, what do you think is the role or space that the patient’s family should have in the EOL process?</p>	To identify practices and the ideal practice, along with experiences with family members
<p>Closing question: After all that we have discussed, what reflections and/or proposals could you put forward to improve the EOL processes in the ICU?</p>	To collect the main or spontaneous reflections of the participants