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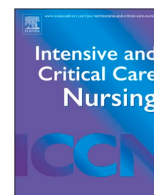

Research Article

Losing a close person to death in ICU: A thematic analysis of bereaved family members' experiences of end-of-life care

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A R T I C L E I N F O

Keywords:
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Qualitative method

A B S T R A C T

Objectives: This study aims to describe bereaved family members experiences of end-of-life care following the death of a close person in ICU.
Methods: A qualitative descriptive design was used. Semi-structured interviews were conducted with 22 bereaved family members (18 women and 4 men, aged 26 to 81 years). The inclusion criteria were being a bereaved family member of an adult patient who had died in one of the seven participating ICUs, being at least 18 years old, and proficient in Swedish. Data was analyzed using reflexive thematic analysis.
Results: The findings are described in five themes: *Time filled with fear and uncertainty, Challenges in understanding critical information, Struggling to grasp the imminence of death, Fear of patient had suffered at the very end of life*, and *The importance of farewell in the ICU*. Family members described the transition from therapeutic treatment to end-of-life care as being unclear, with the realization of death was approaching occurring gradually and sometimes suddenly, leading to confusion and distress. The opportunity to take farewell, whether through physical presence, shared silence, or collective rituals, was described as essential to finding peace and fostering emotional closure.
Conclusions: In ICUs, family members are in great need of compassionate support, characterized by the presence of ICU nurses and their emotionally attuned communication. This support helps family members navigate the complexity in care, fostering trust, meaning-making, and a sense of dignity.
Implications for clinical practice: It is important that ICU nurses have the possibility to prioritize sensitive, individualized communication, emotional support, and opportunities for meaningful farewells. Flexibly accommodating family members' needs and preferences at the end of life is central to delivering respectful family-centered care.

Introduction

Intensive care units (ICU) are often viewed as places where life is preserved through advanced technology. They are also environments where life frequently ends, sometimes suddenly and sometimes after a prolonged struggle. For family members, the experience of losing someone close in an ICU often involves emotional distress, uncertainty and a strong sense of loss [1,2]. It might be crucial for family members to be physically present at the bedside and offering emotional support to their close person [3,4]. In these difficult times, family members often need support themselves to cope with the unfolding reality [5]. Providing support for family members is essential in palliative care, especially throughout the illness and after the loss of someone close [6].

Palliative care extends beyond managing a patient's physical and psychological symptoms. It also attends to the emotional, existential and informational needs of the family members. Core components of

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palliative care, such as clear communication, support in decision-making, and bereavement services, are especially important during the dying process in the ICU setting [7,8]. The manner in which ICU staff communicate and offer support can significantly influence how family members experience and cope with the unfolding events during the ICU stay and the aftermath [9]. End-of-life decision-making in the ICU is often ethically and emotionally challenging. This is especially true when patients are unconscious, sedated, or mechanically ventilated and therefore unable to express their own preferences [10,11]. In such situations, family members frequently serve as surrogate decision-makers. Their choices about care are guided by their understanding of the patient's values and previously expressed wishes [12]. Although medical staff ultimately make the treatment decisions, the involvement of family members is vital. Such conversations are often fraught with ethical dilemmas and emotional weight, requiring sensitive, timely communication to support family members in their role [13,14]. Despite the significance of family members in end-of-life care, research shows that their emotional and informational needs are not always fully met. Many reports dissatisfaction with communication, lack of emotional support, and feelings of exclusion during the patients' dying phase and in their own bereavement [15–17].

Family members play a crucial role in the end-of-life process in the ICU. Yet their experiences are often marked by emotional strain, uncertainty, and unmet needs for information or support. Despite growing recognition of the importance of family-centered care, a deeper understanding of how bereaved family members experience end-of-life care in the ICU remains limited. Previous literature provides only partial insights into what kinds of support families perceive as most helpful during and after the dying process, leaving gaps in knowledge that are directly relevant to clinical practice. Supporting bereaved ICU families is both a recognized responsibility and a documented gap in current ICU practice and literature [18]. This study aims to describe bereaved family members' experiences of end-of-life care following the death of a close person in the ICU.

Methods

Design

The study employed a qualitative descriptive design [19] and is part of a larger project studying the multifaceted experiences of both ICU nurses and family members in the context of end-of-life care in the ICU. The study follows the COREQ checklist (Supplementary).

Study context

In Sweden, ICUs are organized based on the level of resources and specialization available to treat patients. ICUs, with basic resources, provide general care but lack most of the medical equipment and support systems required for more complex cases. ICUs, with expanded resources, offer more general advanced medical equipment, although they do not have the full range of high-level technologies. ICUs, with advanced resources, deliver the most complex and specialized forms of critical care. These units typically offer the latest state-of-the-art monitoring, full-spectrum organ support, and access to specialized services (e.g., neuro-intensive care). In contrast, lower-level ICUs provide essential critical care but may lack the full technological and specialist capacity required for managing highly complex or rapidly deteriorating conditions [20].

Of the seven ICUs involved in this study, four are general ICUs providing general critical care services for a variety of patients. The remaining three ICUs are specialized in thoracic, neuro, and central/trauma intensive care, each focusing on the treatment of patients within its specific field of expertise. Each ICU has four to ten patient care beds, with a mix of single and shared rooms. These units operate 24 h a day, providing continuous care to adult patients. They are staffed by multidisciplinary teams, including at least two anesthesiologists (one of whom is senior), ICU nurses and assistant nurses. ICU nurses hold specialist nursing training in critical care nursing at master's level and are typically responsible for the care of one or two patients, depending on the complexity and intensity of the care required. All ICUs participating in this study maintained an open visiting policy, which included designated visiting rooms for family members.

Participants and procedure

The inclusion criteria for this study were: [1] being a bereaved family member of an adult patient who had died in one of the participating ICUs between July 1, 2021, and June 30, 2022; [2] being at least 18 years old; and [3] being proficient in Swedish.

As part of the larger project on bereaved family members experiences following the death of a close person in the ICU, participants were asked at the end of a survey whether they wished to participate in a follow-up in-depth interview. Those who indicated interest by answering "yes" and providing their contact information were considered for inclusion in this qualitative study.

Of the 141 individuals who responded to the survey, the first 50 were given the opportunity to also take part in an interview study. Within the initial four months of data collection, 37 of these 50 participants expressed interest in being interviewed. Once sufficient information had been gathered, the option to participate in an interview was removed from the survey. The 37 individuals were subsequently contacted by the first author via email and given additional information about the interview study. Ultimately, 22 family members agreed to participate in the study, including 18 women and 4 men, ranging in age from 26 to 81 years. Their relationships with the deceased patients varied and included wife (n = 9), daughter (n = 6), son (n = 3), sister (n = 2), husband (n = 1), and mother (n = 1), The remaining 15 declined due to reasons such as emotional distress, time constraints, or reluctance to revisit their experience.

Data collection

Family members were given the opportunity to schedule interviews at times and locations that were most convenient for them. The sample size was guided by the concept of information power, emphasizing adequacy of data in relation to the study aim [21]. After 15 interviews, information power was reached but yet seven further interviews were performed to ensure this. Of the 22 interviews conducted, 18 took place via telephone, while four were held in a quiet setting at workplaces, homes, or at the university. All interviews were conducted by the first author. A semi-structured interview guide was used, which was informed by relevant literature and clinical experiences of the research group (Table 1). The interview guide was pilot tested with three participants, who provided feedback on the clarity and comprehensibility of the interview questions. Based on their input, minor adjustments were made, including rephrasing certain questions to enhance clarity. The pilot interviews were subsequently included in the study. During the interviews, to further enrich the data collection, follow-up questions, such as" Can you tell me more?" were used to give the family members the opportunity to further develop their answers. The interviews lasted between 13 and 34 min, allowing time for discussion while respecting the participants' availability and emotional comfort. All interviews were audio-recorded with the family members' consent and transcribed by a professional transcription service.

Ethical considerations

The study was conducted in agreement with the Swedish law concerning the Ethical Review of Research Involving Humans [22]. The Swedish Ethical Review Authority approved the study, Dnr 2021-03364.

Participants were provided with verbal and written information

Table 1
Interview guide.

What is your experience of the care your close person received at the end of life?
Can you describe your experience of the care during the last hours of your close persońs life?
Were there any aspects of the care that you felt were not adequately considered?
What experience do you have of the staffś encounter of you as a family member?
How well were you informed about what happened and why measures were taken in the care?
Did you feel involved in the decisions that were made regarding the care of your close person?
What support were you offered by the staff during the end-of-life care?
Did you feel that the support offered was sufficient?
What support do you think family members may need in end-of-life care?

about the study prior to the interviews and were informed that participation was voluntary and that they could withdraw at any time without explanation. Participants were assured of confidentiality. All data were handled in accordance with the General Data Protection Regulation [23] and were pseudonymized during coding and reporting to protect participants' identities. Prior to the interview, participants provided either verbal (which was recorded) or written informed consent.

Data analysis

Data was coded manually and analyzed using inductive Reflexive Thematic Analysis (RTA) as described by Braun and Clark [24–26].

The analysis followed six phases: *familiarization, coding, generating themes, reviewing themes, defining and naming themes*, and *producing the report*. In the first phase of the analysis, the first author became thoroughly familiarized with the data by listening to the audio recordings while simultaneously reading all transcripts multiple times. This iterative process allowed for immersion in the data, facilitating an in-depth understanding of the content. The last author also read a subset of the transcripts to support this initial familiarization. During this phase, the first author made initial notes and markings, which served as the foundation for the coding process. The first author then performed a comprehensive coding process, systematically identifying extracts that were presented to all authors. These extracts were discussed and reviewed jointly with the last author to ensure that the coding accurately reflected the content of the data and the research focus. In the subsequent phases, the coded extracts were grouped into preliminary themes. These themes were continuously refined and developed through regular discussions between the first and the last authors. The iterative nature of this process allowed themes to evolve, ensuring that they were closely aligned with the data while also representing a deeper interpretation of the participants' experiences. All authors met regularly to review and refine the themes, and ensured that each theme was coherent, distinct, and fully grounded in the data. Disagreements were discussed until consensus was reached. This collaborative approach ensured a rich and nuanced understanding of the themes. For increased transparency in the development of the themes, we refer to Table 2. In the final phase, the first and last authors worked together to draft an initial report. All authors contributed to further developing the draft by offering insights and perspectives, leading to a consensus on the final thematization. As member verification was not part of the design, participants were not asked to verify transcripts or coding [27].

Table 2
Exemples of code and theme progession.

Data extract	Coding	Final theme
"That nurse probably told me a lot of things when I arrived… what they had done with Dad, and I don't know, I don't think I really took it in at the time, because I don't remember much of it, unfortunately. (Male, participant 6)"	Careful treatment, family members felt confused. Difficult to assimilate the information given.	Challenges in understanding critical information
"None of us knew what creatinine was before, and I understood that it had something to do with urine and filtration, and that it shouldn't rise too much… There was so much information, and they educated us as much as we needed. But they also said that we didn't have to be fixated on all the numbers all the time. It's the overall picture that tells how Mum is doing, not just this one oxygen number and so on. But of course, there were some values we did get fixated on. (Women, participant 3)"	Family members felt they received extensive information about the patient and the monitoring processes, but struggled to interpret or make sense of it.	

Findings

The findings are described in five themes: *Time filled with fear and uncertainty, Challenges in understanding critical information, Struggling to grasp the imminence of death, Fear of patient had suffered at the very end of life,* and *The importance of farewell in the ICU.*

Time filled with fear and uncertainty

Family members entered the ICU during an emotionally turbulent time filled with fear, uncertainty, and disorientation. Within this high-stakes medical environment, their own emotional needs often felt invisible. However, family members described moments in which staff made efforts to acknowledge, comfort, and involve them. These moments were not only clinically supportive but emotionally significant, transforming a space of crisis into one where dignity, empathy, and human connection could emerge. Feeling seen and heard by ICU staff offered family members a sense of recognition and grounding during one of the most difficult experiences of their lives. One way this recognition was communicated was through emotionally attuned communication. Family members recalled instances where staff engaged with them directly, with empathy and openness, even when conveying painful or complex information. These conversations helped family members feel not just informed but also held emotionally.

> *He focused on me, and then he—the doctor—brought me in for a conversation and said, 'I'm going to tell you some things now that you do not want to hear, but I feel I have to say them to you.' And so we had a conversation, and he was really great. My mother would have liked him very much too, I'm sure of it. And they took care of me. He called me the next day just to ask how I was doing. So I felt that they truly understood how hard it was and that they made an effort. That meant a lot.* (Daughter, participant 3)

Support also came through non-verbal, practical actions that acknowledged family members' presence and emotional needs. Family

members described how nurses made space for physical closeness and comfort. They offered chairs, adjusted the patient's position, or simply remained nearby – actions that helped family members feel more connected.

> *They said [to the patient], 'Here comes your wife now,' and they would turn him on to one side so we could be a bit closer to each other. And they brought in a chair so I could sit close to him. I mean, they were really, really sweet.* (Wife, participant 1)

Family members described a sense of shared humanity in how the staff engaged with them, not just as extensions of the patient but as individuals navigating personal grief. In these moments, even small gestures such as eye contact, a gentle tone, or checking in later by phone contributed to feeling genuinely cared for.

Challenges in understanding critical information

While family members valued the ICU staff's efforts to provide timely and honest information, they found it difficult to fully grasp the meaning and implications. This was especially challenging during the early, high-stress phases of their close person's illness. The emotional intensity of the situation impaired their ability to retain or interpret medical information. As a result, even when the information was technically clear, its significance was often not understood until later. This disconnection between information delivery and emotional comprehension left many family members feeling uncertain and unprepared during key moments in the ICU. Several participants described how the initial shock and emotional overload prevented them from taking in even basic information about the patient's condition. Despite receiving updates, their minds were elsewhere, filled with fear and confusion.

> *That nurse probably told me a lot of things when I arrived… what they had done with Dad, and I don't know, I don't think I really took it in at the time, because I don't remember much of it, unfortunately.* (Son, participant 6)

In contrast, some family members appreciated detailed explanations and noted that the staff helped them gradually make sense of medical data. However, even in these more structured interactions, the volume and complexity of information sometimes became overwhelming. Participants described how they became fixated on certain numbers or measures, trying to find patterns or meaning in a sea of uncertainty.

> *None of us knew what creatinine was before, and I understood that it had something to do with urine and filtration, and that it shouldn't rise too much… There was so much information, and they educated us as much as we needed. But they also said that we didn't have to be fixated on all the numbers all the time. It's the overall picture that tells how Mum is doing, not just this one oxygen number and so on. But of course, there were some values we did get fixated on.* (Daughter, participant 3)

Although most family members felt they were kept informed, some expressed a sense of distance from decision-making, particularly in urgent medical scenarios. They understood and accepted that some decisions had to be made quickly by clinicians, but this also highlighted the limits of their own participation in critical care decisions.

> *I have to say that no one… I mean, no one called to ask if they should put him on a ventilator or anything like that. But those are professional decisions that must be made by the professionals in some way. So, in that sense, I wasn't really involved. But I did receive the information.* (Wife, participant 16)

During moments of patient critical situations, family members often struggled to receive and manage essential information, leaving them unprepared and disconnected from critical decisions.

Struggling to grasp the imminence of death

For family members, understanding that their close person was dying did not occur as a sudden realization but rather as a slow and emotionally complex process. While they often recognized that the situation was serious, the transition from therapeutic treatment to end-of-life care was difficult to comprehend in practice. Hope for recovery coexisted with subtle or unclear communication about prognosis, leaving family members emotionally unprepared when death became imminent. Even when staff attempted to communicate prognosis, the finality of impending death often remained difficult to fully comprehend until death became a reality. The process was shaped by fluctuating hope, interpretive ambiguity, and a need for emotional support to make sense of the unfolding reality.

> *But I didn't understand what it meant—I thought, okay, so there's no more treatment he can receive. That means it's just going to go downhill now. So, I kind of pushed it a bit… sharpened the question and said, 'What do you mean, what does that mean—an hour, a day, a week, a month?' /…/ And then they said, 'Well, we're not sure he'll make it through the night.' That surprised me again. Oh… it's happening now.* (Wife, participant 15)

Others experienced a disconnect between their own sense that death was approaching and the messages given by staff. This mismatch created confusion and inner turmoil, especially when reassurances seemed at odds with what they were witnessing.

> *I had this feeling, like—no, this isn't going to work, you know? When you just have that sense that… it's not going the right way, this won't turn out well. He's probably going to die /…/ But the staff insisted with almost stubborn denial that things were going to be fine.* (Wife, participant 9)

As death drew closer, family members emphasized the importance of emotional support. In this final stage, staff who were present, observant, and emotionally attuned played a vital role in helping family members cope with the unfolding reality.

> *For me, it was like—as soon as I stepped out of the room, I started crying, and there was always someone there to comfort me. They were so… they truly cared about me and noticed… they could read how sad I was or wasn't.* (Wife, participant 9)

Family members recalled moments when the situation was presented as terminal too suddenly, leaving them shocked and unprepared. Others felt that communication came too late or was framed in ways that gave false hope. These inconsistencies made it difficult to emotionally process what was happening. One participant described the absence of clear routines for alerting family when the patient's condition became critical:

> *But once they had noted his condition, you would think they should have made sure to contact the closest family and say, 'now it's urgent'. That's what I think. It wasn't clear, and it was far too late. But my biggest objection is that there was no routine for this – and it turned out there really wasn't, since I later spoke with the day doctor, not at the time but a couple of weeks afterward.* (Wife, participant 15)

During emotionally intense moments, family members highlighted the crucial role of ICU staff in offering empathetic and emotionally attuned support to help them process the reality of loss.

Fear of patient had suffered at the very end of life

A central emotional concern for family members was whether their close person had suffered during their last moments of life. Despite knowing that ICU nurses provided pain relief and sedation, many were haunted by doubts and fears that discomfort, fear, or anxiety had persisted. This concern was often tied to longstanding emotional bonds and a deep desire to protect their close person from distress. Even after death, the uncertainty about whether suffering had truly been avoided

lingered as a painful part of their grief. Some family members described how these fears were shaped by promises made earlier in life. The emotional weight of feeling responsible for ensuring a peaceful death heightened their sensitivity to any signs of discomfort, prolonging the emotional toll after the loss.

> *It was probably a prolonged suffering for us /…/ I was very clear that they shouldn't… that they weren't allowed to save him if he ended up being a [care] package, because I had promised him since I was young that I'd make sure he never ended up like that, if something happened.* (Daughter, participant 5)

Other family members acknowledged that the staff did everything possible to provide comfort. However, they still worried about invisible forms of suffering, particularly emotional distress, such as panic or death anxiety, which might not be fully alleviated through medication.

> *They did everything to make sure she wasn't in pain or anxious and so on. But I really believe she had… that she absolutely experienced death anxiety.* (Sister, participant 13)

A further dimension of this fear related to the effects of sedative medications. Family members expressed concern that, rather than easing distress, these medications might have caused disturbing dreams or hallucinations that added to their close person's suffering.

> *He was given a lot of painkillers, sedatives, and calming medication. And still, I think he had nightmares, and some of those nightmares probably came from the medication.* (Wife, participant 1)

Family members' doubts about their close person's physical or emotional distress – such as fear, anxiety, or disturbing dreams – highlighted their need for clear, compassionate communication and emotional support from ICU staff.

The importance of farewell in the ICU

Saying goodbye to someone close who is dying emerged as a meaningful experience for family members. These moments, whether brief or extended, verbal or physical, helped them make sense of the death and began processing their grief. Farewell often created a space of emotional intimacy amid a highly medicalized setting, especially when supported by staff who enabled closeness and ritual.

> *The care was technical, too, you know. So, it felt kind of heavy… his back was naked, and I could stroke his back a little. And that's not something you can stand there doing for 15 min—you do it for a little while, and then you feel that this is… this is okay, we'll take this as our goodbye, sort of…* (Wife, participant 16)

Shared rituals and symbolic acts were described as transforming the atmosphere from one of loss to one of connection and meaning.

> *We made something very… I think… beautiful out of the farewell. We sang, looked at photos from times when he was alive and happy, and talked about what he had meant to us. And yes, I think it became something very beautiful—in a way I never imagined it could be. But of course, if I had been sitting there alone, it would've been much harder.* (Wife, participant 1)

Family members also expressed farewell of cultural and religious significance, with staff playing a key role in facilitating such practice.

> *Because it's also a religious or traditional thing, you could say, that you should pass away…or at least be buried in new clothes for the afterlife. So, we were given time to go shopping and prepare, and when we came back, we handed everything to the staff, and they received it and arranged everything beautifully. It really was, you could say, good and dignified end-of-life care.* (Daughter, participant 18)

While not everyone was present at the exact moment of death, the ability to say goodbye, whether before, during, or after, was what mattered most. Family members emphasized the importance of having a farewell that was true to their relationship, facilitated by staff who respected their need for closeness and ritual.

> *I've always heard that you should open the window when someone dies, so the soul can leave the room. When my father went into cardiac arrest, I couldn't bear to stay, so I stepped out for a while. After he had passed, they told us: 'We would like to remove all the machines before you come in, so you can see him.' And I said: 'Please, please open the window.' And when we came back in, it was open.* (Daughter, participant 5)

Discussion

This study aimed to describe bereaved family members' experiences of end-of-life care following the death of a close person in an ICU. The findings show that family members found the end-of-life care to be an emotionally turbulent time filled with fear and uncertainty. Family members had difficulties in understanding crucial information during moments of patients' crises, they struggled to grasp the imminence of death, experienced fear that the patient had suffered at the very end of life and highlighted the importance of farewell in ICU. Across all five themes, ICU nurses emerged as pivotal, not only in providing clinical care but also in supporting emotional connection, facilitating meaning-making, and guiding the family members through this difficult time.

Family members in this study entered ICUs during an emotionally turbulent time filled with fear, uncertainty and disorientation. Previous research has noted that this experience is often shaped by the highly clinical and unfamiliar ICU environment, the complexity of medical procedures, and a frequent lack of emotional preparedness for the possibility of death [4,28]. The experiences of family members in this study aligns with the concept of the *ICU family syndrome*, characterized by cognitive overload and impaired processing during moments of crisis [29]. Even well-structured communication can become inaccessible in such circumstances [30]. Language barriers, low health literacy, and socioeconomic challenges can further marginalize families in the ICU [31], especially in multicultural settings like Sweden. As ICU population become increasingly diverse, culturally responsive and individualized family care is essential [30]. This includes early discussions to identify and accommodate spiritual, religious and cultural preferences [6]. ICU nurses, in particular, play a vital role in facilitating culturally sensitive communication and supporting rituals, especially when families lack support. A targeted intervention, such as the use of cultural liaison nurses or trained interpreters, can improve mutual understanding and ensure that family members feel heard, respected and involved throughout the care process [32].

The present study found that family members had difficulties in fully understanding crucial information during moments of patient crisis. They found it difficult to fully grasp the meaning and implications of what was being communicated. In these situations, they valued the ICU staff's efforts to provide timely and honest information. Clear, compassionate communication with information that makes sense of the situation, emotional support, and trust that makes family members feel included in the care process are essential strategies for promoting well-being among bereaved family members [33].

In this study, family members struggled to grasp the imminence of death, often experiencing it not as a sudden realization but as a gradual and emotionally complex process. This study highlights the need for ICU teams to support families in emotional processing and understanding the trajectory of critical illness. Family-centered ICU care underscores the therapeutic value of "family presence" which can strengthen emotional bonds, reduce distress, and build trust in care [34]). To enhance family members' awareness and emotional readiness for end-of-life events, Kentish-Barnes et al. [35] suggest a structured, three-step intervention: i) a preparatory family conference to discuss the prognosis and emotional processing; ii) a guided ICU visit during the dying process; and iii) a follow-up meeting after death to offer closure and condolences

[35]. Additional strategies, such as orientation family members to the ICU environment, explaining medical procedures clearly, and providing access to quit or supportive spaces have also been shown to improve comfort, understanding and engagement [36]. Moreover, tailored and repeated communication from ICU nurses has been shown to improve comprehension and emotional preparedness for end-of-life decisions [37]. Using simplified language, repeating key messages, and routinely checking for understanding during emotionally charged conversations are essential techniques to bridge communication gaps [38].

Family members in this study described the transition from therapeutic treatment to end-of-life care as emotionally complex and often ambiguous. In many cases, they only realized gradually that curative efforts had ceased, largely due to unclear or delayed communication from clinical staff. This experience reflects broader challenges in ICU care, where medical jargon, implicit cues, and unspoken assumptions may obscure the reality of impending death [36]. Nurses were identified as key figures in helping family members make sense of this transition. When nurses provided not only information, but also emotional presence and guidance, it helped family members understand the shift in care focus. A relational approach, marked by compassion, attentiveness, and honesty, has been described as essential in maintaining a sense of dignity and humanity, even within the highly technical and impersonal atmosphere of an ICU [39,40].

In this study, a central emotional concern among family members was whether their close person had suffered during their final moments. Despite clinical efforts to manage pain and provide comfort, family members continued to wrestle with uncertainty about whether their close person had experienced fear, pain, or emotional distress in their final moments. These worries, often accompanied by guilt and moral doubt, reflect findings from an earlier study on the psychological aftermath of ICU bereavement [4]. Such concerns highlight the importance of transparent, proactive communication, where family members are invited into conversations about comfort-focused care and can witness efforts to alleviate suffering. This involvement can help ease emotional distress, reduce lingering guilt, and foster a sense of closure [41].

In the present study, saying farewell to a close person who was dying emerged as a deeply meaningful and personal experience for family members. These moments, whether brief or extended, verbal or physical, were key for the ways that family members in the present study made sense of the death and began processing their grief. Family members in other studies have emphasized that such moments should be sensitively facilitated, not constrained by rigid routines or institutional procedures, but adapted to the individual needs and values of the patient and the family members [36,42]. When respectfully supported, these moments of farewell offered not only immediate emotional comfort but also played a vital role in the long-term grieving process. Previous research supports this finding, indicating that opportunities for personalized goodbye can help family members integrate the experience of loss and support healthier bereavement outcomes [43,44].

Limitations

This study provides insights into bereaved family members' experiences across seven ICUs in an urban region of Sweden. Several limitations should, however, be acknowledged. Most interviews were conducted by telephone, which might have limited the ability to observe non-verbal cues that could have added depth to emotional interpretations. However, the telephone interviews yielded data that was as rich and emotionally resonant as the face-to-face interviews. In fact, it may have been easier for participants to express their feelings more openly when they were separated from the interviewer. The overall quality of the interviews was high, as family members were engaged and shared emotionally detailed accounts across formats and locations. While a few interviews were short (around 15 min), they still provided rich data through emotional expressions and concrete examples. The mix of shorter and longer interviews added variation, capturing both focused accounts and extended reflections. Longer interviews, however, may have offered additional opportunities for depth and nuance. As with all retrospective qualitative research, participants' recollections were shaped by time and emotion. Interviews were conducted four to eight months after the patient's death, a timeframe chosen to balance emotional sensitivity with the potential for accurate recall [45]. It is not uncommon for individuals to retain memories of particularly significant events, even many years later. However, it is important to acknowledge that such long-term recollections may be subject to recall bias, potentially leading to inaccuracies in reporting [45]. Nevertheless, some participants may have forgotten specific details or unconsciously filtered their memories through emotional processing, which could have influenced the tone and content of their narratives. The broad definition of "family member" introduced variation in how participants related to the patient and experienced the ICU. The sample included spouses, partners, parents, adult children, close friends, and others identified through medical records, each with differing emotional and decision-making roles. Furthermore, as the sample predominantly consisted of Swedish female participants, the findings may not be fully representative or transferable to other subgroups, such as men or individuals from diverse cultural and linguistic backgrounds. Their experiences of end-of-life care in the ICU may differ in meaningful ways that were not captured in this study. Finally, self-selection bias is possible, as those with particularly strong views, positive or negative, may have been more likely to participate. The first author is an ICU nurse with no relation to the participants. Nevertheless, this preconception may have influenced the analysis. However, according to Braun and Clark (46), researchers' subjectivity is not a flaw to eliminate but research that inevitably shapes and enriches the analytical process. Despite these limitations, the study provides valuable insights into the emotional and relational needs of bereaved families in ICU settings. The findings from this study may be transferable to other ICUs with comparable care practices, as well as to wider healthcare systems engaged in end-of-life care, although contextual differences should be considered.

Conclusion

This study highlights the emotionally complex and often disorienting experiences of bereaved family members who have lost a close person in the ICU. Their narratives reveal how the intensity of the critical care environment, combined with emotional shock, often limit their ability to process medical information and participate meaningfully in decision-making. Despite this, small acts of compassion held deep significance and helped family members make sense of the crisis. Across the findings, several core needs emerged: the need to feel seen and heard in a time of emotional chaos; the need to understand the implications of treatment withdrawal; the need to be reassured that their close person did not suffer; and the need for a personal and meaningful farewell. When these needs were acknowledged and supported by staff, particularly nurses, family members described moments of emotional clarity, connection, and dignity, even amid profound grief.

These results underscore the critical role of relational and communicative care in intensive care settings. Nurses are uniquely positioned to support family members by guiding emotional meaning-making, facilitating end-of-life conversations, and creating space for individualized farewells. In doing so, they may not only help reduce distress during the ICU stay but also contribute to healthier grieving processes after the loss. Future efforts to improve family-centered ICU care should prioritize emotionally sensitive communication, culturally responsive support, and flexible opportunities for family members to say goodbye. By recognizing the enduring emotional impact of end-of-life care experiences in the ICU, healthcare teams can foster trust, reduce suffering, and uphold the dignity of both patients and family members.

Declaration of generative AI and AI-assisted technologies in the writing process

During the preparation of this work, the authors used Copilot in sections where we saw a need to find appropriate expressions, for example to translate quotes and improve readability and language. After using this tool, the authors reviewed and edited the content as needed to take full responsibility for the content of the published article.

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CRediT authorship contribution statement

Lena Palmryd: Writing – review & editing, Writing – original draft, Methodology, Funding acquisition, Formal analysis, Data curation, Conceptualization. **Anette Alvariza:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Conceptualization. **Åsa Rejnö:** Writing – review & editing, Validation, Supervision, Methodology, Formal analysis, Conceptualization. **Tove Godskesen:** Writing – review & editing, Writing – original draft, Validation, Supervision, Methodology, Formal analysis, Conceptualization.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at https://doi.org/10.1016/j.iccn.2026.104359.

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