



Nurses' perceptions of end-of-life care in neonatal and pediatric intensive care units in Korea: a qualitative descriptive study using thematic analysis

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Purpose: To explore nurses' perceptions of end-of-life care in neonatal and pediatric intensive care units, focusing on the components, facilitators, and challenges of such care in daily practice.

Methods: A qualitative descriptive study was conducted. Data were collected from June to October 2023 through semi-structured individual interviews with 17 nurses from the neonatal and pediatric intensive care units of four tertiary general hospitals in a metropolitan area of South Korea, and were analyzed using thematic analysis techniques.

Results: We identified three themes and nine subthemes: (1) supporting families' emotional and relational closure, (2) perceiving relational and systemic support as enabling end-of-life care, and (3) feeling constrained by systemic and practical challenges. Participants perceived fostering an emotional connection with the child, ensuring opportunities for meaningful farewell, and supporting emotional acceptance of death as ways to support families' emotional and relational closure with their child. Although relational and systemic support, such as collaborative teamwork, clear communication, shared planning, and structured tools, enabled compassionate care, participants also felt unprepared, burdened by heavy workloads, and hindered by environmental barriers.

Conclusion: The findings highlight that delivering quality end-of-life care in neonatal and pediatric intensive care units requires supporting families' emotional needs, strengthening relational and systemic support, and addressing practical challenges. Further research is needed to develop and test practical strategies (e.g., specialized education in compassionate communication, standardized protocols, and supportive care environments) that can improve the quality of end-of-life care for neonatal and pediatric patients and their families.

Keywords: Neonatal intensive care unit; Palliative care; Pediatric intensive care unit; Qualitative research; Terminal care

INTRODUCTION

In Korea, approximately 80% of deaths among children under 15 years of age occur in hospitals [1], with neonatal and pediatric intensive care units (ICUs) being the most common locations of death. Whereas neonatal ICUs provide criti-

cal care to seriously ill neonates (or newborns), pediatric ICUs provide care for seriously ill children across all developmental stages, from infants to adolescents [2]. Neonatal and pediatric populations present distinct developmental needs and clinical characteristics (e.g., primary diseases, complications, and children's involvement in decision-making)

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[2,3]. However, these units are also highly medicalized and emotionally demanding environments, often marked by a child's physiological instability, unpredictable disease trajectories, and separation from family, all of which exacerbate parental stress and anxiety during ICU stay [4]. Furthermore, limited opportunities for physical closeness in these settings may impede the formation of a secure parent-child attachment during a critical developmental period [5]. Prognostication in neonatal and pediatric populations is particularly challenging because end-of-life trajectories are often nonlinear and accompanied by fluctuating signs and symptoms [6]. In this context, nurses in neonatal and pediatric ICUs must provide technically competent and emotionally sensitive care that addresses the multifaceted needs of both ill children and their families.

As primary bedside caregivers in neonatal and pediatric ICUs, nurses strive to provide holistic end-of-life care that addresses the physical, psychosocial, and spiritual needs of children and their families, supporting the possibility of a child's peaceful death [7]. Furthermore, considering that the loss of a child can be an intensely painful and tragic experience for parents and families, nurses should endeavor not only to manage the child's symptoms (e.g., pain) but also to deliver emotional support to parents and families [7]. This indicates that nurses' appropriate end-of-life care attitudes, knowledge, and skills are essential to ensure quality end-of-life care for neonatal and pediatric populations and their families, particularly in ICUs where deaths occur more frequently.

However, neonatal and pediatric ICU nurses often describe end-of-life care as emotionally burdensome, marked by feelings of frustration, guilt, and a sense of professional failure, which can lead to emotional disengagement from patient care or job turnover [8]. Bloomer et al. [9] synthesized three core themes in nurses' post-death experiences in these settings: emotionally charged yet routinized postmortem rituals, challenges in providing culturally sensitive bereavement support to families, and intense personal grief compounded by limited institutional support. Moreover, many nurses feel unprepared to provide neonatal or pediatric end-of-life care owing to insufficient and inadequate relevant education and training [10,11].

End-of-life care for neonatal and pediatric populations is a global research priority [12]. International research has concentrated on end-of-life care components, pediatric palliative care, and ethical and practical issues in neonatal and pediatric

ICUs from the perspectives of healthcare providers or bereaved families [9,13-15]. In Korea, studies have largely focused on neonatal ICU nurses' knowledge and attitudes regarding end-of-life and palliative care [16,17], along with their experiences caring for dying infants [18]. However, limited attention has been paid to how nurses in these settings (particularly in pediatric ICUs) perceive and implement end-of-life care in everyday clinical practice, especially within Korea's distinct sociocultural and legal context, where pediatric palliative care remains underdeveloped.

Therefore, the main research question for this study was: How do nurses perceive their end-of-life care practices in neonatal and pediatric ICUs in South Korea? Specifically, we sought to identify similarities and differences in the components, facilitators, and challenges of end-of-life care between these two settings in the context of nurses' daily practices. Our findings may contribute to the development of innovative and practical strategies to provide better end-of-life care for neonatal and pediatric populations and their families.

METHODS

Ethical statements: This study was approved by the Institutional Review Board (IRB) of Chung-Ang University (IRB no., 2023-06-026-001). Informed consent was obtained from all participants.

1. Study Design

This study employed a qualitative descriptive approach with individual semi-structured interviews and thematic analysis to describe nurses' perceptions of end-of-life care in neonatal and pediatric ICU populations. The study was conducted in accordance with the consolidated criteria for reporting qualitative research (COREQ) checklist [19].

2. Study Setting and Participants

We recruited participants from nine neonatal and pediatric ICUs in four tertiary general hospitals located in a metropolitan area of South Korea. Four hospitals had more than 1,700 beds, and their neonatal and pediatric ICUs contained between 64 and 87 beds. Three hospitals were for-profit, and one hospital was non-profit.

To ensure the richness of the collected data on neonatal and pediatric end-of-life care, we employed purposeful sam-

pling. The participants were nurses who had worked in neonatal or pediatric ICUs in the four aforementioned tertiary hospitals for at least 6 months, had provided end-of-life care to neonatal and pediatric populations, and were willing to share their end-of-life care practices, thoughts, and experiences.

The principal investigator (PI), who received qualitative research training during her master's degree, posted a study advertisement in the bulletins of neonatal and pediatric ICUs and on the units' social media platforms. The advertisement included the PI's contact information and a link to the webpage where nurses could access detailed study information and submit their names and contact details. The PI then contacted these nurses to further explain the study and confirm their interest in participating. Informed consent was obtained in person or via email. Subsequently, snowball sampling was used to expand the recruitment, with participants being asked to refer other nurses who met the inclusion criteria.

The final sample consisted of 17 participants (Table 1). Participants were 29.1 ± 2.7 years (range, 24–35 years), the majority were female ($n=16$), single ($n=13$), and held a bachelor's degree or higher ($n=17$). Nine participants reported no religious affiliation, whereas the remaining were either Catholic ($n=4$) or Christian ($n=4$). The total clinical experience averaged 6.3 ± 2.7 years (range, 2–15 years), and participants were recruited from neonatal ($n=6$), pediatric ($n=9$), and pediatric cardiovascular ICUs ($n=2$). Most were general nurses ($n=14$).

3. Data Collection

This study was conducted from June 28 to October 20, 2023. We developed an interview guide based on previous studies on end-of-life care for children [7,8] and the purpose of the current study. The main interview questions were as follows: (1) "Describe the end-of-life care process provided in the current (neonatal or pediatric) ICU"; (2) "What do you believe to be important for end-of-life care provided in the neonatal or pediatric ICU?"; (3) "What helps with the provision of neonatal or pediatric end-of-life care in the ICU?"; (4) "What are the challenges to providing end-of-life care in the current ICU?"; and (5) "What improvements do you suggest to current neonatal or pediatric end-of-life care?" During the interview, the PI asked follow-up questions based on participants' responses. The interview questions were pretested with two peers in a pediatric ICU to assess their clarity and appropriateness.

The individual semi-structured interviews were conducted by the PI in a conference room at the hospital ($n=11$), a quiet café near the hospital ($n=4$), or via video conference ($n=2$) at a time convenient for participants. Each participant was interviewed from 1 to 3 times. After the first interview, the PI conducted second and third interviews to explore topics that required additional information. During the interview, the PI took notes on non-verbal elements, such as participants' behaviors and facial expressions. The first interview took 60–120 minutes, whereas the second and third interviews took

Table 1. Participants' general characteristics

Participant no.	Age (yr)	Gender	Education	Religion	Marital status	Career (yr)	Affiliation	Position
1	28	Female	Bachelor	None	Single	5–10	PICU	General
2	29	Female	Bachelor	None	Single	5–10	PICU	General
3	34	Female	Master	Catholic	Single	10–15	NICU	General
4	26	Female	Bachelor	Christian	Single	Less than 5	PICU	General
5	24	Female	Bachelor	None	Single	Less than 5	PICU	General
6	30	Female	Bachelor	Catholic	Married	5–10	PCCU	General
7	30	Female	Master	None	Married	5–10	NICU	General
8	27	Female	Bachelor	None	Single	Less than 5	PICU	General
9	28	Female	Bachelor	Christian	Single	5–10	PICU	General
10	30	Female	Bachelor	Christian	Single	5–10	NICU	General
11	31	Female	Bachelor	None	Single	5–10	NICU	General
12	27	Female	Bachelor	Christian	Single	5–10	PICU	General
13	35	Female	Bachelor	Catholic	Married	10–15	NICU	Charge
14	32	Female	Bachelor	None	Married	10–15	NICU	Charge
15	30	Male	Bachelor	Catholic	Single	5–10	PICU	General
16	28	Female	Bachelor	None	Single	5–10	PCCU	General
17	26	Female	Bachelor	None	Single	Less than 5	PICU	General

NICU, neonatal intensive care unit; PCCU, pediatric cardiovascular intensive care unit; PICU, pediatric intensive care unit.

up to 30 minutes. All interviews were digitally recorded and transcribed verbatim immediately afterward, resulting in 342 A4-sized pages. Each participant received a gift card (approximately US\$40) for their participation in this study.

4. Data Analysis

Data were analyzed using the six-step thematic analysis method by Braun and Clarke [20]. In Step 1 (i.e., “becoming intimate with the data”), the PI repeatedly read the transcripts to gain an overall understanding of the interview content and took notes related to the components, facilitator, challenges, and suggested improvements in neonatal or pediatric end-of-life care. In Step 2 (i.e., “creating initial codes”), meaningful units—phrases or sentences relevant study focus—were systematically coded. In Step 3 (i.e., “identifying themes”), by considering the relationships between codes, the PI reviewed and clustered related codes into subthemes, which were subsequently integrated into themes by identifying patterns and connections across the data. In Step 4 (i.e., “reviewing themes”), the coherence and distinctiveness of the subthemes and themes were evaluated, and iterative revisions were made to ensure conceptual clarity and consistency. This process involved regrouping and refining the codes and subthemes as needed. In Step 5 (i.e., “defining and naming themes”), we identified the core essence of each theme and modified theme names to best reflect the essence. Finally, in Step 6 (i.e., “writing the report”), we sought to present the thematic narratives in a clear, concise, and compelling manner.

Themes were initially derived separately from the neonatal and pediatric ICU data to preserve contextual specificity. We then developed a comparative table to identify the similarities and differences between the two care settings. The process revealed only minor distinctions and guided the final refinement of the theme names. Throughout the analysis process, the PI met weekly with the second author, an expert in palliative care and qualitative research methodology, to review and discuss the coding structure, thematic development, and analytic decisions. All authors reviewed and endorsed the final themes and representation quotes. The quotations, originally in Korean, were translated into English using Google Translate and subsequently reviewed and confirmed by the second author.

5. Trustworthiness

To ensure the quality of this study, the four trustworthiness criteria by Lincoln and Guba [21] were applied. To ensure credibility, the PI conducted all interviews in a consistent manner to obtain participants’ experiences and maintained close engagement with the data by repeatedly listening to audio recordings and reviewing transcripts to ensure transcript accuracy. Any unclear statements were clarified through follow-up interviews with participants. To strengthen the accuracy of interpretation, member checking was conducted by sharing preliminary findings with participants, who then confirmed that the findings reflected their experiences. Additionally, the PI discussed coding and thematic development with the second author during weekly meetings to strengthen the credibility of the findings. To enhance transferability (i.e., the applicability of the findings in situations similar to those of the current study), we recruited nurses with extensive experience in end-of-life care in neonatal and pediatric ICUs. Participant characteristics and care settings were also described to facilitate their applicability in similar contexts. Dependability (i.e., whether the study was conducted consistently) was secured by maintaining an audit trail, which included comprehensive and thorough documentation of all study processes from the beginning to the end of the study. Finally, for confirmability (i.e., making efforts to minimize the researcher’s bias or influence), the PI documented reflexive notes and regularly discussed the analytical process and findings with the second author to minimize researcher bias. Additionally, an external peer review of the codes, subthemes, and themes by classmates from a qualitative research course and two experts in pediatric nursing and qualitative research methodology provided further validation and helped ensure that the interpretations were grounded in the data rather than in the researchers’ assumptions.

RESULTS

Analysis of the interview data yielded three themes and nine subthemes (Table 2): (1) supporting families’ emotional and relational closure; (2) perceiving relational and systemic support as enabling end-of-life care; and (3) feeling constrained by systemic and practical challenges. The participants’ accounts indicated their efforts to provide families with nursing care that supported emotional and relational

Table 2. Themes and subthemes regarding nurses' perceptions of end-of-life care in neonatal and pediatric intensive care units

Themes	Sub-themes	Codes
Supporting families' emotional and relational closure	Fostering emotional connection with the child	Providing auditory comfort to the child
		Applying attachment-promoting items
		Valuing memory boxes as bereavement support
	Ensuring opportunities for meaningful farewell	Allowing unrestricted visitation
		Fostering a quiet and respectful environment
		Encouraging parents to hold their child
	Supporting emotional acceptance of death	Addressing fathers' needs
		Providing detailed explanation and guidance to the family
		Helping families prepare through the palliative care team
		Collaborating with co-workers for compassionate care
Perceiving relational and systemic supports as enabling end-of-life care	Gaining strength from co-worker support	Learning from emotionally skilled colleagues
		Hoping for emotional support structures
		Engaging families/children in shared care planning
	Valuing communication and shared planning	Ensuring clear communication for unified care
		Relying on protocols for safe and coordinated practice
	Deriving reassurance from structured tools	Gaining confidence through end-of-life care checklists
		Struggling to support families emotionally
Feeling constrained by systemic and practical challenges	Feeling unprepared for end-of-life care	Experiencing anxiety owing to insufficient experience
		Feeling strained by post-death administrative tasks
	Struggling to focus on end-of-life care amid heavy workloads	Being pulled away by competing responsibilities
		Experiencing disruption from uncontrollable noises
	Confronting environmental barriers to compassionate care	Managing limits imposed by precautionary procedures

closure with the child, facilitated by relational and systemic support. However, they also felt constrained by several systemic and practical challenges.

1. Supporting Families' Emotional and Relational Closure

This theme illustrates how nurses support families in achieving emotional and relational closure in the face of a child's death. Participants reported efforts to promote emotional bonding between children and their parents, provide opportunities for meaningful farewells, and facilitate parents' gradual acceptance of their child's dying process. This type of care was viewed as essential within the emotionally intense context of neonatal and pediatric end-of-life care in ICUs.

1) Fostering emotional connection with the child

The participants provided opportunities for families to maintain or strengthen their emotional connections with their children during the end-of-life period. Most participants encouraged using personally meaningful items, such as photographs, clothing, or familiar sounds (e.g., a mother's recorded voice and favorite songs), to support parents in expressing affection, providing comfort, and sustaining a sense of relational closeness. In the neonatal ICU, memory boxes were prepared containing the infant's footprints, handprints, or personal belongings (e.g., used electrodes) to honor the child's life and help families preserve tangible memories. Through these practices, participants helped sustain the parent-child bond as the child's condition worsened, and created meaningful experiences that could bring comfort throughout bereavement.

We created a memory box for children who were expect-

ed to die from rare diseases after birth. We took photos of the child and the child's parents, who accepted that their child was at the end of life, often wrote letters for the child. We placed the photos and letters into the box, along with the clothes and monitoring lines on which the child was placed. The parents appreciated the memory box a lot. (Participant 7, Neonatal ICU)

2) Ensuring opportunities for meaningful farewell

Participants from neonatal and pediatric ICUs worked to ensure that families had the opportunity to say goodbye to their children in meaningful and personalized ways. They reported efforts to allow extended or unrestricted visits, provide private and quiet spaces (e.g., using a separate room or a curtain, managing noise), and encourage physical closeness (e.g., holding or touching the child) during the final moments. Following the child's death, most participants carefully cleansed and prepared the body to appear peaceful and presentable, allowing families to hold their child once more in a dignified state. These practices helped parents feel present and emotionally engaged at the end of their child's life and contributed to a sense of closure.

A baby weighed around 6–7 kg, but still looked so small. The parents just stood at the bedside, not knowing what to do, simply watching the baby. I told them it was okay to hold the baby and gently placed the baby in their arms. They broke down in tears, saying they did not know it was allowed. I believe it is essential for nurses to support and guide parents in those moments, so they feel comfortable holding their child. (Participant 6, Pediatric ICU)

Simultaneously, some participants noted the provision of mother-centered end-of-life care, whereas fathers often assumed the responsibility for supporting other family members and handling administrative matters during this heart-breaking time. This imbalance left fathers and their children overlooked, leading participants to emphasize the importance of acknowledging and addressing fathers' grief as part of creating truly family-centered farewell moments.

3) Supporting emotional acceptance of death

Participants from neonatal and pediatric ICUs supported families in gradually coming to terms with their child's impending death. This involved providing clear and compas-

sionate explanations about the child's condition, engaging in repeated conversations to prepare parents emotionally, and offering a consistent presence and reassurance, often in collaboration with the pediatric palliative care team. Particularly, some participants described the palliative care team's engagement as not only practical support but also as a critical process that helped families gradually accept the reality of impending death and emotionally prepare for bereavement. Through these supportive approaches, participants sought to ease the psychological burden of anticipatory grief and facilitate a more peaceful end-of-life experience for both children and their families.

Our palliative care team visits parents to prepare them for their child's death. The team provides emotional support to parents and takes the initiative to plan for such death by discussing funeral procedures. When a child is about to die, the team visits and cares for the child's parents. (Participant 12, Pediatric ICU)

2. Perceiving Relational and Systemic Support as Enabling End-of-Life Care

End-of-life care for critically ill infants and children is supported by relational and systemic resources. This support helped participants navigate the emotional and procedural complexities of end-of-life care in neonatal and pediatric ICUs.

1) Gaining strength from co-worker support

Interpersonal support within neonatal and pediatric ICUs from colleagues, senior nurses, and interdisciplinary team members helped the participants provide end-of-life care for infants and children in neonatal and pediatric ICUs. Most participants reported that emotional encouragement, collaborative teamwork (e.g., allocating fewer patients and assisting with work), and role modeling provided psychological relief during emotionally demanding situations and practical guidance on how to communicate with families and manage complex care. This support helped them feel less isolated and more capable of delivering compassionate end-of-life care. Additionally, some participants highlighted the need for accessible psychological resources and informal support, such as on-the-spot debriefings and shared grief rituals to address the profound and lasting emotional impact of caring for dying children. These practices are vital for sustaining nurses'

resilience and their capacity to provide compassionate end-of-life care.

When a baby is dying, senior nurses come and offer words of comfort to the baby's parents, and I am really grateful for that. Since our patients are newborns, emotional support for the parents is especially important. But honestly, I cannot match the communication skills of the senior nurses. The experienced nurses provide support with such calm and grace, which is really moving. (Participant 10, Neonatal ICU)

2) Valuing communication and shared planning

Most participants perceived collaborative communication and shared planning as essential relational supports that enabled quality end-of-life care in neonatal and pediatric ICUs. They emphasized the importance of engaging families—and, when appropriate, older children, particularly adolescents in pediatric ICUs—in care planning to ensure that decisions aligned with their values and needs. Clear and consistent communication among healthcare team members was also described as critical for presenting a unified approach and reducing confusion in care delivery. Through these practices, most participants believed that they could provide end-of-life care tailored to the needs of dying children and their families, while minimizing misunderstandings within the care team.

When the family is not ready to accept that their child is at the end of life, we [clinicians] have to keep trying aggressive treatments. Thus, at the end of life, clinicians should have open discussions about treatment plans with the child's family. The child's family may then think about what would be best for their child and how to let this child go peacefully. (Participant 12, Pediatric ICU)

3) Deriving reassurance from structured tools

Structured protocols and checklists related to end-of-life care facilitated participants in managing the complex tasks involved in neonatal and pediatric end-of-life care. In both neonatal and pediatric ICUs, some participants emphasized the value of having clearly outlined procedures for tasks such as medication discontinuation, documentation, and postmortem arrangements. These systems helped reduce uncertainty, minimize errors, and ensure consistency in end-of-

life care. Some participants also noted that department-level protocol development, often informed by previous challenges, supported safe and coordinated end-of-life care practices.

Our unit has a protocol that guides us in end-of-life care before and after a child's death. For example, it lists the administrative and nursing duties that nurses should complete, such as how to make a reservation for a hearse and funeral home and how a dead child should be prepared for the transfer to a funeral home. Thus, when I have a child dying, I check the protocol line-by-line. As a nurse, this helps me a lot. (Participant 8, Pediatric ICU)

3. Feeling Constrained by Systemic and Practical Challenges

Participants perceived systemic and practical challenges, such as insufficient end-of-life care competency, heavy workloads, and restrictive environments. These issues hindered their ability to provide focused and compassionate care in neonatal and pediatric ICUs. These challenges contributed to participants' moral distress and prevented them from practicing end-of-life care as they believed it should be delivered.

1) Feeling unprepared for end-of-life care

Most participants reported feeling unprepared to provide effective end-of-life care in neonatal and pediatric ICUs, citing insufficient knowledge, skills, and emotional preparedness. Challenges included limited training in symptom management, discomfort in communicating about death and dying, and uncertainty regarding appropriate end-of-life practices. Such gaps often resulted in hesitation in engaging closely with dying children and their families, which contributes to emotional strain and moral distress. To strengthen both competence and confidence in delivering end-of-life care, some participants emphasized the need for communication training to equip nurses with the skills needed to support families, engage in difficult conversations, and respond empathetically to grief.

Who knows how parents feel when watching their child die and when the child's skin color changes? Sometimes, discharge can be delayed because of various situations, including late hearse. I think that such waiting time is the most painful thing for the parents. But I cannot say [to the parents], "It's hard, right?" or "The baby was so

pretty.” I do not know if those words are the right things to say. So, I just do not say anything for emotional support and try to rule out my emotions as much as possible. I do not know whether I am doing the right thing. (Participant 6, Pediatric ICU)

2) Struggling to focus on end-of-life care amid heavy workloads

Most participants faced significant challenges in providing focused and compassionate end-of-life care because of administrative tasks after the child’s death and competing responsibilities for other children. These time constraints hindered their ability to remain fully present with dying children and their families in neonatal and pediatric ICUs, leading to fragmented care and missed opportunities for emotional support. When care fell short of the standards of compassionate practice, some participants experienced frustration and a sense of professional inadequacy.

[After a child’s death], I had to quickly return the opioids and other medications, figure out which funeral home the child was going to, clean the child and show them to the parents... and sometimes accept other children admitted to the ICU at the same time. Therefore, I barely had time or emotional space to comfort the parents or fully or empathize with them. (Participant 9, Pediatric ICU)

3) Confronting environmental barriers to compassionate care

In neonatal and pediatric ICUs, environmental barriers often hinder the provision of focused, compassionate end-of-life care. Participants identified constant medical equipment alarms, crying children, and strict precautionary procedures as environmental barriers. These barriers made it difficult for families to concentrate on the last moments with their children. Consequently, most participants emphasized the importance of private, protected spaces where families could spend uninterrupted time with their dying child in a calm and respectful environment. During the COVID-19 (coronavirus disease 2019) pandemic, visitation policies further limited family presence. This led to emotional distress among participants, who felt that the time allowed was insufficient. Some participants also noted the difficulty of enforcing restrictions, even for closely extended family members (e.g., aunts and uncles).

It is hard to control the noise in the neonatal ICU. Even though most of our babies are intubated or critically ill, there are still some babies who cry on their own. When I hear those cries, I feel strangely sorry toward the parents of the dying child. For them, there is no turning back, and hearing another baby crying, sounding relatively healthy, might be hurtful. Even if a screen is put up, they can still hear everything going on outside. (Participant 11, Neonatal ICU)

DISCUSSION

This study explored Korean neonatal and pediatric ICU nurses’ perceptions of end-of-life care, focusing on its components, facilitators, and challenges in daily practice through semi-structured individual interviews and thematic analysis. Three themes emerged during analysis, namely “supporting families’ emotional and relational closure,” “perceiving relational and systemic supports as enabling end-of-life care,” and “feeling constrained by systemic and practical challenges.” The analysis showed little difference in nurses’ perceptions of end-of-life care between neonatal and pediatric ICUs. These themes reflect the complex interplay of interpersonal and institutional factors shaping nurses’ experiences of providing end-of-life care and highlight critical areas for enhancing such care in neonatal and pediatric ICUs.

In our study, nurses in neonatal and pediatric ICU actively supported families in achieving emotional and relational closure. They did this by fostering bonding, facilitating meaningful farewells, and guiding parents toward accepting their children’s impending death. These efforts include promoting memory-making activities (e.g., a memory box in neonatal ICUs), encouraging physical closeness, providing private and respectful environments, and delivering clear, compassionate communication. Existing literature demonstrates that such practices help bereaved families maintain continuing bonds, alleviate regret and psychological distress, and promote emotional adjustment through anticipatory guidance and emotional preparation [9,22]. For instance, Clarke and Connolly [22] reported that mothers of deceased newborns and children expressed deep appreciation for being introduced to memory-making and highlighted the comfort and emotional support they found in tangible mementos. These findings underscore the importance of neonatal and pediatric ICU nurses in actively facilitating and sustaining family-centered end-of-life care.

Our participants also perceived the engagement of pediatric palliative care teams as essential for providing emotional and practical support to families before and after a child's death. Evidence shows that integrating these teams into ICU care enhances care quality and alleviates the emotional burden on ICU nurses [13,23]. However, access to these services in South Korea remains limited. In 2017, only 9 (14.8%) of the 61 healthcare institutions provided inpatient palliative care to pediatric patients with cancer, and only one institution served children with non-cancerous conditions [24]. Most institutions reported reluctance to provide pediatric palliative care primarily because of insufficient support from trained pediatric palliative care professionals [24]. Addressing this gap requires strengthening specialized education in pediatric palliative care, supporting labor costs for these professionals, and establishing a separate and sustainable pediatric palliative care infrastructure [24]. These findings underscore the urgent need for comprehensive educational, financial, and workforce investments to advance pediatric palliative care service delivery in Korea.

The theme, "perceiving relational and systemic supports as enabling end-of-life care" illustrates how a combination of relational and structural support enables nurses to provide compassionate and effective care during a child's final moments in neonatal and pediatric ICUs. Relational support, including emotional reassurance, collaborative teamwork, and role modeling, helps alleviate nurses' psychological distress during emotionally demanding end-of-life situations. Consistent with our findings, Stayer and Lockhart [7] reported that providing rest time for nurses responsible for dying patients and promoting emotional sharing among colleagues helped reduce the stress and burnout associated with end-of-life care. Implementing both formal and informal emotional support systems is essential to safeguarding nurses' well-being and preventing emotional burnout following the death of a child. Linebarger et al. [23] emphasized nurses' participation in timely debriefing sessions, mourning rituals, and institutions' provision of professional counseling services to staff. Enhancing the emotional resilience of neonatal and pediatric ICU nurses is essential to help them cope with the psychological toll of repeated exposure to end-of-life situations [7]. To this end, institutional leaders should develop and implement structured mental health programs that offer accessible and ongoing psychological support to nurses involved in end-of-life care.

Clear communication among healthcare providers and

shared planning with families and children were also perceived as essential relational supports for providing coordinated and consistent end-of-life care that meets the needs of dying children and their families. This aligns with existing literature emphasizing the importance of clear, collaborative communication for improving care consistency among healthcare providers and shared decision-making between the child/family and healthcare providers in neonatal and pediatric end-of-life contexts [13]. Finally, structured protocols and checklists play a critical role in supporting nursing as they provide end-of-life care in ICU settings [25]. Although the tools mentioned in our study were primarily administrative, focusing on medication returns, documentation, and postmortem arrangements, they helped reduce ambiguity, standardize practices, and enhance care safety. Together, both interpersonal and procedural support within neonatal and pediatric ICUs may help nurses sustain compassionate and coordinated care at the end of a child's life.

The theme, "feeling constrained by systemic and practical challenges," highlights the multifaceted challenges that impede the delivery of compassionate end-of-life care in neonatal and pediatric ICUs. Participants reported feeling unprepared for end-of-life care, particularly regarding compassionate communication. They struggled to focus on dying children and families amid excessive workloads and confronting environmental barriers, such as pervasive noise and lack of privacy. These challenges contributed to moral distress and hindered nurses from providing care consistent with their professional and ethical values. Specifically, nurses' insufficient competency in compassionate communication during the child's final moments are common and impede the provision of appropriate support for bereaved families [7]. The absence of established guidelines for communicating end-of-life care with children further complicates this type of care [26].

To address these gaps, educational programs and standards regarding pediatric hospice and palliative care have been progressively developed worldwide. For example, the End-of-Life Nursing Education Consortium critical palliative care program in the United States provides ICU nurses with training in pain and symptom management, ethical and cultural considerations, communication, bereavement, and leadership [27]. Similarly, the European Foundation for the Care of Newborn Infants established standards to support neonatal care in Europe [28]. In Korea, although pediatric palliative care education was incorporated into the national hospice

care training curriculum in July 2022, it is currently offered only through designated central hospice centers [29]. This limited accessibility underscores the need to expand educational opportunities for ICU nurses (e.g., through online education) and to develop specialized curricula focused on compassionate communication in neonatal and pediatric end-of-life care. Strengthening educational content and integrating it into nursing programs are essential for building communication competencies in this area.

High administrative burdens also intensify emotional strain and compromise the quality of end-of-life care [9]. Additionally, continuous alarms, crying infants, and the lack of privacy in open spaces have been reported to disrupt families' end-of-life experiences and exacerbate distress for both nurses and families [14,30]. Although Korea's Medical Service Act mandates the installation of isolation rooms, including negative-pressure isolation rooms, in ICU settings [31], their availability for end-of-life care is often limited. This indicates the need for increased access to single or private rooms to better accommodate dying children and their families. To ensure holistic, family-centered end-of-life care and reduce the emotional burden on nurses, it is essential to streamline administrative tasks and foster a respectful and supportive ICU environment.

This study has some limitations. Since this study interviewed nurses working in neonatal and pediatric ICUs of advanced general hospitals in a metropolitan area of South Korea, the findings may not apply to the end-of-life care experiences of nurses in other settings. Furthermore, most participants were single women, which may have influenced the findings. Additionally, although data saturation was achieved for the pediatric ICU data, it was not fully reached for the neonatal ICU data owing to the small sample size. However, this study is one of the few on neonatal and pediatric end-of-life care in South Korea, and the findings may contribute to the development of practical strategies to improve the quality of end-of-life care for neonatal and pediatric populations in ICUs.

This study outlines the key components of end-of-life care delivered by nurses in Korean neonatal and pediatric ICUs, along with the facilitators and challenges. To enhance the quality of neonatal and pediatric end-of-life care, it is essential to develop and implement specialized nursing education programs that focus on compassionate communication and standardized care protocols. Creating supportive environments (e.g., quiet, private spaces) can further ensure dignity

and comfort for dying children and their families. Additionally, policy initiatives should prioritize the integration of pediatric palliative care teams into ICU care and the establishment of formal and informal emotional support systems for nurses regularly exposed to end-of-life situations. These efforts are critical for fostering sustainable, family-centered end-of-life care in neonatal and pediatric ICUs.

CONCLUSION

This study indicates that neonatal and pediatric ICU nurses sought to support the family's emotional and relational closure with their child but faced systemic and practical challenges. To address these challenges and improve the quality of neonatal and pediatric end-of-life care, stakeholders should provide educational, administrative, and environmental support. Future research should investigate end-of-life care practices in neonatal and pediatric ICUs on a large scale, explore advance care planning and surrogate decision-making for children in ICUs and their families, develop testable interventions to improve nurses' communication competencies, and study the institutional systems surrounding this type of nursing care.

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Conflict of interest

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Data availability

The data cannot be publicly disclosed. For the research data, please contact the corresponding author.

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