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Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea

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ABSTRACT

Background: Neonatal Intensive Care Unit (NICU) nurses in Korea often experience challenges in providing care for dying infants and their families. However, there is limited understanding about what contributes to the challenges related to end-of-life care.
Purpose: To describe NICU nurses' perceived roles and challenges faced while providing end-of-life care in South Korea.
Methods: A qualitative descriptive study was conducted with 20 NICU nurses in South Korea using semi-structured interviews. Participants were recruited from two NICUs in Seoul, where infant mortality is the highest in South Korea. Transcribed interviews were coded by two research personnel, and subsequently, a developed coding book was translated by three research personnel. The codes developed were categorized and peer-reviewed to develop themes using conventional content analysis.
Results: Nurses' roles during end-of-life care were grouped into four categories: providing information and support, enhancing attachment between the parents and infants, providing direct care to the infant, and completing documentation. Nurses' perceived challenges during end-of-life care included providing end-of-life care without adequate experience and knowledge, environmental constraints on end-of-life care, and conflicted situations during end-of-life care.
Conclusion: Although the nurses provided the best care they could, their end-of-life care practice was hindered for various reasons. To enhance NICU nurses' ability to provide and make them more capable of providing high quality EOL care, hospitals need to support nurse education and improve staffing level, and create in NICUs an environment that is favorable for providing EOL care.

1. Introduction and background

End-of-life (EOL) care is the care provided to people who are dying, and "includes physical, emotional, social, and spiritual support for patients and their families" (National Cancer Institute [NCI], n.d.). To maintain the best quality of life with dignity until the time of death, high quality EOL care should be provided to persons irrespective of medical diagnosis, condition, and age (NCI, n.d.; Izumi, Nagae, Sakurai, & Imamura, 2012). Although children have the right to a quality EOL experience, EOL care for children is not as well studied as it is for the adult population, particularly in the South Korean population. In South Korea, infant death accounts for 46% of all pediatric deaths until the age of 19 years. About 73% of infant deaths are caused by congenital anomalies and birth-related issues, including premature birth and low birth weight (Korean Statistical Information Service, 2015). Because infants with these conditions require immediate and intensive hospital treatment, providing quality EOL care for dying infants and their families in a hospital, especially in a neonatal intensive care unit (NICU), is crucial.

Healthcare providers' EOL practice is influenced by the common beliefs of death in the culture (Cheng et al., 2015; Kim, Savage, Hershberger, & Kavanaugh, 2019). In South Korea, 59% of palliative

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care physicians experienced family's reluctance to discuss EOL care, and 48% reported the reason of the reluctance as people believe that “bad things happen after you say them out loud” (Cheng et al., 2015). Providing quality EOL care within this culture can therefore, be very challenging. Previous research has shown that South Korean NICU nurses experience high stress from caring for dying infants and complain of a lack of education and limited resources to provide the appropriate EOL care (Jang, 2013; Kang & Bang, 2013; Wi & Kang, 2016). Severe stress has been attributed to the difficulty in providing EOL care, lack of knowledge of EOL care, lack of space and supportive policies, and emotional distress (Jang, 2013). Because of the lack of adequate resources, NICU nurses provide care for dying infants and cope with the deaths on their own. This negatively impacts nursing care, as they avoid talking with the parents and work without empathy (Kang & Bang, 2013). A recent study has shown a low overall level of knowledge about EOL care or palliative care that persists among Korean NICU nurses (Wi & Kang, 2016). There is a need to explicate the specific aspects of the NICU nurses' role in EOL care that causes distress for the nurses.

Development of EOL care protocol and educational programs for nurses can decrease their stress and reported difficulties, and improve the quality of EOL care they provide (Cavinder, 2014; Murakami et al., 2015; Rogers, Babgi, & Gomez, 2008). Although a clear understanding of nurses' roles in providing EOL care is necessary to develop adequate protocols and educational programs, no research has been undertaken to understand the EOL care practice nurses provide in South Korean NICUs. The purpose of this study was to describe NICU nurses' roles and the challenges they face when providing EOL care in South Korean NICUs by exploring the nurses' experiences of EOL care practice and how they perceive such care.

2. Materials and methods

2.1. Design and sample

A cross-sectional qualitative descriptive design (Thorne, Kirkham, & MacDonald-Emes, 1997) was used for this study. Qualitative description was used to examine specific aspects, such as the nurses' roles and the challenges they faced. After obtaining the approval of the respective university institutional review board, approvals were obtained from the NICU administrators in the two participating hospitals in Seoul, South Korea, where most infant deaths occur (Shim et al., 2013). From the two NICUs, a total of 20 nurses met the following inclusion criteria and participated in this study: (a) at least 1 year of experience working in the NICU, (b) experienced at least one patient death in the NICU, and (c) able to speak and understand Korean. Maximum variation sampling was used to capture the variety of nurses' clinical experience. When nurses expressed an interest in the study, the first author confirmed their eligibility to participate and obtained informed consent.

2.2. Data collection procedure

A semi-structured interview guide and a sociodemographic questionnaire were used for data collection. The interview guide contained questions that explored the nurse's experience with EOL care. Sample questions included “Tell me about the typical EOL care that is provided for infants and families in your unit,” “Which profession provides this care?” “What makes it difficult to provide quality care at the end of life?” and “What were some of the challenges you had to overcome?” The sociodemographic questionnaire sought demographic information such as the participants' age and marital status, and unit and professional characteristics, such as, education in EOL or palliative care, years of experience as a nurse and as a NICU nurse, and number of infants given end-of-life care. Participants were also asked to describe the NICU visiting policy. Interviews were conducted via Skype audio call to improve access to and accommodate the schedules of the participants, and they lasted between 32 and 85 min, with an average of 55 min.

2.3. Data management and analysis

Interviews were transcribed verbatim by a transcriber who was fluent in Korean. Transcribed interviews were reviewed by the first author for accuracy. The transcripts were managed using Atlas T.I. 8.0 (Scientific Software Development GmbH, Berlin, Germany). The Korean-language data were coded using a conventional content analysis (Hsieh & Shannon, 2005). The first author read all 20 transcripts comprehensively and repeatedly, highlighted text segments, recorded key thoughts that seemed to appear in each segment, and then developed an initial code book. To minimize subjective bias in coding the transcript contents, the first author and a PhD researcher with experience in qualitative research and NICU nursing, and fluent in Korean, independently coded the transcripts using the code book, and the inter-coder agreement was reached.

Guided by Guest, MacQueen, and Namey (2012), subjective assessments were performed by comparing and discussing coding results for five transcripts that were independently coded by the two coders. Then, using five other transcripts, percent agreement was examined by calculating the percentage of coding found to be in agreement as recommended for the interrater coding of qualitative data. The code book was continuously modified to achieve greater clarity, and the interview data were re-coded as necessary. The final inter-coder agreement was 100%. A professor of nursing with expertise in both qualitative research and EOL care, and fluent in Korean, reviewed the code book.

After finalizing the coding scheme, themes were generated and the code book and the important passages were translated into English by the first author and a bilingual PhD researcher who had worked at a South Korean hospital. The translated passages were reviewed and modified by one nursing faculty member in the United States to accurately convey the meaning of the nurses' quotes in English. Two nursing faculty members with expertise in neonatal nursing and palliative care then reviewed the generated themes. In addition, the first author reviewed the modified English passages again to ensure the translated passages accurately captured what the South Korean NICU nurses conveyed. Themes related to the nurse's role and the challenges they faced are presented in this paper.

2.4. Rigor and credibility

Rigor was maintained by employing traditional qualitative research methods throughout the study (Lincoln, Guba, & Pilotta, 1985). Credibility was maintained by means of peer-debriefing, thick description, and an audit trail. The strategies included having bilingual nursing experts review the data management and analysis, using maximum variation sampling, double coding of data by two researchers, and maintaining an audit trail.

3. Results

3.1. Demographic and clinical experiences

The average age of the 20 participants was 32.85 years (*SD* = 6.83). About half reported no religion, half were married, and seven of the married nurses had children. The participants averaged 8.9 years of work experience in the NICU. Other work characteristics are reported in Table 1.

3.2. Description of nurse's role in EOL care

The participants' description of the nursing role in EOL care were categorized as follows: providing information and support, strengthening the attachment between the parents and the infant, providing direct care to the infant, and completing documentation. Participants stated that the attitudes of nurses toward EOL care had become more favorable than what was observed in the past. However, one participant

Table 1
Participants' work characteristics (N = 20).

Variable	Number (%)
Hospital type	
Private hospital (open visiting policy for infants' parents)	13 (65)
University hospital (restricted visiting - twice a day by two family members)	7 (35)
Work level	
Staff nurse	17 (85)
Clinical nurse specialist	3 (15)
Experience with palliative care education/training	
Yes	12 (60)
No	8 (40)
Type of palliative care education/training (n = 12)	
University/certificate course work	5 (25)
Continuing education	4 (20)
1-day seminar in master's course	3 (15)
Experience of infant palliative care education/training	
Yes	2 (10)
No	18 (90)
Type of infant palliative care education/training (n = 2)	
1-day seminar in master's course	1 (5)
Unit conference	1 (5)
Experiences with caring for dying patients	
1	0 (0)
2–5	5 (25)
6–10	1 (5)
> 10	14 (70)
Experiences with caring for dying and dead patients in NICU	
1	0 (0)
2–5	5 (25)
6–10	2 (10)
> 10	13 (65)
Experiences with caring for dying and dead patients in NICU during previous year	
1	3 (15)
2–3	9 (45)
4–5	3 (15)
6–10	4 (20)
> 10	1 (5)

Note. NICU = Neonatal intensive care unit.

pointed out that although nurses' perceptions have changed to be more receptive to such care, she felt that nurses were still reluctant to see EOL care as their primary responsibility.

3.2.1. Providing information and support to parents

The participants reported that they provided information about patients' conditions and supporting parents by assessing their wishes and by providing consolation/empathy/emotional support and religious support. Participants reported that their role entailed informing parents about the current changes in the infant's condition and offering available EOL care support, such as having more flexible visiting hours or helping parents hold their infant. One nurse stated that

> *If such situations occur [the baby's condition deteriorates], we first call the parent regardless of the time [of day] because they don't stay at the hospital. So, first, by calling them, we let them know the current situation and status of the baby and ask that they come [to the hospital].* (Participant 2).

Participants also explained that making decisions around life-sustaining treatment and do-not-resuscitate (DNR) was the physician's responsibility. They reported that the nurse's role was to assess parents' intention to participate in actual EOL, such as holding the infant while the infant was dying or after death, dressing up the infant after death, and choosing a mortuary after the infant's death. As one nurse said, "*[At this time] when we make parents visit, we would ask parents if they want to hold their baby…but some parents say that they don't want to because they are worried the baby's condition could worsen.*" (Participant 1). Some participants reported that, over time, nurses had become more willing to assess and follow parents' wishes regarding EOL care.

Providing emotional support for parents was one of the most important nursing roles. However, many nurses also tended to depend on the CNS or other experienced nurses to support parents emotionally. One nurse stated that "*usually the CNS communicates a lot with the mom or parents. So, they provide the emotional support and the charge nurse or experienced nurses help the primary nurse to do end-of-life care.*" (Participant 7).

Nurses also stated that nurses informed parents about the availability of religious services and the clergy's visits to the NICUs, and that the clergy provided direct religious support. In addition, based on parents' wishes, nurses provided some other forms of religious support by playing recordings of religious scriptures while caring for dying patients.

3.2.2. Enhancing attachment between the parents and infant

According to the participants, enhancing attachment between the parents and the infant was a critical nursing role. Seven participants even stated that they devoted time to focus more on supporting the parents. According to one nurse, "*Since babies in the NICU cannot express themselves, complain about feeling uncomfortable from the treatments, or choose the treatment in their last moments, I pay more attention to the parents, who are the main decision makers.*" (Participant 16).

Most participants described regretting that a dying infant and the parents could not be together even though they were a family. They explained that, as nurses, they wanted to strengthen the attachment between a dying infant and the parents by trying their best to minimize the distance between them. They would do this by letting parents hold or touch the infant and maximize their shared-space and time by allowing more frequent visits by the parents or other family members, providing separate places and times for the families, and making the NICU environment more peaceful and comfortable. One nurse said *"Usually, I give time to allow (parents) to cuddle (baby)….give enough time (for parents) to say good bye (to baby), and (baby) dies at that moment… While monitoring (baby's condition), when heart rate decreases, (I) make the alarming sound quieter."* (Participant 2). However, participants further explained that because most dying infants were in critical condition, they were typically intubated and had various equipment attached. Therefore, some reported that they needed the help of the CNS or other nurses to safely move the infant from bed to the parents' arms and back.

Most participants felt that being flexible by allowing family visits outside of the policy was a part of their role. However, aspects of this practice, such as allowing grandparents' visits or unrestricted visits, varied by the individual nurse and the perceived policy of their unit. Half of the participants said they would provide separate places and times for families' visits using screens or partitions in the open unit environment rather than providing a private room. One nurse stated *"Once baby's condition gets worse, I use the screen to separate them (from other patients and their family) because there is no private space."* (Participant 7). Several participants described their efforts to make the environment more peaceful and comfortable by controlling the light and sound of alarms and care providers' chatting. In addition, one participant, who was an experienced nurse with children of her own, said that she had contacted several parents of infants who had died in the NICU and had kept in contact in cases where she had established a rapport with them.

Most participants with > 10 years of experience in the NICU reported changes over that time in the practice and perception of EOL care. Several reported the change in the practice of letting parents hold a dying infant. They also identified a positive change in the forms of facilitating memory-making, assessing parents' wishes, having a more liberal visiting policy, and controlling the NICU environment to provide families with more privacy and comfort.

3.2.3. Providing direct care to the infant

Participants focused their description of the physical EOL nursing care as managing and administering prescribed medications and handling the infant after death. About half of the participants described difficulty related to preparing and administering frequently changed prescriptions of medication at the time of EOL of infants. Most of them stated that the medication was administered for pain management. In addition, participants described nurses' responsibilities of direct care after an infant's death as removing all medical devices and inserted tubes, lines, and other equipment; closing the skin where tubes had been inserted; cleaning, bathing, and dressing the body in clothing and a hat; and cleaning the infant's bed. One nurse said:

> *The part of most concern to me is how I can clean the baby… so the baby can be wrapped and appear comfortable (after death) and be pretty, because definitely parents will open (the wrapped blanket)… I do not want to make (parents) remember the baby's appearance (that shows how the baby may have suffered from many medical devices) as their last memory… so, I dress them up with the most beautiful clothes, the cleanest one.* (Participant 8).

3.2.4. Completing documentation

Participants described the extensive documentation—related to administrative work such as discharge papers and the death certificate—that nurses had to complete after an infant's death. In addition, they stated that nurses provided information to the parents about the hospital mortuary and arranged to have a mortuary worker collect and transport the body to the mortuary accompanied by the parents.

Participants described another type of documentation that the nurses completed. Nurses put together a "diary" of written messages to the infant and give it to the parents after the infant's death. One nurse explained the diary thus:

> *Well, if there was a diary that had been written, we suggest parents bring it home…. Nurses write in the diary every three days. Because we had started the diary from the day the baby was born, some parents are touched by that. They think that "it is not only me that is happy with my baby's birth. Not only me who remembers my baby." So, they used to consider it a kind of memorial.* (Participant 9).

3.3. Challenges faced by nurses during EOL care

The challenges faced by nurses during EOL care in the NICUs were categorized into lack of adequate experience in and knowledge of EOL care, hospital policy and environmental constraints on EOL care, and conflicts in deciding the best course of action to take.

3.3.1. Lack of adequate experience in and knowledge of EOL care

Most participants perceived difficulties in providing EOL care because of their lack of relevant experience and knowledge; they expressed feelings such as sorrow, guilt, and regret. This lack of preparation led to such consequences as feeling detached after a death. Enhancing attachment between infants and their families and providing information and support for parents were reported most often as the most difficult roles to perform. Specifically, some reported that the signs of dying and signs of pain were difficult to recognize. Further, most participants with <10 years of NICU experience reported that emotionally supporting parents at the moment of an infant's death were difficult. One nurse stated, "*In fact, it is hard [for me] to approach [the parents]. There is nothing [I can do other] than keep watching it…I am ignorant about such things…So, I could do only small things such as handing tissue to parents who are crying a lot.*" (Participant 5).

Some participants perceived that their own feelings toward EOL care were not empathetic. They had come to think of EOL care practice as work that they performed without empathy. They expressed feelings of numbness in these situations and perceived their care as being far from good EOL care. One nurse described her feelings:

> *Well, I think I became numb. I first thought that I finished the work without any fault rather than that the baby had a good death…When I was a younger nurse, I cried a lot and thought about the experience for many days after the baby died. But, as time went by, I became number and number. So I just think that, well, I finished my work with the babies who have died. So, I think good end-of-life care is when I sincerely feel sad for the baby.* (Participant 20).

3.3.2. Hospital policy and environmental constraints on EOL care

Participants reported a number of constraints on care, including the unit's policy for family visits, the NICU layout, and extensive documentation with an ineffective nursing charting system. Five participants reported that their NICU's current policy for family visits was too restrictive. Many thought that their NICU's open environment and overcrowded layout were not conducive to EOL care. They stated that such an environment makes it hard to provide a separate time and place for parents to hold the infant and allow them the appropriate amount of privacy. One nurse explained,

> *We only set up the screen. So, we can hear mom's crying and so on. Maybe she does not consider such things, but… I wish there was some private place for mom and dad… Or, by moving the baby a little bit, it may be difficult because the baby is in critical condition. But, in the best case, mom and dad can hold the baby undisturbed by us, or other patients and families…* (Participant 2).

Six participants expressed concerns about the nurses' requirement to focus on completing paperwork right after the death instead of supporting the family. One nurse said,

> *Although the baby died, the primary nurse is busy entering materials [into EMR] that were used for treatment…such as administrative responsibilities…Yes, in fact, the administrative work is also important. But, often the baby is alone after death…it would be better, at least, if we say good-bye to the baby and send the baby and parents off peacefully together…taking more time and with more sincerity.* (Participant 4).

Participants pointed out that completing the required paperwork with parents during after-death care for the infant often made the nurses feel unsympathetic to parents' needs at the moment. One nurse said that "*while their minds are spinning, we need to explain the death certificate, where it is issued... this was difficult. And even though I explain it to them, dad cannot understand it all under these circumstances….*" (Participant 13).

Some participants stated that nursing charting does not reflect what they have done for the EOL care. Nurses tended to be very matter-of-fact in their descriptions of their charting. One nurse described her nursing charting for EOL care thus:

> *There isn't much charting related to EOL care or its practice. We don't document "because the baby's pain was this level, we administered this much of pain medication." Just, as usual, we record vital signs. And if parents and the physician discussed DNR, we record "we discussed DNR."… I think there is no special charting related to EOL care that we can do.* (Participant 7).

3.3.3. Experiencing conflicts in deciding the best thing to do for patients and families

About half the participants described situations where they felt conflicted about the best way to carry out the best course of treatment for EOL care. The most frequently stated conflict occurred between providing comfort care only and continuing curative treatment. Most participants stated that they felt conflicted when they believed that comfort care should be given, but physicians ordered aggressive treatment or parents wanted to continue aggressive treatment. In other words, these nurses did not want to continue "futile" life-sustaining treatment. In contrast, some participants felt guilty about providing comfort care. They viewed discontinuing aggressive treatment as “giving up.” One participant stated that “*when it comes to dying, right before the death, we let parents hold their baby. But this is giving up to me because we cannot keep doing [life-sustaining] treatments anymore.*” (Participant 7).

Another conflict that some participants described was the difficulty in deciding whether it was better to minimize the patient's pain or to enhance attachment between the parents and infant. They explained that nurses wanted to administer pain medication to help the infant sleep and avoid suffering, but they also acknowledged that parents wished to see their infant awake and moving so that they might touch or interact with their infant.

Participants reported many other ethical conflicts where nurses have to decide on the best choice. One example is providing information on EOL care versus withholding information on what is considered a taboo subject. Another example is respecting parents' hopes versus persuading parents to consider comfort care. One participant explained:

> *Even if we explained enough, accepting [the child's death] will not be easy at all. Even though they see the infant is suffering and they have heard explanations about the status of the suffering baby, they are optimistic [about their child's condition] and think that their baby will be fine. In such a situation, if I suggest hospice care to the parents, they might be angry. It would be so hard to accept it the first time it is suggested… if we mention such care, we can be viewed as a weird person by the parents. They will think, “Why does the nurse think that my baby will get worse? Can I believe that nurse?” and they will refuse end-of-life care.* (Participant 15).

Other examples concerned allowing family visits versus maintaining infection control protocol and providing continuity of care versus preventing nurse burnout. One participant described the difficulty of taking care of a dying infant continuously, although continuity of care is important:

> *This is a problem that one nurse keeps caring for a dying patient. Even though the patient is getting worse, they don't die soon. They are treated with so many medications and treatments for many days, then it is so stressful for the nurse. Caring for a baby who is facing imminent death for one day, two days, three days, and four days…. When I feel that I cannot be successful, no matter how hard I try, I think, “Why I am so busy the whole day to treat the baby, is this right for the baby?” But, when I keep thinking this as I keep working, I make my mind up, “Let's just complete my work.” It seems that [my attitude becomes] shutting off my emotional part toward the baby and just working, just administering medications. So, of course, if a nurse who cared for this baby yesterday cares for the baby again, it would be good as she could catch changes in the patient's condition. But, then the nurse's emotional exhaustion will be so serious. And, the exhaustion would be so hard to withstand physically, too. This is right for the baby, but we should change [the assignment] for the nurse.* (Participant 5).

4. Discussion

This study contributes to the literature on neonatal EOL care in Korea by providing a detailed description of NICU nurses' roles and challenges faced when providing EOL care. Four categories of their perceived roles for EOL care was described: providing information and support, enhancing attachment between the parents and infant, providing direct care to the infant, and completing documentation. The nurses' perceived roles were compared with the guidelines and a statement developed in the United States (Catlin & Carter, 2002; De Lisle-Porter & Podruchny, 2009; National Association of Neonatal Nurses [NANN], 2015) and previous studies that contain practical information on recommended EOL care and palliative care in NICUs.

Research conducted in the United States reveals that in EOL care practice in NICUs, nurses play pivotal roles by listening to families' concerns and wishes, recognizing signs of approaching infant death, notifying the neonatologists, giving information to families, managing signs of infants' pain, and supporting the families' bereavement process (Epstein, 2010; Kain, 2006; Kavanaugh, Moro, & Savage, 2010; Wocial, 2000). Therefore, nurses' perceptions of their need for more EOL and palliative care education may lead to more training and eventually can directly influence their EOL care practice.

In this study, although the nurses perceived that providing emotional support to parents is one of their important roles, many of them stated that providing such care to parents at the time of the infant's death was difficult. This difficulty was reported by many of the less experienced nurses and could be a result of the nurses' lack of experience and training in communicating such information to parents, as previous Asian studies have shown (Chen et al., 2013; Wi & Kang, 2016). In addition, the primary nurses avoid communicating directly with parents when they need to provide information about EOL care or when emotional support is required at the time of an infant's death. They felt that the role is better suited to the CNS or other more experienced nurses. However, as not every South Korean NICU has a CNS, staff nurses need to be trained to communicate directly with parents and provide emotional support. In 2009, an American national education program, the End-of-Life Nursing Education Consortium (ELNEC), administered by the American Association of Colleges of Nursing (AACN), became available in the Korean language, and ELNEC-PPC (Pediatric Palliative Care) training was held in Seoul, South Korea, in 2012 (Kang et al., 2014). Providing such training to NICU nurses will improve their knowledge of and attitudes toward EOL care and help them implement such knowledge in practice (Murakami et al., 2015). In addition, the presence of an EOL care expert in the unit will be a resource for staff nurses. If such personnel are not available, consulting or collaborating with the hospice team of the hospital would be useful.

The nurses clearly addressed their role in enhancing attachment between the parents and infant by assessing parents' wishes, providing religious support, and letting parents hold or touch their infant. However, parents' participation in caring for the dead body and in spiritual support, which were suggested by the U.S. guidelines, were rarely mentioned by the South Korean nurses. This may be because this study mainly focused on describing nurses' perceptions, not those of parents. To obtain more information, the parents' perspectives should be explored in a future research. In addition, providing personal space and a private environment were considered as aspects of the role of enhancing attachment, and recommended in the guidelines and statement (Catlin & Carter, 2002; De Lisle-Porter & Podruchny, 2009; NANN, 2015). However, although nurses wanted to provide a private place and time for dying infants and their families, because of the limited space and a limited number of nursing staff per shift in the NICU, they could not provide an optimal environment for the families. The best they could do was place screens to separate the dying patient and family from others. However, such screens could not block the sounds of other patients' alarms or the voices of healthcare providers and other families, and this situation made nurses feel that this gesture was inadequate. In addition, although the South Korean nurses perceived that parents need enough time to prepare for the infant's death, this was often problematic because of a lack of private space and limited visiting hours (Chen et al., 2013; Forouzi, Banazadeh, Ahmadi, & Razban, 2017; Jang, 2013). However, these challenges can be overcome with institutional support allowing for dedicated spaces and flexible visiting times for dying patients.

Providing direct care including handling the body, managing prescribed medication, and completing charting and administrative tasks after an infant's death, were also considered as aspects of the nurses' role. Because the dying infants are in critical condition and receive intensive life-sustaining treatment up to the point of death, nurses might feel burdened by having to manage the frequently changing prescriptions for numerous medications. However, ironically, managing increased medication and documentation related to EOL care were frequently reported as tasks that took primary nurses away from infants' bedsides during the process of EOL and after-death care. Providing direct care and completing documentation were part of the unique roles reported by South Korean NICU nurses. Interestingly, despite the heavy workload of managing medication, nurses did not frequently or comprehensively state that pain management was part of their role, as emphasized in the statement and guideline. Rather, some nurses asked, “Is sedating the baby to manage its pain appropriate to encourage interaction between the infant and parents?” They complained that they experienced difficulties in deciding between managing infant pain and encouraging family interactions. This may be because of a lack of knowledge or misunderstanding of pain management for EOL care (Jeong, Park, Lee, Choi, & Lee, 2014).

The U.S. guidelines and professional position statement recommended providing EOL care as one aspect of the palliative care that could be offered with advance planning, a comprehensive assessment of the patient's condition and parents' wishes, and extensive communication with parents regarding decision making from early in hospitalization (Catlin & Carter, 2002; De Lisle-Porter & Podruchny, 2009; NANN, 2015). However, advanced planning of EOL care or provision of palliative care was not mentioned by the South Korean NICU nurses. Rather, the nurses revealed that they felt ethical distress in providing life-sustaining treatment when awaiting the parents' arrival in the NICU or when the nurses disagreed with the desire of physicians or parents for aggressive treatment, because they perceived the prolonged life-sustaining treatment to be futile. However, in South Korean NICUs, decision making about life-sustaining treatment is part of the physician's role to communicate with parents and make treatment decisions (Chun, 2009). Given that South Korean ICU physicians tend to pursue aggressive treatment for dying patients (Phua et al., 2015), the nurses' distress is likely to remain unchanged until NICU physicians see the value in providing EOL care and palliative care (Cavinder, 2014).

The guidelines and professional position statement suggest providing continued bereavement care for parents after the death of the infant by calling or e-mailing parents, holding a memorial day, storing photographs, and introducing the parents to local support groups (Catlin & Carter, 2002; De Lisle-Porter & Podruchny, 2009; NANN, 2015). Although the guideline and statements deal with continuing bereavement care, the study results showed that the current EOL care in South Korean NICUs was mainly focused on care during the actual dying and after-death phases during the patient's hospitalization, as most South Korean NICU nurses did not mention bereavement care to be a part of their EOL care practice.

In addition to previous South Korean studies, detailed knowledge of the nurses' faced challenges during EOL care in the NICUs were identified and categorized: lack of adequate experience in and knowledge of EOL care, hospital policy and environmental constraints on EOL care, and conflicts in deciding the best course of action to take. Consistent with previous Korean studies (Jang, 2013; Wi & Kang, 2016), the nurses in this study also lamented their lack of knowledge in EOL care; only two out of 20 nurses had any EOL education. As like the previous studies (Jang, 2013; Kang & Bang, 2013; Wi & Kang, 2016), nurses expressed difficulty in providing EOL care because of environmental constraints that hinder the provision of EOL care. In particular, the nurses in this study added details of the environmental constraints; extensive documentation and an ineffective nursing charting system were stated by the nurses. Although the previous studies acknowledged the NICU nurses' experience of ethical distress during EOL care (Jang, 2013; Kang & Bang, 2013), this study provided more insight into their experience of difficulty in facing various ethically challenging situations that occurred during EOL care.

The stress that NICU nurses experience as a result of such conflicts can lead to burnout (Mendel, 2014; Vachon, 2012). Nurses would benefit from education and training that not only enhance their EOL care knowledge but also equip them with the ethical decision-making skills they need to effectively identify, articulate, and resolve such conflicts. Based on the study results and discussion, recommendations for hospitals include providing additional training in emotional support and ethical decision making, optimizing the unit layout, accommodating the need for increased nursing time through staffing when there is a patient at EOL, improving physicians-nurse communication that will facilitate timely decision making with regard to EOL care, and improving communication among the healthcare team.

This study was a qualitative descriptive study that described South Korean NICU nurses' perceptions of current EOL care practice. One limitation of this study involves the sampling strategy. Participants were recruited from two hospitals located in Seoul, which has the highest frequency of infant death in South Korea. Therefore, the study results may not reflect the perspectives of NICU nurses who work in other regions of Korea, nurses who have not experienced infant death, or other nurses in these two NICUs who chose not to participate. However, by providing thick descriptions illustrated by participants' quotes, readers will be able to decide whether the study results resonate with their practice settings.

Another limitation of this study involved language. The interviews were conducted in Korean, but the analysis was done in English without the benefit of member checking. Therefore, the nurses' meanings might have been misrepresented during the translation of their quotes despite our rigorous approach to translation. To minimize such errors and effectively convey their meaning, the quotations were translated by a team. One bilingual researcher who had worked in a South Korean hospital and the first author translated the quotes into English, and one nursing faculty member with expertise in palliative care in the NICU reviewed and modified the quotes to make them more comprehensible in English. Finally, the first author reviewed the modified quotes to ensure the quotes accurately conveyed the nurses' meaning. Because this study only used interviews with NICU nurses, the results reflect only the nurses' perceptions. In future studies, parents' and other healthcare providers' perspectives should be studied to better understand the EOL care in NICUs and the surrounding dynamics so as to enable the development and maintenance of quality EOL care for dying infants and their families.

5. Conclusion

This study comprehensively revealed the roles of South Korean NICU nurses during EOL care and the challenges they face. Although these nurses experience high stress regarding EOL care, they did not have an EOL care protocol and only two nurses had received any infant EOL care education. Hospitals should consider providing educational opportunities for NICU nurses on infant EOL care or palliative care, and make changes to the NICU environment and nursing staff levels when there is a dying infant in the unit. In particular, the conflicts that the nurses experience in current practice might be reduced if decisions about life-sustaining treatment were made in advance and fully discussed and communicated among all members of the healthcare team. Building on these results, exploration in greater depth of the ethical distress that nurses experience, other aspects of EOL care in South Korean NICUs, and educational intervention studies can be suggested for future research.

Declaration of competing interest

None.

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