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## Research paper

## Psychometric properties of the Korean version of the Palliative Care Nursing Self-Competence scale for infant use

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## A B S T R A C T

**Background:** Despite the significant advances in neonatal treatment and care over the past 30 years, palliative care in the neonatal intensive care unit has not been fully provided in South Korea. Neonatal nurses are essential professionals in palliative care as they are directly involved in the care, but there is little information on their palliative care competency because no assessment instrument is available in Korea.

**Objectives:** The aim of this study was to develop and test the validity and reliability of the Korean version of the Palliative Care Nursing Self-Competence scale for neonatal palliative care.

**Methods:** This scale for infant care was developed through parallel translation techniques and revised based on cognitive interviews. Survey data were then collected from 220 neonatal nurses who worked in 13 neonatal intensive care units in Korea. Internal consistency reliability, construct validity based on exploratory factor analysis, and criterion-related validity were tested.

**Results:** The final version of the scale included 40 items in five domains that explained 53.4% of the variance. Criterion-related validity was confirmed based on a positive correlation with the Korean version of the attitudes towards neonatal palliative care measurement tool. The Cronbach's alpha for the scale was 0.95.

**Conclusions:** The Korean version of the Palliative Care Nursing Self-Competence scale for infant care has satisfactory construct validity and reliability to measure palliative care self-competence of neonatal nurses in Korea and evaluate an education program in future studies.

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## 1. Introduction

In Korea, one out of every eight newborns are born prematurely. Despite the highly skilled healthcare delivery and increased margins of viability, some newborns die in the neonatal intensive care units (NICUs), often as a result of prematurity and congenital anomalies.<sup>1,2</sup> The loss of an infant increases the risk of adverse psychological outcomes including prolonged grief responses,

depressive symptoms, anxiety, and post-traumatic stress among parents.<sup>3–8</sup> Facing an infant's death in the NICU can have a greater impact on parents' lives than on any other family members' deaths.<sup>5,6</sup> Therefore, comprehensive care for parents with infants during the end-of-life (EOL) period is imperative,<sup>9,10</sup> and palliative care is an option for patients and families in such situations.<sup>11</sup>

Paediatric palliative care is "total care of a child with a life-limiting illness, including care for body, mind, and spirit, and support for the family".<sup>12</sup> In the NICU, palliative care includes holistic care based on family-centred care.<sup>13</sup> As NICU nurses are the primary caregivers for infants and parents, they can significantly influence parents' experience of witnessing the death of their infant and provide quality palliative care.<sup>10,14,15</sup>

However, nurses face several challenges during palliative care in the NICUs, such as lack of adequate knowledge, constraints of hospital policy and environment, and conflicts in deciding the best

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course of caretaking.<sup>16–20</sup> In particular, because paediatric palliative care is at an early stage in Korea, NICU nurses often complain about the lack of opportunity to receive palliative care education.<sup>16,18</sup> Moreover, they experience significant stress while providing care to the dying infant.<sup>16–22</sup> In previous qualitative studies that have explored the NICU nurses' experiences during EOL nursing, they have expressed emotions of helplessness, frustration, and guilt.<sup>16,18,22</sup> Such emotional and psychological distress has been linked to nurses considering resigning from their work.<sup>16,18</sup>

To mitigate NICU nurses' distress and provide palliative care qualitatively, a comprehensive understanding of neonatal palliative care and associated challenges for NICU nurses is crucial. A better understanding of NICU nurses' palliative care capabilities would enable nursing educators to provide appropriate and effective education, which has been reported to relieve emotional distress and improve attitudes and beliefs about palliative care among health-care providers.<sup>10,23</sup> However, there are currently no instruments to assess the capabilities of NICU nurses in neonatal palliative care.

Several instruments have been introduced to measure self-competence of palliative care for clinical adult patients.<sup>24–29</sup> However, most of these instruments are limited apropos incorporation of the family aspect and have reported little information regarding the instrument development process and psychometrics. The Palliative Care Nursing Self-Competence (PCNSC) scale was developed to measure nurses' perceived competence of palliative care.<sup>29</sup> The PCNSC scale is applicable to the paediatric environment as it deals with integrated nursing care not only for patients but also for their families.

The PCNSC scale is composed of 50 items in 10 dimensions to measure palliative care self-competency for patients, families, and caregivers. Although the development process of the PCNSC scale was reported and it has good content validity in the development study, its construct validity and internal consistency have not been tested. Therefore, this study attempted to translate the PCNSC scale into Korean to measure neonatal nurses' self-competence of palliative care and test the validity and reliability of the translated PCNSC scale.

## 2. Methods

### 2.1. Design

This methodological study followed three steps: a parallel translation, cognitive interviews, and testing of the psychometric properties of validity and reliability.

### 2.2. Sample and procedure

The original PCNSC scale consisted of 50 items in 10 dimensions: physical needs (pain, other symptoms), psychological needs, social needs, spiritual needs, needs related to functional status, ethical and legal issues, interprofessional collaboration and communication, personal and professional issues related to nursing care, and EOL care. Each item was answered on the score of 1 (not at all capable) to 6 (highly capable), and the possible total score range was from 0 to 300. The higher the mean score, the higher the palliative care nursing competency. Drs. Desbiens and Fillion, who developed the original PCNSC scale, granted the use of the scale for translation.

This study was approved by the institutional ethics committee of the respective institution (IRB Y-2020-0208).

#### Step 1: parallel translation

Three bilingual experts in neonatal palliative care were recruited to translate the original English PCNSC questionnaire to

Korean. They translated the scale to Korean independently at first and then met to compare translations and reconcile discrepancies. The final version incorporated the best of the independent translations, which was agreed upon during the discussion. Through this parallel translation, all 50 items of the original PCNSC scale were translated. Thereafter, eight items that required patients' verbal communication ability were excluded because the instrument would be applied to NICU nurses. Specifically, six of the excluded items required patient verbal communication that was not applicable to neonates. The other two items were related to communication issues or conflict between the patient and caregiver (parents). Examples of these excluded items were as follows: "Provide information to a palliative care patient concerning the legal issues associated with life-limiting illnesses" and "Assist a palliative care patient to explore the meaning of their illness experience". Thus, the first modified version was a 42-item questionnaire.

#### Step 2: cognitive interviews

The goal of the second step was to identify and correct problems with the translated questionnaire by administering the instrument via cognitive interviews. A validity of an instrument development can be enhanced using qualitative methods.<sup>30</sup> A cognitive interview is a qualitative method that focuses on the respondents' performance of cognitive tasks in the response process.<sup>31</sup> This process enables the prevention of potential errors that can arise from the use of inappropriate vocabulary of an intended concept or complex sentence structure through requesting information that is difficult to understand or inconsistent with one's knowledge and experience.<sup>32</sup>

Five NICU nurses in one major hospital in Seoul were recruited for cognitive interviews using purposive sampling. Prior to the interviews, the study was approved by the ethics committee, and written informed consent was obtained after explaining to the participants the method and assuring their anonymity. All participants were women, aged from 24 to 41 years. Their experience as NICU nurses ranged from 3 to 15 years, which was considered sufficient to cover the varying degree of understanding of neonatal palliative care. All nurses were individually instructed to read the Korean version of the scale and answer the questions without assistance. Subsequently, individual interviews were conducted to verify each item and gather opinions on ambiguity, misunderstandings, awkward expressions, and cultural differences. Interviewers explored the survey response process using a verbal probing technique to ask specific questions (probe).<sup>32</sup> Example questions included "Is it easy to answer this question?" "What does 'provide effective care' mean to you?" and "Do you think it's appropriate for palliative care for infants?" After the interview, the recorded file was reconfirmed and items were revised if the comments of the interviewees were deemed valid based on the researchers' judgement. There were no deleted items; however, 20 items were modified to focus more on the neonatal palliative care context. For instance, assessing the psychosocial needs of palliative care patients and their families was not appropriate for infants; therefore, these questions were modified to refer to the infant's family members. Some participants asked for examples of pain assessment methods and nonpharmaceutical pain interventions to be included. So, the final version of the instrument incorporated these two items.

#### Step 3: testing of validity and reliability

Internal consistency reliability using Cronbach's alpha, criterion-related validity using a correlation with attitudes on bereavement and EOL care, and construct validity using an exploratory factor analysis (EFA) were tested to validate the

questionnaire items. In this study, 220 NICU nurses from 13 hospitals, which was considered a sufficient number of participants based on the sample size of 150–200 subjects required for EFA, were recruited.<sup>33,33</sup> Nurses who agreed and consented to participate in the study received the online survey (Google Forms) link from the principal author. The survey questionnaire included the Korean version of the PCNSC scale, the Korean version of the Bereavement/End-of-Life Attitudes About Care: Neonatal Nurses Scale (BEACONNS), and demographic information. Data were collected from February 25, 2021, to March 30, 2021.

### 2.3. Measures

To test the criterion-related validity of the Korean version of the PCNSC scale, the BEACONNS<sup>21,34</sup> was used. This scale was developed based on a thorough literature review on families' involvement and bereavement, focussing on nursing roles in bereavement care. The scale's clarity and redundancy was confirmed via tests conducted with 24 experienced NICU nurses.<sup>34</sup> The Korean version of the BEACONNS showed a significant correlation with the revised grief experience inventory's comfort and role subdomains.<sup>21</sup>

Although this scale consists of three domains (comfort, role, and involvement), only the domains of comfort and role were selected because the involvement domain assesses nurses' perception of the importance of each factor influencing participation in EOL care, which is not related to their competency.

A total of 37 items in two domains were answered on a five-point scale and calculated for an average score. The higher the score, the higher the positive attitude towards neonatal bereavement/EOL.

### 2.4. Data analysis

Data were analysed using IBM SPSS Statistics for Windows version 24.0 (IBM Corp: Armonk, NY). To analyse characteristics of the NICU nurses, mean, standard deviation (SD), frequency, and percentage were used. Before an EFA, the Kaiser–Meyer–Olkin

(KMO) value of sampling adequacy was examined. To conduct factor analysis, the KMO value must be 0.922 and above.<sup>33</sup> Through Bartlett's sphericity test, the matrix between items was confirmed, and it was confirmed that there was no relationship ( $p < .001$ ). Principal component analysis was applied to find the most valid structure, and a varimax rotation was used. The principal component factors with eigenvalues greater than 1.0 were extracted, and items with factor loadings of 0.40 or higher were selected.<sup>35</sup> For criterion-related validity, Pearson's correlation coefficient between the Korean version of the PCNSC scale and BEACONNS was calculated. In addition, Cronbach's alpha was calculated for internal consistency.

## 3. Results

### 3.1. Participant's characteristics

Among 220 NICU nurses from 13 hospitals, most were female (99.5%). The mean age of nurses was 31.6 years ( $SD = 6.4$ ), and the mean NICU experience of the nurses was 7.2 years ( $SD = 5.8$ ). Most nurses had a bachelor's degree or higher (93.2%). In terms of the number of experiences with infants' deaths in the NICU, 96 nurses (43.6%) reported "once per year" and 59 nurses (26.8%) reported "once per six months". Many of the nurses (74.1%) had never received palliative care education (Table 1).

### 3.2. Construct and criterion-related validity

The EFA revealed five factors: family support, personal and professional issues related to nursing, interprofessional collaboration and communication, patient comfort care, and EOL care (Supplementary Table 1). Two items were deleted due to factor loadings lower than 0.4: "Provide proper mouth care to promote comfort in a PC patient" and "Encourage expression of cultural and religious traditions for family of a PC patient during the last hours of

**Table 1**  
Participant's characteristics (N = 220).

Variables	Categories	Characteristics	
		n (%)	Mean $\pm$ SD
Gender	Female	219 (99.5)	
	Male	1 (0.5)	
Age, y	<30	104 (47.3)	31.6 $\pm$ 6.4
	30 $\leq$ , <40	84 (38.2)	
	40 $\leq$ , <50	30 (13.6)	
	50 $\leq$	2 (0.9)	
Total clinical experience, y	<3	44 (20.0)	8.4 $\pm$ 6.9
	3 $\leq$ , <5	42 (19.1)	
	5 $\leq$ , <10	61 (27.7)	
	10 $\leq$ , <20	52 (23.6)	
	20 $\leq$	21 (9.5)	
NICU experience, y	<3	51 (23.2)	7.2 $\pm$ 5.8
	3 $\leq$ , <5	46 (20.9)	
	5 $\leq$ , <10	69 (31.4)	
	10 $\leq$ , <20	41 (18.6)	
	20 $\leq$	13 (5.9)	
Education	Associate's degree	15 (6.8)	
	Bachelor's degree	171 (77.7)	
	Master's degree	31 (14.1)	
	Doctor's degree	3 (1.4)	
Number of experiences of infants' deaths	Less than once/year	0 (0.0)	
	Once/1 year	96 (43.6)	
	Once/6 months	59 (26.8)	
	Once/3 months	59 (26.8)	
	Once/month	6 (2.7)	
Participation in EOL care education	Yes	57 (25.9)	
	No	163 (74.1)	

EOL = end-of-life.

life.” The five-factor model with 40 items was confirmed and explained 53.4% of the total variance.

The scores of the Korean version of the PCNSC scale indicated a significant positive correlation with the scores of the comfort ( $r = 0.369$ ,  $p < .001$ ) and role ( $r = 0.148$ ,  $p < .001$ ) BEACONNS domains (Table 2).

### 3.3. Internal consistency reliability

Cronbach's alpha values for the overall Korean version of the PCNSC scale were 0.95 and 0.79 for personal and professional issues related to nursing, 0.81 for patient comfort care, 0.83 for EOL care, 0.90 for interprofessional collaboration, and 0.94 for family support (Table 3).

### 3.4. The Korean version of the PCNSC scale for NICU nurses

NICU nurses in the survey demonstrated family support competency (mean = 4.04), followed by EOL care (mean = 3.59), interprofessional collaboration (mean = 3.49), personal and professional issues related to nursing (mean = 3.34), and patient comfort care (mean = 3.20) competencies (Table 3). There was no significant difference in the neonatal palliative care self-competencies between gender, units, ages, experiences, and education.

## 4. Discussion

NICU nurses play a key role in providing palliative care for infants and families with life-limiting illnesses.<sup>36,37</sup> It is critical for NICU nurses to develop and evaluate their palliative nursing competency. To measure the neonatal palliative care competency of nurses objectively, a standardised instrument is required. Thus, the objective of this study was to develop the Korean version of the PCNSC scale for NICU nurses in Korea and confirm its validity and reliability. A three-step process was followed: translating the English version of the scale to Korean, using parallel translation, conducting cognitive interviews, and subsequently, performing psychometric evaluation.

In the first step, the scale was translated into Korean, and eight items needing palliative care communication ability were deleted, leaving 42 items related to infant and family support. This process enabled the translated version of the scale to be used for nurses in the NICU.

Five nurses participated in cognitive interviews to review and refine the terms, questions, and sentences of the Korean version scale. The study participants had different experiences and knowledge of palliative care, resulting in differences in understanding of

**Table 2**  
Correlation coefficient between the Korean neonatal PCNSC and BEACONNS's subscales.

Group	BEACONNS_Comfort	BEACONNS_Roles
$r(p)$	0.369 (<0.001)	0.148 (<0.001)

BEACONNS = The Bereavement/End-of-Life Attitudes About Care: Neonatal Nurses Scale; PCNSC = Palliative Care Nursing Self-Competence Scale.

**Table 3**  
Mean and internal consistency of the Korean neonatal PCNSC (n = 220).

Domain	Number of questions	Mean $\pm$ SD	Cronbach's coefficient
Family support	16	4.04 $\pm$ 0.74	0.935
Personal and professional issues related to nursing	5	3.34 $\pm$ 0.74	0.787
Interprofessional collaboration and communication	6	3.47 $\pm$ 0.94	0.899
Patient comfort care	9	3.20 $\pm$ 0.63	0.805
End-of-life care	4	3.59 $\pm$ 0.91	0.832
Total	40	3.65 $\pm$ 1.11	0.952

PCNSC = Palliative Care Nursing Self-Competence.

survey items, particularly regarding neonatal delirium. This adaption process further enabled the use of the scale for NICU nurses in Korea.

The construct validity of the Korean version of the PCNSC scale was tested using EFA and criterion-related validity analysis. The construct validity of the original scale has not been tested to date, and this study modified the PCNSC scale to measure neonatal palliative nursing self-competency. Therefore, an EFA was conducted using all items, regardless of the original instrument's subscales. The following five factors were constructed to measure the palliative care competencies of neonatal nurses.

Family support (Factor 1) relates to the care of psychological, social, spiritual, and functional needs of the family. These competencies reflect the NICU nurses' ability to support families in grief, depression, and confusion. Family support is an important factor in neonatal palliative care because this care should be provided based on family-centred perspectives, and developed family support competencies contribute to changing the quality of the future life of parents who have suffered the death of their children.<sup>38–40</sup>

Personal and professional issues related to nursing (Factor 2) relate to nurses' competence in taking care of themselves. When nurses with insufficient experience or education perform palliative care, the nurses struggle between ethical issues and reality, are confused, and are often unable to provide adequate nursing care to infants and their families.<sup>16,18,41</sup> In neonatal palliative care, role conflicts as well as communication with caregivers and families are common causes of stress.<sup>42</sup> This can result in significant stress, and support should be available to assist NICU nurses in managing personal and professional issues as well as stress.

Interprofessional collaboration and communication (Factor 3) is a core competency of palliative care.<sup>43–45</sup> Collaboration and mutual respect between disciplines is the optimal model of communication.<sup>39</sup> Communication in palliative care is not a naturally occurring process but requires continuous effort and training. However, nurses are a constant presence in clinical settings and often act as the key person for communicating with families.<sup>46,47</sup> Effective and compassionate communication promotes collaboration with families, which is the foundation of palliative nursing care.<sup>43</sup>

Patient comfort care (Factor 4) competency is a key component of neonatal palliative care along with family support.<sup>12</sup> Palliative care assists pain and symptom management and honours individual values and needs.<sup>38</sup> Nurses are key professionals responsible for the assessment of comfort and pain.<sup>48</sup> Furthermore, listening to parents and explaining pain and discomfort assessment and management allows parents to advocate for their infant.<sup>40</sup>

EOL care (Factor 5) for infants is defined as care provided in the time leading up to a newborn's death. It contains items about providing emotional support to parents during the most stressful period and allowing parents to stay with their infant and say goodbye during the dying process.

The criterion-related validity was confirmed with a significant positive correlation between the scores of the Korean version of the PCNSC scale and BEACONNS. The “comfort” domain of BEACONNS showed a moderate correlation, indicating that the higher the competency was, the more comfortable the nurses were while

providing palliative care in the NICU. However, the correlation of the “role” domain of BEACONNS and the Korean version of the PCNSC scale was rather weak. This can be explained by the cultural difference in the NICU in Korea. Some items of the BEACONNS, such as “I am comfortable allowing siblings of the patient to visit outside specified visiting hours,” are not currently implemented in Korea.

The Korean version of the PCNSC scale is the first palliative care competency scale for healthcare providers within a paediatric setting in Korea. Nurses in this study reported the overall mean of the Korean version of the PCNSC scale as 3.65. In particular, the family support competency (Factor 1) was the lowest; this was consistent with previous Korean studies that indicated that NICU nurses in Korea often avoided parents when faced with an unexpected situation, such as the death of an infant they had cared for. As a result, they had difficulties in dealing with parents and infant patients, further attempting to ignore emotional difficulties.<sup>16,18</sup> Hence, the Korean version of the PCNSC scale can help NICU nurses enhance their competency in providing palliative care by assessing their competency and evaluating the effectiveness of neonatal palliative care education.

This was the first study to investigate the construct validity of the Korean version of the PCNSC with an adequate sample size. There were no correlations between general characteristics of nurses and the Korean version of the PCNSC scale. However, results with more culturally diverse and larger samples may differ from current samples. Further validation of the scale is required to test it in other contexts. Furthermore, psychometric testing to establish test–retest reliability and confirmatory factor analysis would strengthen the validity of the scale.

There were a few limitations to this study. In the cognitive review, comments on sibling or grandparents support were made; however, those comments were not applicable to the present NICU situation in Korea because infants' siblings and grandparents are not allowed to visit the NICU. We could not reflect this situation in the current scale development. Future studies are needed to investigate items related to sibling or grandparent support of the family of dying infants in the NICU to enhance the perceptions of and policy towards neonatal palliative care in Korea.

## 5. Conclusions

Although palliative care nursing competency in the NICU is widely recognised as important nursing care for infants, no instrument has been developed to assess neonatal palliative nursing competency of nurses in Korea. This study is the first to develop the Korean version of the PCNSC scale for use in the NICU to assess neonatal palliative nursing competency. Assessing and evaluating self-competency regarding palliative care in the NICU would stimulate and foster the quality care ability of these nurses. Therefore, the Korean version of the PCNSC scale should be made available to NICUs for educational purposes, as well as for research to foster the further development of neonatal palliative care nursing competence.

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## CRedit authorship contribution statement

Eun Sook Kim: Conceptualisation, Methodology, Formal analysis, Investigation, Visualisation, Writing – Original Draft, Writing – Review & Editing. Sujeong Kim: Investigation, Writing – Review

& Editing. Kyua Kim: Methodology, Investigation, Writing – Original Draft. Hyejung Lee: Conceptualisation, Methodology, Supervision, Validation, Writing – Review & Editing, Project administration.

## Conflict of interest

None.

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## Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.aucc.2022.12.010>.

## References

- [1] Korea National Statistics Office 2017.
- [2] National Vital Statistics Reports. Department of health and human services centers for disease control and prevention. 2016. Available from: <https://www.cdc.gov/nchs/fastats/infant-health.htm>.
- [3] Harper M, O'Connor RC, O'Carroll RE. Increased mortality in parents bereaved in the first year of their child's life. *BMJ Support Palliat Care* 2011;1(3):306–9.
- [4] Werthmann J, Smits LJ, Li J. Parental mortality rates in a western country after the death of a child: assessment of the role of the child's sex. *Gend Med* 2010;7(1):39–46.
- [5] Kim MA, Kim CK, Jung DH. Needs and preferences of bereavement support services from the perspectives of parents who lost a child and adolescents with cancer. *Health Soc Welf Rev* 2020;40(4):360–400.
- [6] Choi KH, Kim S, Son YE, Nam SI. Psychosocial service needs of families with childhood cancer. *J Korean Converg Soc* 2014;45:171–97.
- [7] Li J, Precht DH, Mortensen PB, Olsen J. Mortality in parents after death of a child in Denmark: a nationwide follow-up study. *Lancet* 2003;361(9355):363–7.
- [8] Harper M, O'Connor R, Dickson A, O'Carroll R. Mothers continuing bonds and ambivalence to personal mortality after the death of their child—an interpretative phenomenological analysis. *Psychol Health Med* 2011;16(2):203–14.
- [9] Gibson J, Finney S, Boilanger M. Developing a bereavement program in the newborn intensive care unit. *J Perinat Neonatal Nurs* 2011;25(4):331–41.
- [10] De Lisle-Porter M, Podruchny AM. The dying neonate: family-centered end-of-life care. *Neonatal Netw* 2009;28(2):75–83.
- [11] Madden K, Wolfe J, Collura C. Pediatric palliative care in the intensive care unit. *Crit Care Nurs Clin N Am* 2015;27(3):341–54.
- [12] WHO. Definition of palliative care. Available from: <https://www.who.int/cancer/palliative/definition/en/>.
- [13] Catlin A, Carter B. Creation of a neonatal end-of-life palliative care protocol. *J Perinatol* 2002;22(3):184–95.
- [14] Sieg SE, Bradshaw WT, Blake S. The best interests of infants and families during palliative care at the end of life: a review of the literature. *Adv Neonatal Care* 2019;19(2):e9–14.
- [15] Armentrout D, Cates LA. Informing parents about the actual or impending death of their infant in a newborn intensive care unit. *J Perinat Neonatal Nurs* 2011;25(3):261–7.
- [16] Kang HJ, Bang KS. Neonatal intensive care unit nurses' experience in caring for infants who are dying. *Child Health Nurs Res* 2013;19(4):252–61.
- [17] Kwon EH, Ju HO, Jeung EO, Han CH, Im JJ, Lee YR, et al. Stress due to end-of-life care, coping strategies, and psychological well-being among nurses in neonatal intensive care units. *Child Health Nurs Res* 2018;24(4):475–83.
- [18] Kim YM, Yun HY, Choi YJ, Shin DS. Neonatal ICU Nurses' coping with death of high risk newborn. *J Health Info Stat* 2019;44(2):103–10.
- [19] Wi DH, Kang SJ. Relationship among nurses' knowledge, attitude towards palliative care and perception of death in neonatal intensive care units. *Child Health Nurs Res* 2016;22(4):257–64.
- [20] Jang SH. Neonatal intensive care unit nurses' stress of end-of-life care for high-risk newborn [Master's thesis]. Seoul: Ewha Womnas University; 2013.
- [21] Yi YH, Yang HM. Nurse's grief experience and attitudes toward bereavement/end-of-life care of families of dying infants in the neonatal intensive care units. *J Korean Data Anal Soc* 2015;17(2):1045–60.
- [22] Kim S, Savage TA, Song MK, Vincent C, Park CG, Ferrans CE, et al. Nurses' roles and challenges in providing end-of-life care in neonatal intensive care units in South Korea. *Appl Nurs Res* 2019;50:151204.

- [23] Murakami M, Yokoo K, Ozawa M, Fujimoto S, Funaba Y, Hattori M. Development of a neonatal end-of-life care education program for NICU nurses in Japan. *J Obstet Gynecol Neonatal Nurs* 2015;44(4):481–91.
- [24] Shipman C, Burt J, Ream E, Beynon T, Richardson A, Addington-Hall J. Improving district nurses' confidence and knowledge in the principles and practice of palliative care. *J Adv Nurs* 2008;63(5):494–505.
- [25] Fillion L, Fortier M, Goupil RL. Educational needs of palliative care nurses in Quebec. *J Palliat Care* 2005;21(1):12–8.
- [26] Landmark BT, Wahl AK, Bohler A. Competence development in palliative care in Norway: a description and evaluation of a postgraduate education program in palliative care in Drammen, Norway. *Palliat Support Care* 2004;2(2):157–62.
- [27] Lehna C. A needs assessment for an end-of-life care curriculum for advanced practice nursing students. *Internet J Adv Nurs Pract* 2003;5(2).
- [28] World Health Organization. Cancer pain relief and palliative care. Geneva, Switzerland: World Health Organization; 1990. Available from: <http://www.who.int/cancer/palliative/definition/en/> [Accessed 20 September 2005].
- [29] Desbiens JF, Fillion L. Development of the palliative care nursing self-competence scale. *J Hosp Palliat Nurs* 2011;13(4):230–41.
- [30] Rowan N, Wulff D. Using qualitative methods to inform scale development. *Qual Rep* 2007;12(3):450–66.
- [31] Willis GB. Cognitive interviewing: a tool for improving questionnaire design. Thousand Oaks, Calif: Sage Publications; 2004.
- [32] Collins D. Pretesting survey instruments: an overview of cognitive methods. *Qual Life Res* 2003;12(3):229–38.
- [33] Hinkin TR. A brief tutorial on the development of measures for use in survey questionnaires. *Organ Res Methods* 1998;1(1):104–21.
- [34] Engler AJ, Cusson RM, Brockett RT, Cannon-Heinrich C, Goldberg MA, West MG, et al. Neonatal staff and advanced practice nurses' perceptions of bereavement/end-of-life care of families of critically ill and/or dying infants. *Am J Crit Care* 2004;13(6):489–98.
- [35] Hair JF, Anderson RE, Tatham RL, Black WC. *Multivariate data analysis*. Prentice-Hall; 1995.
- [36] Reid S, Bredemeyer S, van den Berg C, Cresp T, Martin T, Miara N. Palliative care in the neonatal nursery, guidelines for neonatal nurses in Australia. 2010. Available from: <https://www.acnn.org.au/resources/clinical-guidelines/G3-Palliative-care-in-the-neonatal-nursery.pdf>.
- [37] Catlin A, Brandon D, Wool C, Mendes J. Palliative and end-of-life care for newborns and infants: from the national association of neonatal nurses. *Adv Neonatal Care* 2015;15(4):239–40.
- [38] Kenner C, Press J, Ryan D. Recommendations for palliative and bereavement care in the NICU: a family-centered integrative approach. *J Perinatol* 2015;35(1):S19–23.
- [39] Reid S, Bredemeyer S, van den Berg C, Cresp T, Martin T, Miara N, et al. Palliative care in the neonatal nursery. *Neonatal Paediatr Child Health Nurs* 2011;14(2):2–8.
- [40] Foster C, Monterosso L. The ventilator-dependent infant requiring palliative care in the neonatal intensive care unit: a literature review. *Neonatal Paediatr Child Health Nurs* 2012;15(1):8–19.
- [41] Cavinder C. The relationship between providing neonatal palliative care and nurses' moral distress: an integrative review. *Adv Neonatal Care* 2014;14(5):322–8.
- [42] Peters L, Cant R, Sellick K, O'Connor M, Lee S, Burney S, et al. Is work stress in palliative care nurses a cause for concern? A literature review. *Int J Palliat Nurs* 2012;18(11):561–7.
- [43] Malloy P, Virani R, Kelly K, Munevar C. Beyond bad news communication skills of nurses in palliative care. *J Hosp Palliat Nurs* 2010;12(3):166–74.
- [44] Bradley CT, Brasel KJ. Core competencies in palliative care for surgeons: interpersonal and communication skills. *Am J Hosp Palliat Med* 2008;24(6):499–507.
- [45] Gueguen JA, Bylund CL, Brown RF, Levin TT, Kissane DW. Conducting family meetings in palliative care: themes, techniques, and preliminary evaluation of a communication skills module. *Palliat Support Care* 2009;7(2):171–9.
- [46] Griffie J, Nelson-Marten P, Muchka S. Acknowledging the 'elephant': communication in palliative care. *Am J Nurs* 2004;104(1):48–57. quiz 8.
- [47] Johnston B, Smith LN. Nurses' and patients' perceptions of expert palliative nursing care. *J Adv Nurs* 2006;54(6):700–9.
- [48] Matthews AL, O'Conner-Von S. Administration of comfort medication at end of life in neonates: effects of weight. *Neonatal Netw* 2008;27(4):223–7.