



Development of an End-of-Life Nursing Care Protocol for Intensive Care Units

Delphi Survey Method

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Because of the lack of guidelines and standardized protocols for end-of-life nursing care in intensive care units in Korea, many nurses have reported facing difficulties when providing care for patients. This study attempted to develop a standardized end-of-life nursing protocol for use in intensive care units. A draft of the end-of-life nursing care protocol was developed after a literature review. A Delphi survey was carried out twice with 30 experts, and the content validity ratio of the items was investigated. The draft end-of-life nursing care protocol was divided into 3 separate stages with 24 items: 8 initial end-of-life care assessment items, 5 ongoing end-of-life care items, and 11 post-end-of-life care items. The content validity ratios of the first and second rounds were 0.

33 or greater in each category, demonstrating the validity of the proposed draft as a standardized protocol. Furthermore, at the suggestion of the experts, an extra item was added in the last stage, resulting in 25 items. The results of this study are expected to help leading hospitals in South Korea outline the roles and range of tasks for end-of-life care in an intensive care unit and thereby resolve difficulties for nurses. Furthermore, this will improve the medical services that family members receive during end-of-life care.

KEY WORDS

critical care, Delphi technique, end of life, intensive care unit, nurses

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An intensive care unit (ICU) is a space for the intensive observation and treatment of critically ill patients who cannot maintain the hemodynamic conditions necessary to stay alive or who experience organ failure due to life-threatening diseases or conditions.¹ Therefore, many patients die in an ICU while undergoing treatment. In such situations, it is reasonable to question the quality of end-of-life care.¹ Some nurses, especially novices, are inexperienced in accepting patients' dying processes and experience anxiety about patient deaths, emotional frustration, and exhaustion.² They also feel stressed when they are inadequately prepared for providing end-of-life care.

In the ICU, deaths are frequent and abrupt,³ unlike in other hospital wards, and they occur despite the best efforts of medical personnel using cutting-edge technologies.⁴ Therefore, ICU nurses are required not only to have specialized knowledge but also to switch roles to provide a peaceful end-of-life care to patients. However, ICU nurses often experience extreme stress while providing such care.⁵ They also experience psychological difficulties such as sadness, depression, and helplessness.³ These negative experiences while caring for dying patients are directly linked to occupational exhaustion, poor job satisfaction, and turnover intentions, and they make it difficult to actively care for the dying patient.⁵

Intensive care unit nurses need more preparation such as end-of-life nursing skills and knowledge than those working in other wards because the severity of the patient's condition is high and immediate intervention is required if the patient's condition changes.² Therefore, the quality of end-of-life care in ICUs should be improved.¹ Intensive care unit nurses have reported that specialized guidelines for end-of-life care should be prepared and that they would like to receive systematic education on end-of-life care, including work with role models.⁶ Most Korean nurses begin their work in the ICU after receiving training, classes, and end-of-life nursing education for a considerable period. However, many such nurses are unfamiliar with end-of-life care and experience difficulties due to the burden of end-of-life care.⁶ In other words, it is necessary to develop practical end-of-life care procedures and methods that can be used in ICUs by nurses, doctors, and specialists.^{7,8} Providing guidelines for end-of-life nursing care to medical staff, especially nurses, on patient- and caregiver-centered decision-making processes is an important way to improve end-of-life care.^{7,8} In addition, because the provision of nursing care for terminally ill patients is affected by the department and nursing awareness, it is necessary to differentiate nursing education for end-of-life care by department.⁹

However, there are very few guidelines or research related to end-of-life care, and there is no standardized protocol. In particular, there is a need for a systematic and specialized nursing system for end-of-life care in the ICUs of general hospitals. In many cases, the timing of the transition from life-sustaining treatment to end-of-life care is un-

certain, but the discussion of DNR is considered to be the starting point in actual clinical practice.

Therefore, this study reviewed practical guidelines and protocols in the field of end-of-life care, developed standardized protocols, and suggested future directions to provide ICU nurses with easy access to relevant knowledge. The specific purpose of this study was to develop an end-of-life care protocol for ICU nurses and verify its validity through expert investigation and analysis.

METHODS

Design

This study used the Delphi technique to develop a standardized end-of-life care protocol for nurses working in the ICUs of general hospitals. The Delphi technique is a series of procedures for deriving consensus by synthesizing the opinions of related experts on topics for which knowledge is considered incomplete.¹⁰ It has the advantage of guaranteeing respondents' anonymity; therefore, they can express their opinions more freely than in a face-to-face discussion. Furthermore, opinions can be gathered repeatedly using a structured questionnaire form, such that the experts can change their opinions as necessary without social consequence.¹¹ To verify the validity of the drafted end-of-life nursing protocol, a panel of experts completed 2 rounds of Delphi analysis, with the opinions collected in the first period shared with the group in the second analysis. The most important factor in any Delphi investigation is the organization of the group of experts. Experts who participate in the Delphi research should be recognized for their expertise and experience in their field.

Protocol Draft Preparation

To prepare the draft protocol for the Delphi analysis, the researcher completed the End-of-Life Nursing Education Consortium (ELNEC) program, which was developed by the City of Hope Hospital and the American Association of Colleges of Nursing.¹² The ELNEC program includes general pain or symptom management, ethical issues in the ICU, cultural considerations, communication, loss, depression, bereavement, life and last time content, and leadership.¹³ A literature search was also conducted using the following criteria: domestic and foreign studies published from 2014 to 2018 and listed in PubMed or CINAHL. The search term "(End of life care) AND (Education) AND (Program) AND (Nurs*)" was used to search by Medical Subject Headings term. In the case of domestic databases, academic research information from the Research Information Sharing Service was used to search a combination of terms for "end-of-life care nursing" and "education," and the final search date was January 28, 2019. After removing duplicate data through a bibliography management program (EndNote), the resulting literature was sorted using abstract review. The literature search produced 117 studies, of which 13 were used in the final

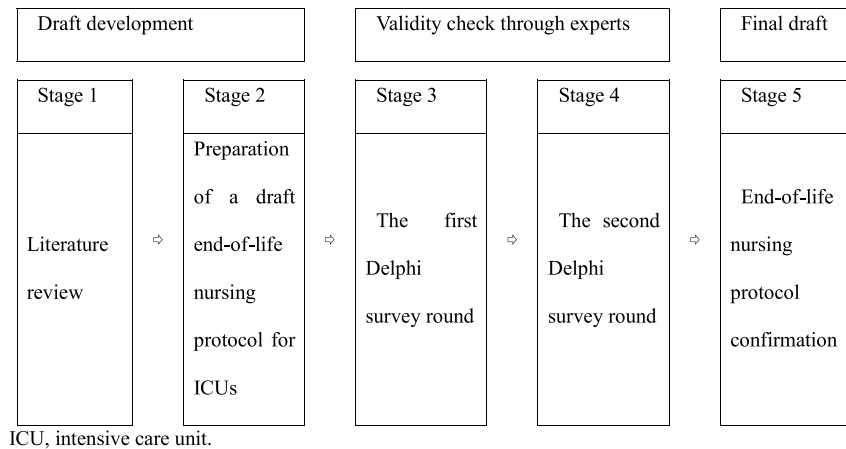


FIGURE. Research procedure.

analysis after excluding 8 overlapping studies, 31 studies that were not directly related to deathbed nursing education, 19 studies that were not about nurses, and 46 studies that were not intervention studies.

According to that literature, the ELNEC program module has been used to provide training and workshops for nurses^{14,15} and is even being used as part of the palliative care curriculum for nursing students.^{16,17} In addition, training workshops have included content such as “symptoms just before death” and “communication.”¹⁸ Other content in nursing education programs has included the management and evaluation of symptoms, family education, emotional support, knowledge of end-of-life care nursing, skills, and communication.¹⁹⁻²³ Considering this, nurses could be provided essential quality education and support for caring for terminally ill patients and caregivers in a variety of countries through the ELNEC program.¹³

Therefore, the protocol was developed in Korean by referring to the literature and guidelines of major domestic general hospitals: Clinical Practice Guidelines for Quality Palliative Care, 4th Edition²⁴; ELNEC Critical Palliative Care¹²; end-of-life patient hospice and palliative care recommendation²⁵; Severance Hospital's End-of-life Patient Checklist; and Severance Hospital's End-of-life Patient Nursing Care Guidelines. The proposal used in the first Delphi phase contained 24 divisions across 3 subject areas: (1) initial assessment, (2) ongoing assessment, and (3) post-end-of-life care.

The procedures for this study were discussed hereinafter (Figure).

Recruitment of Experts

Each expert consulted for the Delphi analysis in this study met one of the following selection criteria:

- Doctor in an ICU
- Nurse with a bachelor's degree with more than 10 years of ICU work experience
- Nurse or professor specializing in the dying process

The research recruitment adviser explained the research to relevant experts and recruited them through snowball sampling. In addition, a hospice palliative care professional was emailed an explanation of the study. Through this process, 30 experts were selected as Delphi members: 18 ICU specialists, 10 palliative care specialists, and 2 intensive care and palliative care specialists. The palliative care professionals included 2 hospice palliative care professors (see Supplemental Digital Content 1, <http://links.lww.com/JHPN/A83>). Delphi members included clinical experts from university hospitals in Korea. Moreover, because the study includes experts represented in end-of-life care and ICU experts working in the field at university hospitals, the resulting protocol can be applied nationwide. After explaining the purpose and method of the study via email to experts who met the criteria for participation, their consent was obtained. In addition, consent was obtained from those who voluntarily participated in the study through a recruitment notice at the Severance Hospital, Yonsei University Medical Center. The consent form indicated that applicants could refuse to participate at any time and that they would face no consequence in refusing to participate in the study. It also explained that the survey would be used only for research purposes and that anonymity and confidentiality were guaranteed. In the Delphi research process, results of the systematic literature review of existing end-of-life care guidelines were shared with each expert. After receiving opinions from each expert by email, the researchers collected items to be corrected, deleted, and edited according to the comments received. The revised protocol was arranged and sent again to the experts. The protocol was completed after receiving the opinion that there was no difficulty in applying it in actual clinical practice.

This study was conducted after obtaining approval through a research ethics review (approval number Y-2019-0167) by the Institutional Ethics Committee of Severance Hospital, Yonsei University Medical Center to which the researchers belong. Each Delphi survey provided experts



sufficient time to respond, and an advisory fee was paid to all participating experts. For each detail of the protocol, the validity score was measured on a 4-point Likert scale (1, strongly disagree; 2, disagree; 3, agree; 4, strongly agree). Content validity was verified by calculating the content validity ratio (CVR) and stability (variance coefficient). The formula for calculating the CVR value is as follows²⁶:

$$CVR = \frac{ne - \frac{N}{2}}{\frac{N}{2}}$$

ne = number of panelists responding with 3 points or more (I agree),

N = number of total panelists

The CVR value ranges from -1.0 to +1.0, with a positive number indicating that most of the panelists indicated “I agree” (3 or 4 points) and 0 meaning that half the panelists responded that the item was appropriate. A negative CVR value indicates that most panelists voted “I do not agree” (1 or 2 points). The minimum CVR value for determining the content validity depends on the number of panelists. This study had 30 panelists; therefore, content was deemed valid when the CVR value was 0.33 or more.²⁶ *Stability* is the coefficient of variation, which is obtained by dividing the standard deviation of each item by the average. *Stability* was deemed secure; that is, the correspondence of the experts' responses was high when the coefficient of variation was less than 0.5.¹⁰ The items were modified and supplemented using the opinions collected from the 30 panel members.

RESULTS

The results of this study were organized based on the responses collected through the 2 Delphi surveys for each protocol item in stages 1, 2, and 3 (initial assessment, ongoing assessment, and post-end-of-life care). The results of the first Delphi survey have been explained by stage; results of the second Delphi survey and final end-of-life nursing care protocol for ICUs are presented in Supplemental Digital Content 2 (see Supplemental Digital Content 2, <http://links.lww.com/JHPN/A84>).

Results of the First Delphi Survey

Each of the 24 items for initial assessment, ongoing assessment, and post-end-of-life care achieved a CVR of 0.33 or higher, confirming that the proposed items were all valid for an end-of-life nursing care protocol in ICUs.

The original initial assessment protocol contained 8 items: confirm the presence/absence of an advance directive and physician orders for life-sustaining treatment, confirm the patient's disease state, confirm the patient's physical needs, confirm patient and family needs in the ICU, assess the emotional status of the patient and family, assess

the patient's and family's perceptions of the current status, check whether the patient's and family's funeral procedures are unusual, and provide the family with information about the dying process and ensure that team members and family members are notified of the patient's impending death. All 8 items were deemed valid.

The ongoing assessment protocol contained the following 5 items: The patient's staff nurse takes on a key role than other nurses and reviews plans related to withdrawing life-sustaining treatment with medical doctors, manage physical problems, check whether the specific ICU environment is being considered, confirm the adequacy of the psychological/spiritual support and management being offered, and determine family needs and provide management and emotional support. All 5 items were deemed valid.

The 11 post-end-of-life care items were as follows: confirm the doctor's death declaration; print the “asystole EKG slip” on the result sheet for nursing records; allow family members to contact one another, give them time to say goodbye, and allow them to make last physical contact, if possible; consider holding religious ceremonies, if necessary; give death certificate issuance confirmation paper to the primary caregiver, making sure to reconfirm the address and receipt of the medical certificate on the resident registration copy; check that the family has chosen a funeral home and contact that facility; ask the family to wait in the waiting room and use curtains to keep privacy as nurses take necessary care of the deceased; allow the family to visit in an orderly manner; perform necessary administrative procedures after death; when the funeral home staff arrive, help move the body onto a mobile cart and call in a security guard to move the body with the family, if necessary; accompany the deceased and family members to the elevator (charge nurse); and record the time of death declaration, check electrocardiographic heart rate records, remove invasive lines, and complete deathbed nursing records and discharge protocols. All items were deemed valid.

Participants suggested modifications and supplements at each stage. The details are as follows (see Supplemental Digital Content 2, <http://links.lww.com/JHPN/A84>).

For the 8 items of the initial assessment stage, the suggestions were to revise the name of the legal form for content, add agitation and delirium to the physical symptoms in “confirm the physical needs of patients,” present detailed requirements in “check the needs of patients and their families in intensive care,” modify the assessment of patients' and families' emotional state to be specific to feelings and fears about death, evaluate acceptance when assessing the current state of patients and families, and consider the values of religion, culture, and individuals when checking for anything specific to the funeral procedures of patients and families. Other suggestions included the production and provision of standardized guidebooks for the end-of-life process,



the unification of terms such as family or caregivers, and providing record sheets for field use.

The modifications and supplementations for the 5 ongoing assessment items generally involved increasing their specificity. For example, it was suggested that the content about physical problem intervention should include pain assessment and intervention information. Other suggestions for collecting information included airway maintenance and standards for fluid and oxygen therapy, guidelines for visiting times, classification of the implementation document and consent form, and details about the use of neuromuscular blockers. Experts suggested that the protocol provides standards for the use of ventilators and details specific acts that could help the family realize the patient's end-of-life status, such as asking about organ and body donation, adjusting visiting times, and collecting information about whom to contact at the time of death. In the list of gastrointestinal symptoms to be checked, "anorexia," which received the lowest score of 3.27, was deleted. It had a CVR of 0.6 but was deemed inappropriate when nursing a patient at the end of life in an ICU.

Corrections and supplementations were also made for the 11 post-end-of-life care items. At this stage, the details accepted within each item were as follows: report the death to the police if the cause of death was not a disease, confirm the time of death, simplify the death certificate, notify the funeral home of the deceased's cause of death (whether infection), provide guidelines and an explanation for using an ambulance to transport the deceased, specify actions for deceased patient care (removing tubes, etc), check in advance if the family has any clothing they would like hospital staff to put onto the deceased, treat open wounds, and create specific manuals for bereavement programs. Upon the suggestion of the experts, 1 item, "deliver any personal items of the deceased to the family," was added, leading to a total of 12 items in this stage. Thus, after the first Delphi investigation, the end-of-life nursing protocol contained 25 items. Other opinions, such as asking the family about clothes for the body, providing sufficient time for the family to mourn after death, and smoothing follow-up management with the palliative care team, were also collected and added.

The first Delphi investigation confirmed that the stability of all items was 0.5 or less and that all contents were valid. The second Delphi survey was conducted to confirm agreement between the additional and supplemental items.

Results of the Second Delphi Survey and Final Draft

The results of the second Delphi survey, which contained the revised and supplemental content from the first Delphi survey, are shown in Supplemental Digital Content 2 (see Supplemental Digital Content 2, <http://links.lww.com/JHPN/A84>). All 25 items for initial assessment, ongoing as-

essment, and post-end-of-life care were found to have CVR values of 0.33 or greater, indicating their validity within end-of-life nursing care protocol for ICUs. In addition, the stability of all items was confirmed to be less than or equal to the standard value of 0.5; therefore, no further investigation was required. Additional corrections and supplementary content were presented for each stage, and their details are shown in Supplemental Digital Content 2 (see Supplemental Digital Content 2, <http://links.lww.com/JHPN/A84>). Within the 8 items in the initial assessment stage, the terms in the physician orders for life-sustaining treatment were corrected to prevent confusion. In addition, the second Delphi survey confirmed the need to verify the presence or absence of bronchial secretions in the item "check the patient's physical needs."

Opinions about the 5 items in the ongoing assessment stage included adding nonpharmacological interventions and checking for and managing symptoms of sleep disorders, including providing an environment (light, noise) conducive to sleep. Checking for and managing bronchial secretions, if necessary, was added to this stage because checking for the presence of bronchial secretions was added to the initial assessment. In this section's consideration of ICU specificity, it was suggested that the alarm setting of the bedside monitor and the ventilator be minimized, and in the "check for psychological/spiritual support and provide intervention as needed" section, having ICU nurses explain the end-of-life process to patients and caregivers at every visit was deleted because it could be impractical depending on the situation or the severity of the work. This item was replaced by "provide educational materials to confirm the intention of the patient or family to donate the body" because it is difficult for nurses to confirm a patient or family's intention for organ or body donation unless they make the original request. Other suggestions indicated that it would be difficult for the nurse in charge to explain the end-of-life process at every visit at the stage of ongoing assessment, so it was decided that nurses should be instructed to guide the family in advance of any documents that need to be prepared.

In the 12 items for post-end-of-life care, some additional corrections and supplementations were investigated and analyzed. At this stage, the suggested additions included checking for duplicate orders when issuing death certificates, and checking and issuing the necessary documents (other than death certificates). Because the proposed protocol should be applicable in clinical practice, 1 opinion suggested including an intervention to address the sense of loss felt by nurses who directly cared for deceased patients. The suggestion was to add "medical staff who cared for the deceased patients should have a moment of mourning" to the section titled "give final comfort to the deceased and family." The decision to add examples was taken, because a protocol for nurses should provide assistance through specific examples.



Through this process, the 30 experts on the panel agreed that the 8 items at the initial assessment stage, 5 items at the ongoing assessment stage, and 12 items at the post-end-of-life stage were suitable for an end-of-life nursing protocol for ICUs.

DISCUSSION

This study was conducted to develop a standardized end-of-life nursing protocol for ICUs and used the Delphi research method to derive a consensus from relevant practical and academic experts. First, the basic scope of the draft protocols was derived from a comprehensive domestic and foreign literature review and the Clinical Practice Guidelines for Quality Palliative Care (4th Edition),²⁴ ELNEC Critical Palliative Care,¹² end-of-life patient hospice and palliative care recommendation,²⁵ Severance Hospital's End-of-life Patient Checklist, and Severance Hospital's End-of-life Patient Nursing Care Guidelines.

Generally, background knowledge can vary depending on the occupation of those who provide direct care for end-of-life patients, such as nurses, nursing professors, doctors, and hospice specialists in the ICU. Therefore, the content validity of each item was checked, and additional opinions from the expert panel were collected to supplement the draft protocol items. Then, the degree of agreement on all items was checked repeatedly. The analysis found that the protocols for all 3 stages for end-of-life care in an ICU—the initial assessment, ongoing assessment, and post-end-of-life care protocol items—were valid.

The resulting protocol of the initial assessment might reflect the need for nurses with responsibility for end-of-life care to be better prepared than they generally are to improve the quality of their nursing for dying patients in ICUs.^{1,2} The Delphi process used here affirmed the need for specialized and specific guidelines for end-of-life care nursing in ICUs.⁶ The protocol proposed here is expected to help general hospitals recognize their need for an end-of-life nursing protocol for ICU nurses who take care of dying patients because, in practice, it is difficult to actively approach patients and families about death.

The protocol for ongoing assessment could affirm the need for careful preparation for end-of-life care nursing, which is a very special case.²⁻⁴ A standardized protocol for end-of-life nursing is necessary to reduce stress,⁵ psychological difficulties,³ and negative perceptions.³

The protocol for the post-end-of-life care reflects the difficulty of supporting death acceptance and actively intervening with the families of dying patients. The protocol is thus necessary to improve end-of-life care and emphasize the importance of end-of-life nursing education.⁹ Because each ICU in a general hospital has a different environment, ICU nurses should proceed in accordance with their insti-

tutional situation and environment, rather than indiscriminately following the protocol.

All results emphasize the necessity for a standardized end-of-life nursing protocol and present specific items for each stage. Because this study comprehensively reviewed and synthesized the opinions of clinical experts who play an important role in the relevant field at the forefront, the resulting protocol should be clinically useful. In general, ICU nurses in Korea begin working after a long period of training, including end-of-life nursing education. Therefore, it should not be too difficult to understand and apply this protocol. It can be used as a checklist for end-of-life care in ICUs.

CONCLUSION

This study's results are significant in terms of nursing and national health policies for the following reasons: First, this standardized end-of-life nursing protocol is expected to qualitatively improve ICU nursing. Second, this protocol can be used in nursing education to prepare and provide some structure to deal with the difficult events of end-of-life care and death. Third, the research process can be used as basic data for further studies on end-of-life care, and this protocol itself may be adapted for use in standardized manuals at general hospitals and other medical institutions. Fourth, it can be used as supporting data when determining health policies for end-of-life care. However, this end-of-life care protocol is for ICU nurses and focuses on supporting terminally ill patients and their families in performing end-of-life care tasks in the ICU. Therefore, additional education programs should be developed to improve the performance of end-of-life care, with a focus on supporting nurses through psychological difficulties and reducing other difficulties of working in ICUs. In addition, communication and interpersonal skills related to end-of-life care could not be included, because they were difficult to incorporate into the protocol. It is necessary to add communication components to terminally ill patients and their caregivers.

In addition, there are limitations to applying this protocol to all ICUs, but it has an advantage in that it was developed through the Delphi method with the help of multidisciplinary experts. Further research is required in evaluating the effectiveness of this protocol.

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