



Nurses' Perceived Needs and Barriers Regarding Pediatric Palliative Care: A Mixed-Methods Study

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Purpose: This study aimed to describe nurses' perceived needs and barriers to pediatric palliative care (PPC). **Methods:** Mixed methods with an embedded design were applied. An online survey was conducted for nurses who participated in the End-of-Life Nursing Education Consortium- Pediatric Palliative Care (ELNEC-PPC) train-the-trainer program, of whom 63 responded. Quantitative data were collected with a survey questionnaire developed through the Delphi method. The 47 items for needs and 15 items for barriers to PPC were analyzed with descriptive statistics. Qualitative data were collected through open-ended questions and analyzed with topic modeling techniques. **Results:** The mean scores of most subdomains of the PPC needs were 3.5 or higher out of 4, and those of PPC barriers ranged from 3.22 to 3.56, indicating the items in the questionnaire developed in this study properly reflect each factor. The needs for PPC were divided into 4 categories: "children and adolescents," "families," "PPC management system," and "community-based PPC." Meanwhile, PPC barriers were divided into 3 categories: "healthcare delivery system," "healthcare provider," and "client." The keywords derived from the topic modeling were perception, palliative, children, and education for necessities and lack, perception, medical care, professional care providers, service, and system for barriers to PPC. **Conclusion:** In this study, by using mixed-methods, items of nurses' perceived needs and barriers to PPC were identified, categorized, and weighted, and their meanings were explored. For the stable establishment of PPC, the priority should be given to improving perceptions of PPC, establishing an appropriate system, and training professional care providers.

Key Words: Child, Adolescent, Palliative care, Nurses, Perception

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INTRODUCTION

In recent decades, South Korea achieved remarkable developments in medicine, including reduced infant and child mortality [1]. As a result of improvements in medical outcomes, the survival rate of child and adolescent patients with severe illnesses has increased rapidly [2]. However, attention toward and systematic support for the experience and quality of life of patients and family members after a patient's diagnosis, such as managing side effects, are lacking. Research on how to support children and adolescents with severe disease, who ultimately may face death despite the increased survival rate, and their family members is crucial.

It is very difficult to predict the prognosis of children and adolescents with severe diseases due to high uncertainty [3]. Healthcare providers therefore face the challenge of choosing between administering meaningless life-sustaining treatment with uncertainty and maintaining and improving the quality of remained life. In this process, healthcare professionals also experience difficulties and ethical dilemmas when informing patients' parents about the situation [4–6]. Therefore, palliative care for children and adolescents (pediatric palliative care, PPC) in which holistic care along with treatment of the disease from the moment of diagnosis has been suggested as an alternative model for child and adolescent patients with severe illnesses and their families [3]. However, this is a new model that has been in place for fewer than 10 years. Following an increase in social need and public attention regarding well-dying, South Korea enacted the Act on Decisions on Life-Sustaining Treatment for Patients in Hospice and Palliative Care or at the End of Life (referred to as the Act on Decisions on Life-Sustaining Treatment) in 2018 [7]. PPC was introduced at the same time. In 2018, two institutions (Seoul National University Hospital and Yonsei University School of Medicine Severance Hospital) established PPC programs. These PPC pilot programs run by the government were expanded every year, and, since 2022, PPC specialists have conducted programs at 10 hospitals across the country [8]. Although PPC services, unlike those for adults, are not restricted to the terminal stages of diseases, the awareness of healthcare providers who care for children and adolescents is still insufficient in many areas, such as screening of patients who need such care,

deciding the time when to refer a patient to palliative care, and providing the required services.

In PPC, nurses occupy a critical role in identifying symptoms and needs, distributing and managing care resources, supporting and advocating for patients, and educating patients and their family members [9]. Pediatric nurses, however, have expressed difficulties when handling situations related to the end-of-life and deaths of patients [4,5,10]. Specifically, nurses have reported experiencing difficulties when facing patients at the end of life and the anger of patients' family members, communicating with patients at the end of life and their family members [4], and providing care with insufficient knowledge and resources [10]. While previous studies have examined the difficulties nurses experience, their perceptions, and related factors using qualitative research methods, these studies were limited with regard to understanding nurses' perceptions about which services were needed, which barriers existed, and the policies and strategies that should be implemented for improvement.

Nurses' lack of awareness about pediatric palliative care is a significant barrier to institutionalization and service expansion. In 2012, for the first time in South Korea, a training-the-trainer program of the End-of-Life Nursing Education Consortium–Pediatric Palliative Care (ELNEC–PPC) was conducted. At that time, the participants' awareness of PPC was surveyed, but there were limitations since no measurement tools yet existed that reflected the situation in South Korea [11]. Since then, the PPC pilot program was launched in 2018, and it is therefore important to examine nurses' perceptions about pediatric palliative care in greater depth to successfully implement PPC programs in South Korea. A comprehensive exploration of nurses' needs and barriers related to PPC can provide foundations for the development of a PPC nursing model.

Therefore, this study aimed to develop and use a tool to examine nurses' perceptions about PPC based on factors related to needs and barriers. This study adopted a mixed-methods approach by using quantitative research methods, topic modeling, and open-ended questions about the details of each factor. Topic modeling refers to a probabilistic model using the concept of topics based on the assumption that documents are comprised of many topics [12]. This study's results could be used as foundational data for improving the nursing quality of PPC services.

METHODS

1. Study design

This study was conducted in two stages—development and administration of the developed questionnaire—to assess the needs and barriers related to PPC among nurses. To develop a questionnaire, the authors derived a preliminary list of factors related to the needs and barriers to PPC from a literature review. Then, a three-round Delphi survey was conducted to build systematic consensus among experts on needs and barriers to facilitate PPC, and to and validate the preliminary questionnaire. The Delphi study design is beneficial for gaining consensus on a topic of interest using anonymous and iterative rounds with structured feedback, when there is limited evidence [13]. The first stage was followed by a descriptive observational study, in which a developed questionnaire was administered. Written responses to open-ended questions were analyzed using topic modeling. Therefore, this study employed a concurrent, embedded mixed-methods design [12] incorporating both quantitative and qualitative data.

2. Participants

For the Delphi study, a nationwide panel of hospice and palliative nursing was recruited through convenience sampling.

The members of the panel were identified and invited if they met one of the eligibility criteria: 1) clinical practitioners in the field of PPC or advanced practice nurses in hospice; 2) academic scholars who have published in the field of hospice and palliative nursing; or 3) professionals who completed an ELNEC train-the-trainer program. The cross-sectional survey was carried out to examine the needs and barriers to PPC among nurses enrolled in the ELNEC-PPC program conducted from October 15 to October 16, 2021. Among the 72 nurses who voluntarily consented to and participated in the study (response rate=73.5%), 63 eligible responses were included in the final analysis.

3. Instrument

To develop a questionnaire measuring the needs and barriers related to PPC among nurses, a preliminary draft was developed from a literature review, the validity of which was tested by conducting three rounds of Delphi surveys (Figure 1).

Previous studies on the needs and barriers related to the implementation of PPC in South Korea were selected as follows: a study examining pediatric palliative care needs among parents of children with complex chronic conditions [14], pediatricians [15], palliative care providers [6], and a study examining patients' and healthcare providers' needs for community-based palliative care [16]. Relevant items were extracted from

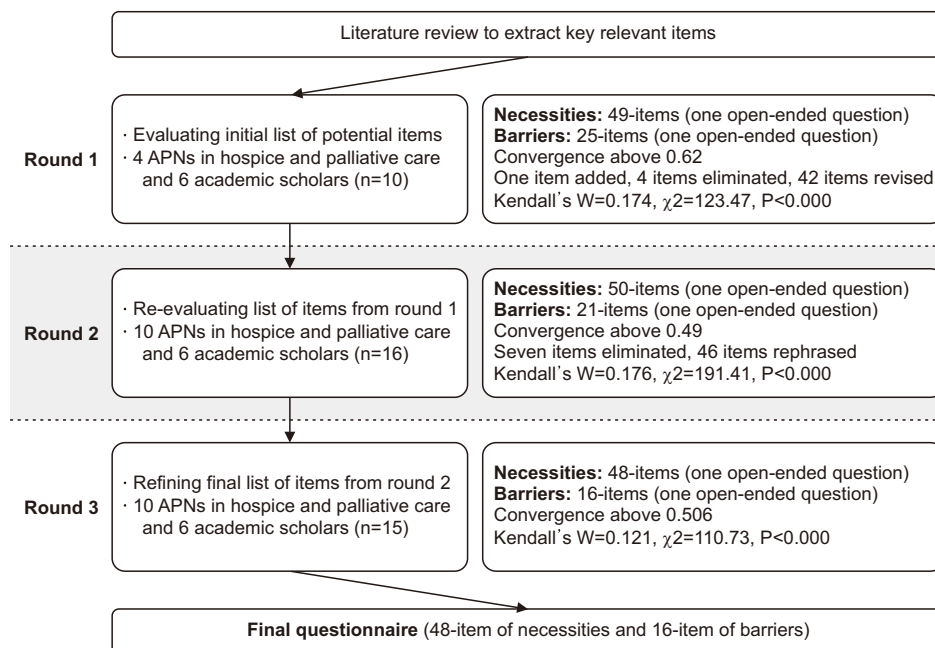


Figure 1. Delphi process to develop a questionnaire on nurses' perceptions of the needs and barriers regarding pediatric palliative care (PPC). APN: advanced practice nurse.

each study and collated to create a draft comprising 49 items about needs and 25 items about barriers. Two open-ended items were added at the end of each section to get comprehensive expert opinions.

The Delphi survey was distributed and returned by email from August 4 to September 15, 2021. In the first round, potential items for the questionnaire identified from the literature were presented. Panelists who voluntarily consented to participate in the study were asked to evaluate the relevance, representativeness, and clarity of each item of the questionnaire. Each item was evaluated on a 4-point Likert scale (1=not appropriate at all; 4=very appropriate). Panelists were also asked to freely comment on each item and section. The research team analyzed the mean, standard deviation, and median of each item and consolidated all open-ended suggestions. The content validity was evaluated by calculating the content validity ratio (CVR). Items with CVR scores above 0.62 were considered significant and remained based on a Lawshe table with 10 panelists [17]. Any item with a CVR score below the critical value was discussed until consensus was achieved and then deleted.

In the second round, the results of the first round were presented to the panelists so they could reflect their own opinions by comparing their opinions to the summative results. They re-evaluated the revised items and answer the open-ended questions freely. The research team analyzed the results, as in the first round. In the third round, similar to round 2, the results from the first and second rounds were presented to the panelists. The panelists reviewed and approved the final list of items. Based on these items, the research team created the final questionnaire which included 48 items on needs and 16 items on barriers measuring nurses' perceptions of PPC. The positive coefficient of experts, which is the recovery rate of the Delphi survey, is considered high and acceptable when it is greater than 70% [18]. The recovery rates of the three rounds of the Delphi surveys in this study were 100%, 100%, and 93.8%. The degree of expert coordination was evaluated using Kendall's W test [19]. Kendall's W coefficients were statistically significant for all three rounds of the Delphi surveys in this study, which objectively indicated that the panelists consistently reached a consensus.

4. Data collection

An online survey was performed by administering the developed questionnaire from September 24 to October 15, 2021, after approval from the Institutional Review Board of S University (No. 2021110HR). A link to the online survey was distributed to those who enrolled in the ELNEC pediatric curriculum and agreed to the terms of collection and usage of personal information. Participants were provided with information about the purpose of the study and the data protection policy, and they indicated that they were willing to participate voluntarily. The survey took approximately 10 minutes to complete.

5. Data analysis

All quantitative data including the sociodemographic characteristics of the participants and the results of the survey, were analyzed using descriptive statistics in SPSS (version 26; IBM Corp., Armonk, NY, USA). Continuous variables were presented using means and standard deviations, and categorical variables were presented using frequencies and percentages. The narrative responses to open-ended questions about needs and barriers regarding PPC, which comprised the qualitative data in this study, were analyzed using topic modeling, which is a text-mining technique. Keywords related to needs and barriers were visualized as word clouds. The latent Dirichlet allocation (LDA) topic modeling method was applied; this process involves making inferences about the distribution of topics within the document as well as the distribution of words within the topics based on the text [20,21]. The authors set α and β to 0.01 and the number of iterations to 1000. In total, 5 topics were derived as final results, after reviewing the top 3 keywords and eliminating redundancies [22].

RESULTS

1. Participant characteristics

A total of 98.4% of the study participants were women, and their average age was 35.81 ± 7.76 years. A roughly equal proportion of participants were single (49.2%) and married (50.8%). In total, 41.3% of participants completed the stan-

standard training program for hospice and palliative care, and 14.3% were nurse specialists in hospice or oncology. Most participants (38.1%) had 6~10 years of clinical experience as a nurse. While 50.8% did not have hospice and palliative care experience, 22.2% of participants had 1~5 years of experience, 15.9% had less than 1 year of experience, and 11.1% had more than 6 years of experience. In total, 36.5% of the participants had fewer than 5 years of experience in a pediatric ward, while 20.6% had 6~10 years of experience, 19.0% had more than 11 years of experience, and 23.8% had no experience in a pediatric ward. The participants' current occupations included nurses (52.4%) and nurse specialists (20.6%), comprising approximately 73% of the participants in clinical practice (Table 1).

2. Needs of PPC

According to the survey on needs related to PPC, the average scores for each of the 46 items rated on a 4-point Likert scale ranging from 3.49 to 3.89, excluding one item that allowed multiple choices. The Delphi analysis results indicated that the need factors could be categorized into four areas (children and adolescents, family, PPC operation system, and community-based PPC) (Table 2).

The first category, children and adolescents, was composed of three sub-categories: physical care, psychosocial care, and spiritual care. Psychosocial care had the highest mean score, followed by spiritual care and physical care. The mean score for the psychosocial care sub-category was 3.83 ± 0.30 , and the range was 3.68~3.89. Within the psychosocial care sub-category, the item with the highest score was "the perception of being loved" (3.89 ± 0.32), and the items with the lowest scores were "ownership over life" (3.78 ± 0.46) and "recognition of being remembered forever by others" (3.78 ± 0.46). The mean score for the spiritual care sub-category was 3.72 ± 0.39 , with a range of 3.68~3.78. The item with the highest score was "spiritual comfort" (3.78 ± 0.46), and the item with the lowest score was "understanding the meaning of existence" (3.68 ± 0.50). The mean score for the physical care sub-category was 3.68 ± 0.37 , and the range was 3.49~3.87. The item with the highest score was "alleviating pain" (3.87 ± 0.34), and the item with the lowest score was "maintaining and improving cognitive function" (3.49 ± 0.59).

The second category, family, was composed of two sub-

Table 1. Characteristics of the Participants (N=63).

Characteristics	n (%)
Sex	
Female	62 (98.4)
Male	1 (1.6)
Age (yr)	
<29	17 (27.0)
30~39	25 (39.7)
40~49	17 (27.0)
>50	4 (6.3)
Mean \pm SD	35.81 \pm 7.76
Marital status	
Unmarried	31 (49.2)
Married	32 (50.8)
Education	
Graduated from a junior nursing college/bachelor's degree	33 (52.4)
Graduate school	30 (47.6)
Hospice palliative care curriculum	
Nurse specialist (hospice or oncology)	9 (14.3)
General education for hospice palliative care	26 (41.3)
None	28 (44.4)
Clinical career (yr)	
<5	14 (22.2)
6~10	24 (38.1)
11~15	14 (22.2)
>16	11 (17.5)
Hospice palliative care career (yr)	
<1	10 (15.9)
1~5	14 (22.2)
>6	7 (11.1)
None	32 (50.8)
Pediatric care career (yr)	
<5	23 (36.5)
6~10	13 (20.6)
>11	12 (19.0)
None	15 (23.8)
Current unit/workplace	
Hospice palliative care unit	14 (22.2)
Other wards	26 (41.3)
University	16 (25.4)
Other	7 (11.1)
Current position	
Nurse	33 (52.4)
Charge nurse or unit manager	11 (17.5)
Nurse specialist	13 (20.6)
Professor	6 (9.5)

categories: psychosocial care and spiritual care. The mean score for psychosocial care was 3.78 ± 0.37 with a range of 3.71~3.84, and the item with the highest score was "alleviating anxiety and fear" (3.84 ± 0.37). The item with the lowest score

Table 2. Nurses' Perceived Needs Regarding Pediatric Palliative Care (PPC) (N=63).

Items			Mean	SD	Range
Children and adolescents					
Physical care					
Relief from physical symptoms	1	Helping relieve symptoms	3.87	0.34	
	2	Helping regulate body temperature	3.70	0.50	
	3	Helping relieve convulsions	3.73	0.48	
	4	Helping alleviate nutritional problems (anorexia, malnutrition, nausea, vomiting)	3.73	0.45	
	5	Helping relieve breathing problems (coughing, sputum, shortness of breath)	3.79	0.45	
	6	Helping relieve dehydration or edema	3.65	0.51	
	7	Helping relieve bowel (diarrhea, constipation) and urination problems	3.70	0.50	
	8	Helping relieve skin problems (rash, itching, pressure sores)	3.68	0.47	
	Subtotal	3.73	0.38	3.65~3.87	
Improvement in bodily function	9	Helping maintain and improve cognitive functions (thinking, memory, language) in cooperation with the Department of Rehabilitation Medicine (e.g., use of aids for communication)	3.49	0.59	
	10	Helping maintain and improve motor function (mobility) through cooperation with the Department of Rehabilitation Medicine (e.g., use of exercise orthosis)	3.54	0.53	
	11	Helping maintain and improve sensory functions (visual and hearing) in cooperation with the Department of Rehabilitation Medicine	3.62	0.52	
	Subtotal	3.55	0.52	3.49~3.62	
	Subtotal	3.68	0.37	3.49~3.87	
Psychosocial care					
Emotional support					
	12	Helping children and adolescents develop a sense of ownership and control over their lives (for school-age children and adolescents)	3.78	0.46	
	13	Alleviating anxiety or fear, and helping patients feel emotionally secure	3.84	0.41	
	14	Reducing depression (for school-age children and adolescents)	3.84	0.37	
	15	Helping children realize that they are important (self-esteem) (for school-age children and adolescents)	3.87	0.34	
	Subtotal	3.83	0.34	3.78~3.87	
Communication					
	16	Helping children and adolescents express their feelings	3.86	0.35	
	17	Helping children and adolescents (if desired) participate in discussions about the treatment plan, and the decision-making process	3.81	0.40	
	Subtotal	3.83	0.34	3.81~3.86	
Relationship					
	18	Helping children and adolescents recognize that they are loved by family, friends, teachers, and others	3.89	0.32	
	19	Helping children and adolescents recognize that they are always remembered by their family, friends, teachers, and others	3.78	0.46	
	Subtotal	3.83	0.35	3.78~3.89	
	Subtotal	3.83	0.30	3.68~3.89	
Spiritual care					
Meaning of existence					
	20	If children and adolescents believe in the existence of God, helping them identify the meaning of existence by promoting relationships with transcendental beings (God, Buddha) (for school-age children and adolescents)	3.68	0.50	
	21	Helping children and adolescents realize their dreams (wishes, things they want to achieve) (for school-age children and adolescents)	3.70	0.50	
	Subtotal	3.69	0.43	3.68~3.70	
Spiritual peace					
	22	Helping children and adolescents accept the pain or death they are experiencing, and feel spiritually at peace	3.78	0.46	
	Subtotal	3.72	0.39	3.68~3.78	

Table 2. Continued 1.

Items		Mean	SD	Range	
Families					
Psychosocial care					
Emotional support	23	Alleviating anxiety or fear, and helping patients feel emotionally secure	3.84	0.37	
	24	Reducing depression	3.81	0.44	
	25	Helping parents feel that they have done their best for their children	3.83	0.38	
	26	Enabling siblings' psychological stability	3.79	0.45	
	Subtotal		3.81	0.37	3.79~3.84
Communication					
	27	Facilitating open communication within the family (married couples, parent-child relationships, siblings)	3.78	0.46	
	28	Helping strengthen family cohesion	3.71	0.52	
	29	Helping parents comfortably communicate with health care providers about their child's medical condition or treatment	3.84	0.37	
	30	Helping parents guide their other children about the disease/treatment/prognosis according to their developmental stage	3.75	0.47	
Subtotal		3.77	0.41	3.71~3.84	
Social support and bereavement counseling					
	31	Building a social support network (family, relatives, patient associations) through collaboration with members of the PPC team, and helping them feel fully supported	3.81	0.40	
	32	Providing short-term care services so that caregivers can take breaks	3.73	0.48	
	33	Supporting the grief of loss during the bereavement of the child (e.g., telephone or in-person counseling, depending on the individual needs of the person)	3.78	0.46	
Subtotal		3.77	0.39	3.73~3.81	
Subtotal		3.78	0.37	3.71~3.84	
Spiritual care					
Meaning of existence	34	Helping a parent or sibling identify the meaning of existence (e.g., promoting a relationship with a transcendental being such as God or Buddha)	3.65	0.60	
	35	Accepting the child's pain and death, and helping parents feel spiritually at peace	3.84	0.37	
Subtotal		3.74	0.45	3.65~3.84	
PPC management system					
PPC team support					
	36	Building and managing the PPC team	3.86	0.35	
	37	Reinforcement of specialized education for PPC (e.g., professional training, general medical staff education, education for other helping professionals)	3.83	0.42	
	38	Support for professional activity of PPC (e.g., art therapy, music therapy)	3.79	0.41	
Subtotal		3.83	0.36	3.79~3.86	
Financial support	39	Development and application of medical fee system for PPC	3.78	0.46	
Subtotal		3.78	0.46	3.78	
PPC intervention and referral (duplicate response)					
	40	Diagnosis of pediatric cancer, and non-cancerous diseases with low cure potential	1.32	0.47	
		Difficulty predicting the time of death, and persistent deterioration	1.35	0.48	
		Expected to die within months	1.46	0.50	
	Expected to die within weeks or days	1.71	0.46		
Community-based PPC					
Community-based PPC liaison plan					
	41	Establishment of home-care PPC service system through regional children's hospitals, or hospice institutions designated by the government	3.81	0.44	
	42	Efficient liaison system between the main treatment hospital (children's hospital) and regional children's hospitals	3.79	0.45	
	43	Efficient liaison between regional children's hospitals and hospice institutions designated by the government	3.84	0.41	
Subtotal		3.81	0.41	3.79~3.84	

Table 2. Continued 2.

		Items	Mean	SD	Range
Desired community-based PPC services	44	Helping children and adolescents at home control their pain and symptoms (e.g., administering drugs such as narcotic analgesics according to a prescription)	3.89	0.36	
	45	Home visits by medical personnel and PPC team members from regional children's hospitals or hospice institutions designated by the government (if desired by the parents)	3.81	0.47	
	46	Provision of non-pharmacological PPC interventions for children and adolescents in the home (e.g., music, art, and expression therapy such as play therapy)	3.76	0.47	
	47	Sharing medical records between the main treatment hospital and the PPC team (limited to what is necessary)	3.73	0.45	
Subtotal			3.80	0.36	3.73~3.89

Table 3. Nurses' Perceived Needs Regarding Pediatric Palliative Care (PPC): Results of an Open-Ended Question Analyzed Using Topic Modeling.

Topic	Number of documents (%)	Keyword			Categories related to needs identified through Delphi surveys
		1st	2nd	3rd	
Topic 1	24 (34.79)	Medical treatment	Alleviation	Children & adolescents	Palliative care for children and adolescents, and their families
Topic 3	9 (13.04)	Pain	Management	Bereavement	
Topic 5	18 (26.09)	Perception	Medical staff	Patient	PPC team support: education
Topic 4	9 (13.04)	Human resources	Service	Children	PPC team support: team building
Topic 2	9 (13.04)	Hospital	Team	Liaison	Community-based PPC liaison plan

was “strengthening family cohesion” (3.71±0.52). The mean score for the spiritual care sub-category was 3.74±0.45, and the range was 3.65~3.84. The item with the highest score was “spiritual comfort” (3.84±0.37), and the item with the lowest score was “understanding the meaning of existence” (3.65±0.60).

Three sub-categories were identified within the PPC operational system, the third category: PPC team support, financial support, and PPC intervention and referral. The mean score for PPC team support was 3.83±0.36 with a range of 3.79~3.86, both of which were higher than those of the other two sub-categories. The item with the highest score was “building and managing the PPC team” (3.86±0.35), and the item with the lowest score was “support for professional activity of PPC” (3.79±0.41). The financial support sub-category included one item, with an average score of 3.78±0.46. The participants' thoughts on the ideal timing of intervention and referral to PPC were recorded using a single item that allowed more than one response. The most-selected answer was “when death can be anticipated in a few weeks or a few days.”

The community-based PPC category had two sub-categories, which were a community-based PPC liaison plan (3.81±0.41) and desired community-based PPC services (3.80±0.36),

and they had similar mean scores.

The results of topic modeling analysis and word cloud visualization of responses to the open-ended question (“What is most needed for the effective implementation of PPC services in South Korea?”) are presented in Table 3 and Figure 2. According to the results of the topic modeling analysis, the top 3 keywords across five topics had the least amount of redundancy and were used in the analysis. Topics 1 and 3 were applicable to the child and family categories of the 47 items about need factors constructed based on the Delphi analysis. Keywords included “medical,” “pain,” “alleviation,” and “management.” Topic 5 was related to education in the PPC team support sub-category. The keywords were “awareness” and “medical staff.” Topic 4 was related to the building PPC team of the PPC team support sub-category, and the keywords included “manpower” and “service.” Topic 2 was related to the plans for making community-based PPC liaison plan sub-category, and the keywords were “hospital,” “team,” and “connection.”

3. Barriers to PPC

The barriers to PPC were organized into 15 items across

Table 5. Nurses' Perceived Barriers Regarding Pediatric Palliative Care (PPC): Results of an Open-Ended Question Analyzed Using Topic Modeling.

Topic	Number of documents (%)	Keyword			Categories related to barriers identified through Delphi surveys
		1st	2nd	3rd	
Topic 2	17 (34.79)	Perception	Negative view	Lack	Client
Topic 4	11 (13.04)	Alleviation	Medical treatment	Perception	
Topic 1	16 (26.09)	Lack	System	Professional	Healthcare provider
Topic 3	6 (13.04)	Patient	Service	Project	
Topic 5	21 (13.04)	Lack	Human resources	Insufficiency	Healthcare delivery system

in South Korea?") are presented in Table 5 and Figure 2. The top three keywords across five topics had the least amount of redundancy and were used to analyze the results. Among the 15 items, topics 2 and 4 from the Delphi analysis were relevant to the client category. The keywords were "awareness," "negative," and "alleviate." Topics 1 and 3 were related to the healthcare delivery system category, and the keywords included were "lack," "system," and "service." Topic 5 was related to the healthcare provider category, and the keywords were "lack" and "manpower."

DISCUSSION

In this study, a survey aimed at improving the quality of palliative care provided to children and adolescents was developed through a literature review and three rounds of Delphi analysis. Using this survey, this study aimed to understand the nurses' perceived needs and barriers related to PPC. This study conducted analyses using topic modeling methods and used word clouds to visualize the keywords. The study is meaningful since it identified the topics related to nurses' perceptions of the needs and barriers concerning pediatric palliative care and examined the significance of the topics in relation to each other.

It can be inferred that the items constructed through the Delphi analysis adequately reflected each factor since the mean scores of the items on the need and barriers related to PPC were all above 3.5 out of 4.

The highest-scoring items in the 3 sub-categories of the children and adolescent category related to the needs concerning PPC were "the perception of being loved" in the psychosocial care sub-category, "spiritual comfort" in the spiritual care sub-category, and "alleviating pain" in the physical care cat-

egory. For children and adolescents, death and end-of-life are psychosocially uncomfortable situations, and patients typically fear the dying process [23]. It is crucial for healthcare providers to help patients be able to recognize that they are loved and important to their families and spend their final moments peacefully and comfortably. Symptom treatment and pain alleviation are essential factors, with many pediatric oncologists considering them the primary goal of PPC [24]. Pain control is important in children and adolescent patients with terminal diseases, and a palliative care team needs to conduct a multi-dimensional assessment for effective pain control according to each patient's developmental stage and pain patterns [25]. PPC patients vary in terms of cognitive capacity according to their developmental stage, and specialized techniques are required for effective communication. Therefore, PPC nurses must use therapeutic communication skills suited to the developmental stage of each individual child or adolescent to assess and manage his/her pain. In previous studies, while the need for spiritual care scored the lowest among the physical, social, and spiritual care needs of family members of child or adolescent cancer patients [26], "assessment of the spiritual status of patients and family members" was reported as the most difficult part of the job by hospice and palliative care nurses [27]. Spiritual care nursing in clinical practice, therefore, can be considered one of the most difficult tasks among PPC nurses. However, as it is important to help children and adolescents accept the pain they experience as they face the ends of their lives and feel comforted, spiritual care should be practiced as a part of PPC.

Within the family category, the item with the highest score in the psychosocial care sub-category was "alleviating anxiety and fear," and in the spiritual care sub-category, it was "spiritual peace". Laronne et al. [24] suggested that palliative care for parents of child cancer patients required first provid-

ing them with practical help, such as structuring everyday life, balancing the parents' work and child's medical needs, and assisting with the collection of their social security pension, and second, offering emotional support, such as expressing sympathy and encouraging therapy for their emotional suppression, worries, and pain, and encouraging communication that enables emotional support. Most people generally expect to die based on their biological age, so the deaths of children and adolescents can be hard to accept for patients and their family members. Therefore, psychosocial intervention to alleviate the anxiety and death-related fear of patients and family members who care for patients is very important in PPC. One way to alleviate anxiety and fear would be to help family members and patients accept the pain of the dying process and death and feel spiritual comfort. However, given that nurses reported difficulty when providing spiritual care to adults [27], nurses are also likely to experience difficulties when providing spiritual care for children and adolescents. Intervention programs to improve nurses' spiritual care of children and adolescents at the end of life and their family members should be developed in the future.

The item with the highest score in the PPC team support sub-category of the PPC management system category was "separate composition and operation of a PPC team." In order to improve the quality of PPC, a multidisciplinary approach is needed. Rather than clinical nurses exclusively providing PPC, a separate, dedicated team is required. Moreover, while the suggested timing of intervention and referral to PPC has been suggested as when the predicted survival time is fewer than 6 months according to the Patient Protection and Affordable Care Act [23], in this study, many of the participants suggested "a few weeks or a few days remaining until death" as the recommended timing. This response may be based on the social perceptions that children and adolescents are less likely to die or the fact that the PPC pilot program had only been in place for approximately 3 years at only 10 institutions, resulting in insufficient awareness. This study found that nurses may also have insufficient awareness regarding the timing of referral or eligible patients for PPC. Therefore, public awareness should be increased through national advertisements using mass media, and a systematic education program about PPC for nurses should be created.

The category of community-based PPC comprised the two sub-categories of plans for PPC liaison and desired PPC services. When the expected survival is prolonged, or in situations when the patient cannot be hospitalized for a long time, efficient connection to regional children's hospitals, hospice and palliative care institutions, or at-home PPC services would be helpful. However, most hospice institutions in South Korea lack experience in providing PPC services. Other than one or two institutions, most South Korean hospice facilities exclude children and adolescents from their services. Thus, systematic support for education and training related to PPC services for healthcare providers, including both doctors and nurses, would have a substantial impact on the development and expansion of PPC.

After analyzing the responses to the open-ended question ("What is necessary for the effective implementation of pediatric palliative care?") using topic modeling and visualized using word clouds, the keywords were "awareness," "alleviation," "medical staff," "children," "education," "improvement," and "hospice." Increased awareness of PPC is therefore important for the establishment of PPC services in South Korea. Increased awareness of PPC is a condition that should precede improvement in the quality of end-of-life care and is an important factor for the implementation and expansion of PPC.

The item with the highest score in the healthcare delivery system, which was the first of three categories related to the barriers to PPC, was "lack of a medical fee system for PPC." Medical insurance in South Korea is based on a fee-for-service system, and since the necessary services of PPC are not clearly defined, it is difficult to calculate the costs using a fee-for-service or diagnosis-related group system. An adequate reimbursement system should therefore be implemented when the necessary services and delivery systems for PPC are realized in the clinical field [28]. In addition, PPC services have only recently been launched. Since South Korea is still only beginning to introduce PPC services, an effective and fair reimbursement system would help expand the use and establishment of PPC services. The items with the highest scores in the healthcare provider category were "lack of professional staff for PPC" and "lack of education and training for PPC." The item with the highest score in the client category was "lack of awareness about PPC."

In Moon's study [6], the perceptions of PPC based on a survey of hospital personnel in hospice and palliative care institutions were analyzed, and the lack of specialized personnel was reported as a main barrier to PPC. The second most frequently reported barrier to providing palliative care to children and adolescent non-cancer patients was the negative perception of palliative care among patients and caregivers. For nurses, the deaths of children and adolescents were harder to accept than those of adults [4] and were less common. The unit of nursing care is the family, and the psychological burden of providing end-of-life care was higher among nurses in pediatric intensive care units than those in adult intensive care units [29]. The nurses' intention to leave their nursing jobs was higher when they perceived and experienced more barriers to end-of-life care for children and adolescents [30]. Nurses are the health-care providers at the core of providing PPC services. A lack of awareness among nurses about PPC is not only a main barrier to the institutionalization and expansion of service of PPC but also a reason for turnover among nurses. Based on the results of this study, the factors related to the needs concerning the development of PPC should be strengthened, and the barriers should be removed. This can improve nurses' perceptions of PPC and provide foundational data for the development of education and training programs by identifying the contents of palliative care services in detail.

When the responses to the open-ended question ("What are the barriers to the effective implementation of pediatric palliative care?") were analyzed using topic modeling and visualized through word clouds, the keywords were "awareness," "medicine," "insufficient," "system," and "personnel." According to this result, the primary barrier to the implementation of PPC services in South Korea is the lack of awareness, a system, and specialized personnel for PPC. This result may be due to the fact that only a small number of hospitals in South Korea provide PPC services as part of the government's pilot program. In order to expand PPC services, increased awareness and sufficient systemic support and specialized personnel are necessary.

The generalizability of this study is limited due to the small number of participants recruited among nurses who were registered for an ELNEC-PPC training program, and variation in the characteristics of nurses who provide PPC in the clinical field was not reflected in the sample. The needs related to the

development of PPC services should be examined among nurses with various job characteristics, including pediatric nurses, in the future. Efforts to remove barriers would also lead to the implementation of improved PPC services for patients and their family members.

CONFLICT OF INTEREST

No potential conflict of interest relevant to this article was reported.

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SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/jhpc.2022.25.2.85>.

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