



# Current Status of the Pediatric Palliative Care Pilot Project in South Korea Based on the Experience of a Single Center

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**Purpose:** We evaluated the status of patients enrolled in South Korea's pediatric palliative care pilot project based on the experience of a single center. This study examined factors related to end-of-life services and differences in medical costs. **Methods:** The medical records of 120 patients referred by a pediatric palliative care team were analyzed retrospectively. Data from July 1 to February 28, 2022 were collected and analyzed using the chi-square test and the Mann-Whitney U test. **Results:** Volunteer programs and psychological support (100%), family support and education (99.2%), and financial support through institutional linkage (62.5%) were provided to the participants. In the deceased group, there were no significant differences in general characteristics, which included age, gender, primary disease, religion, duration of hospitalization in an intensive care unit (ICU) and non-intensive care unit (non-ICU). However, the ICU group had fewer opportunities to access individual pain and physical symptom management than the non-ICU group and there were limitations in linking with external resources. Medical expenses were significantly different for the ICU group, with a 3-times higher average cost than the non-ICU group. **Conclusion:** Although an individualized approach is needed for each patient in pediatric palliative care, psychosocial care is essential. In addition, if early intervention for end-of-life pediatric patients is available from a palliative care team, the cost burden of medical care for patients and their families should be minimal.

**Key Words:** Palliative care, Pediatrics, Health care costs

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## INTRODUCTION

### 1. Background

As technology develops, advances in medical care are increasing the survival rate of pediatric patients with life-threatening diseases and life-limiting conditions. However, pediatric patients with these conditions still do not often return to a normal standard of living, and the number of patients who depend on medical devices to treat complex disorders or

receive intensive treatments has increased [1]. Pediatric palliative care (PPC) was developed to address these situations, and the World Health Organization defines PPC as “the active total care of the child's body, mind and spirit, which also involves giving support to the family. It begins when illness is diagnosed, and continues regardless of whether or not a child received treatment directed at the disease” [2]. PPC is different from the concept of palliative care for adults since it is aimed at children and adolescents who are growing and developing. In South Korea in particular, the PPC pilot project stipulates

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that PPC should be provided to pediatric patients aged 24 years or younger with life-threatening diseases and their families [3], which ensures that a wide range of patients, most of whom are in desperate need of the service, are not deprived of the opportunity to receive care rather than simply setting the cutoff at the age of 18 years, which is the legal age of adulthood. The Ministry of Health and Welfare established a national comprehensive plan for cancer management and introduced the PPC pilot project in 2018. In 2022, 10 tertiary hospitals nationwide participated in the project to present a model for future PPC programs and determine an appropriate cost for the program in a domestic context [4]. However, even in its fifth year, there is insufficient data supporting the establishment of professional PPC services due to a lack of indicators. In particular, various cancers and rare incurable diseases included in PPC often have an uncertain prognosis due to the nature of pediatric care. It is relatively common to be treated in intensive care units (ICUs) during the course of these diseases, and there are cases in which decisions about end-of-life care must be made abruptly. Additionally, the ability to generalize the outcomes of pediatric patients is limited since a temporary recovery occasionally occurs right before death. For this reason, a previous study emphasized the need for follow-up studies to analyze the characteristics of pediatric patients who receive PPC and develop tools that assess the needs of PPC to examine and identify the most suitable criteria for patients [5]. In addition, over the past 2 years during the coronavirus disease 2019 (COVID-19) pandemic, the difficulties of pediatric patients who receive PPC and their families have increased substantially due to limited visiting hours and caregiver shifts. The bereavement process for end-of-life pediatric patients and their families during the COVID-19 pandemic faced time limits due to the risk of infection, and the considerations of families' needs have also changed in PPC. In particular, repeated meetings with PPC teams have led to decisions regarding hospice care by pediatric patients and their families, who may not have yet considered treatments other than regular intensive care. Based on this context, this study aimed to analyze the use of PPC at a single center since the introduction of the pilot project in 2020 to understand the future direction of PPC.

## 2. Purpose

Using the experience of a single center, this study aimed to investigate the status of PPC services provided to pediatric patients including those with cancer and rare incurable diseases. By analyzing end-of-life services according to the place of hospitalization of pediatric patients whose PPC services ended due to death, this study also aimed to investigate the status of the use of PPC services and the economic burden due to medical costs.

## METHODS

### 1. Study design

This is a retrospective study that analyzed PPC services and the medical costs of pediatric patients using medical records.

### 2. Study sample

The study sample comprised pediatric patients who received PPC services at S Hospital of C University. From the initiation of the pilot project in May 2020 to February 28, 2022, 130 pediatric patients were referred to the PPC team among those who visited the pediatric outpatient department or those who were hospitalized in the pediatric ward. The patients received a request for referral from the attending physician based on the determination of medical professionals that PPC was necessary. Pediatric patients and their caregivers were provided with written information, and written consent to voluntarily participate in the pilot project and agreement to the use of personal information were obtained during in-depth counseling. From July 1 to August 31, 2022, the researchers conducted a retrospective analysis using the medical records of 120 patients who provided written consent.

### 3. Data collection

This study was conducted after data utilization was approved by the institutional review board of C University Hospital (No. KC22RISI0233). From May 1, 2020, to February 28, 2022, the researchers reviewed the electronic medical records of 120 pediatric patients registered by the PPC team at C University Hospital and collected data on individual variables from care

report forms. The variables were selected by the researchers to investigate the current status of PPC and were recorded in the database of PPC recipients at the National Hospice Center on a mandatory basis. They included sex, age, diagnosis, date of diagnosis, family relationship, area of residence, religious status, consent to service, referral date, main caregiver, where service was received, details of service, reason for terminating service, and date of death. Additionally, the medical costs of deceased patients according to where the service was received (ICU or non-ICU) were examined.

Since 2020, the Ministry of Health and Welfare has required hospitals operating the PPC pilot project to record the data of the referred pediatric patients to the palliative care assessment system and the information management database for pediatric patients. This is legally based on Article 21 (Hospice Projects) and Article 29 (Evaluation of Institutions Specialized in Hospice Care) of the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life and Article 12 (Entrustment of Evaluation Affairs of Institutions Specialized in Hospice Care) and Article 13 (Management of Sensitive Information and Personally Identifiable Information) of the Enforcement Decree of the same Act. The recorded items are classified into five categories: basic information about pediatric patients, information about bereaved family members, initial assessment information, hospice service information, and survival information about pediatric patients. Medical costs were investigated using medical records and included the costs related to treatment, medication, medical imaging and laboratory tests, admissions, and meals, as well

as any other costs borne by pediatric patients who terminated PPC. Since this was a retrospective study that reviewed medical records, all identifiable personal information was digitized. The collected data were in a safe and secure place and were not used for any purposes other than research. All research-related records were stored for 3 years and will be destroyed after this retention period.

#### 4. Data analysis

The collected data were analyzed using SPSS for Windows (version 26.0; IBM Corp., Armonk, NY, USA). The general characteristics of the pediatric patients and their caregivers were analyzed using real numbers and percentages. The homogeneity of pediatric patients who received PPC in ICUs and non-ICUs was analyzed using the chi-square test. Since the 2 groups did not show a normal distribution, the Mann-Whitney U test was conducted to analyze age, length of hospitalization, duration of disease, and medical costs.

## RESULTS

### 1. General characteristics of the patients

Of the 120 pediatric patients ultimately enrolled in the national pilot project, 53 patients received PPC, and the service was terminated for 67 patients. The reasons for termination included the achievement of goals at the time of referral—namely, pain and symptom management, support for the decision-making process including future treatments, support

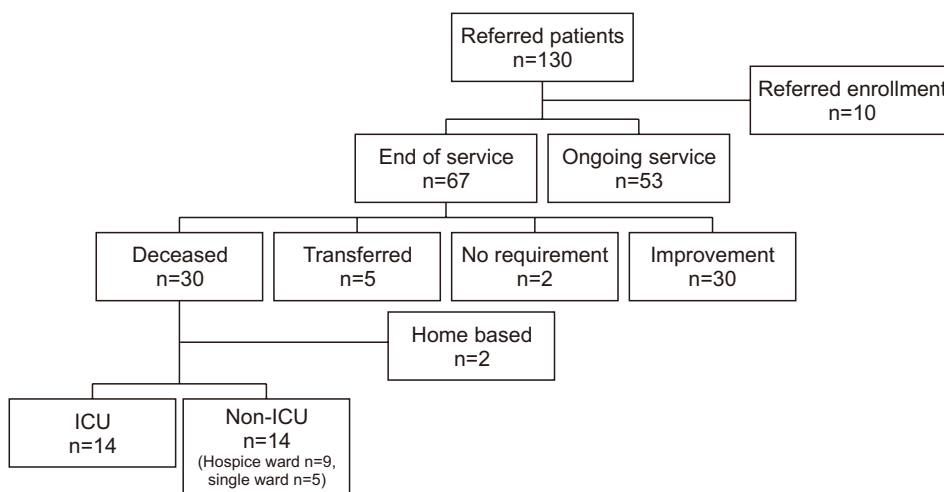


Figure 1. Flowchart of patient enrollment. ICU: Intensive care unit.

related to life-sustaining treatment decisions, psychological and emotional support for pediatric patients and their families, social support, discharge support including nursing place coordination, support for end-of-life care and the bereavement process, and others (program). The service was automatically terminated for 2 patients since they did not visit the hospital for over 4 months. It was also terminated for five patients after they were transferred to other hospitals for either different treatment or to be in a hospital closer to their homes. The service was terminated for 30 patients following the death of the patient (Figure 1). The mean age at enrollment was  $9.05 \pm 5.53$  years old, and there was a higher proportion of girls, with a boy-to-girl ratio of 1:1.5 (48 boys:72 girls). A higher pro-

portion of patients ( $n=81$ , 67.5%) had cancer than other non-cancer diseases ( $n=39$ , 32.5%). Most patients lived in Gyeonggi Province or Incheon ( $n=64$ , 53.3%) and Seoul ( $n=24$ , 20.0%), near C University Hospital. The majority ( $n=68$ , 56.7%) were non-religious, followed by Protestant ( $n=25$ , 20.8%), Catholic ( $n=24$ , 20.0%), and Buddhist ( $n=3$ , 2.5%). Caregivers were most commonly mothers ( $n=108$ , 90.0%), followed by fathers ( $n=7$ , 5.8%) and others ( $n=5$ , 4.2%). More than half of the patients ( $n=63$ , 52.5%) were referred to the PPC team from general wards ( $n=63$ , 52.5%), followed by outpatient departments ( $n=24$ , 20.0%) and the ICU ( $n=33$ , 27.5%) (Table 1).

## 2. Service provided to the patients

In terms of physical support services, 17 patients (14.2%) received pain management, and 13 patients (10.8%) received physical symptom management. In terms of psychological support services, all of the patients ( $n=120$ , 100%) received counseling, and 49 patients (40.8%) received art and music therapy. Thirty-seven patients (30.8%) received counseling for spiritual support. Thirty-two patients (26.7%) were supported by communication between medical staff through co-

**Table 1.** Characteristics of the Patients (N=120).

Characteristics	n (%) or Mean (SD)
Age (yr)	9.05 ( $\pm 5.53$ )
<2	16 (13.3)
2~5	20 (16.7)
6~12	51 (42.5)
13~24	33 (27.5)
Gender	
Boy	48 (40.0)
Girl	72 (60.0)
Type of disease	
Cancer	81 (67.5)
Non-cancer	39 (32.5)
Area of residence	
Seoul	24 (20.0)
Gyeonggi/Incheon	64 (53.3)
Gangwon	3 (2.5)
Chungcheong	11 (9.2)
Jeolla	5 (4.2)
Gyeongsang	13 (10.8)
Religious status	
None	68 (56.7)
Protestant	25 (20.8)
Catholic	24 (20.0)
Buddhist	3 (2.5)
Main caregiver	
Mother	108 (90.0)
Father	7 (5.8)
Others	5 (4.2)
Time of palliative care consultation	
General ward	63 (52.5)
Outpatient clinic	24 (20.0)
ICU	33 (27.5)

ICU: Intensive care unit.

**Table 2.** Services Received by Patients Who Completed Palliative Care (N=120).

Category	n (%)
Physical support	
Pain management	17 (14.2)
Symptom management	13 (10.8)
Psychological support	
Counseling	120 (100.0)
Art and music therapy	49 (40.8)
Spiritual support	
Counseling	37 (30.8)
Communication support	
Between medical staff	32 (26.7)
Between patient and medical staff	31 (25.8)
Socioeconomic support	
Economic support	75 (62.5)
Volunteer program	120 (100.0)
Discharge support	
Discharge plan support	19 (15.8)
Institutional linkage involving other hospitals	1 (0.8)
End-of-life care	
End-of-life support	19 (15.8)
Funeral plan support	19 (15.8)
Family support	
Family support and education	119 (99.2)

operative practice, and 31 patients (25.8%) were supported by communication between patients and medical staff. All of the patients (n=120, 100%) received volunteer program support, and 75 patients (62.5%) received economic support through institutional linkage. A total of 19 patients (15.8%) received discharge plan support, and one patient (0.8%) was linked to another hospital. Nineteen patients (15.8%) received end-of-life support. Nineteen patients (15.8%) also received funeral plan support, and 119 patients (99.2%) received family support and education (Table 2).

### 3. Comparison of the patients' general characteristics by place of end-of-life care

Of the 120 patients who received PPC, 30 patients died. Other than two patients who died during home care, 12 patients received end-of-life care in a single bedroom or a hospice ward (non-ICU), and 14 patients received end-of-life care in the ICU, and these were the 2 groups that were compared. There were no significant differences between the groups in terms of age, sex, diagnosis, religious status, length of hospitalization from the last admission to death, or the duration of time from diagnosis to death, but the mean number of hospitalization days from the last admission to death tended to be shorter among those in the non-ICU group than among those in the ICU group (Table 3). The ICU group had fewer opportunities to receive individual pain and physical symptom management, less communication support between medical

staff through cooperative practice, less communication support between the patient and medical staff, and fewer opportunities for institutional linkage involving other hospitals (Figure 2).

### 4. Comparison of medical costs according to the place of end-of-life care

The medical costs for the 7 days immediately preceding the

Table 3. Characteristics of the Patients by Place of Death (N=28).

Characteristics	Non ICU	ICU	P
	n (%)	n (%)	
Number of patients	14	14	
Age of death (yr)			
<2	1 (7.1)	2 (14.3)	0.940
2~5	1 (7.1)	1 (7.1)	
6~12	4 (28.7)	4 (28.7)	
13~24	8 (57.1)	7 (50.0)	
Median (Min, Max)	14 (0,20)	12 (0,19)	0.213
Gender			
Boy	6 (42.9)	7 (50.0)	1.000
Girl	8 (57.1)	7 (50.0)	
Primary disease			
Cancer	13 (92.9)	10 (71.4)	0.139
Non-cancer	1 (7.1)	4 (28.6)	
Religious status			
Yes	8 (57.1)	6 (42.9)	0.464
No	6 (42.9)	8 (57.1)	
Hospitalization period (days)*	58.5(11,192)	84.2(1,251)	0.578
Time from diagnosis to death (days)	466 (45,3277)	375 (1,3443)	0.787

ICU: Intensive care unit, \*Duration from last admission to death (Min, Max).

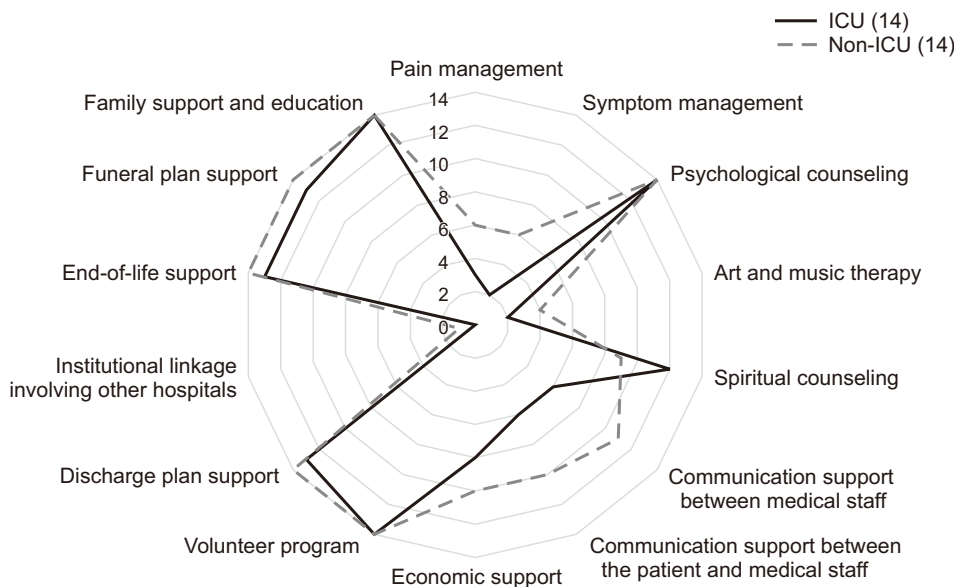


Figure 2. Services received by ICU and Non-ICU. ICU: Intensive care unit.

**Table 4.** Comparison of Medical Costs according to the Place of Death (N=28).

Variable (cost)	Non-ICU (n=14)			ICU (n=14)			P
	Mean (SD)	Min	Max	Mean (SD)	Min	Max	
Total amount (1000 KRW)	6482.22 (3946.73)	920.22	14135.25	19280.46 (6629.26)	4206.99	28374.06	<0.001
Treatment (1000 KRW)	1992.45 (2669.89)	0.00	9317.29	7655.70 (2802.23)	2268.40	12431.22	<0.001
Medication (1000 KRW)	1038.40 (1358.63)	13.96	4014.54	5176.87 (3193.18)	157.57	9689.93	<0.001
Medical imaging and laboratory tests (1000 KRW)	607.82 (617.45)	0.00	1600.68	2658.80 (717.68)	1063.27	3664.94	<0.001
Admission charge (1000 KRW)	1387.99 (1183.78)	0.00	3288.00	3090.58 (864.35)	463.06	3878.26	<0.001
Meal (1000 KRW)	73.77 (73.75)	0.00	166.60	35.84 (40.62)	0.00	96.20	0.150
Other cost (1000 KRW)	1381.78 (1119.07)	276.64	3103.43	662.66 (418.40)	254.69	1645.51	0.352

ICU: Intensive care unit, KRW: Korean rate won.

Costs were calculated based on the 7-day period immediately preceding death.

deaths of 28 patients were compared. The average total medical cost per week was three times higher in the ICU group (19,280,460 KRW) than in the ICU group (6,482,220 KRW). The total medical cost, treatment costs, medication costs, medical imaging and laboratory tests costs, and admission costs were higher in the ICU group ( $P<0.001$ ), but there were no significant differences in meal costs or other costs between the groups (Table 4).

## DISCUSSION

This study was conducted to identify the current status of PPC for pediatric patients who enrolled in South Korea's national PPC pilot program based on the experience of a single center. According to the National Hospice Center's annual report on pediatric patients enrolled in PPC services in South Korea, there were more pediatric patients with non-cancer diseases ( $n=876$ , 55.8%) than with cancer ( $n=695$ , 44.2%) [3]; however, the proportion of pediatric patients with cancer ( $n=81$ , 67.5%) was higher in the hospital examined in this study, which accounted for approximately 11.7% (81 out of 695 patients) of pediatric cancer patients in South Korea. These differences in the patient group by hospital may suggest that medical services in future PPC programs should be implemented that reflect the specific needs of each hospital rather than all hospitals adopting identical methods. All pediatric patients received counseling for psychological support and requested and were enrolled in a volunteer program for socioeconomic support. Our findings are similar to those of a

study on caregivers, which identified that families with pediatric cancer patients require emotional, psychological, social, and spiritual care, in descending order [6]. The findings of this study indicate consistency between the needs of service recipients and the care that was actually provided. In particular, it is believed that caregivers were positively influenced by their sympathy with the situations of other caregivers and supportive counseling for their difficult situations, which was consistent with the findings of a previous study [7], which found that PPC significantly reduced the anxiety and stress of families. Moreover, exposure to new stimuli in the hospital through the program may be beneficial for pediatric patients, who are still growing and developing. However, pain and physical symptom management were not sufficiently provided compared to the program's addressing of the needs of health care professionals and caregivers. Given that most patients included in this study were cancer patients and that pain is a common cancer symptom experienced by pediatric cancer patients [8–11], the low degree of pain and physical symptom management may be the result of various factors, including difficulties accurately assessing and controlling the pain of pediatric patients, caregivers' perceptions about analgesics, and medical professionals' understanding of pain. Therefore, in the long term, the perception of caregivers, patients, and medical professionals regarding the pain of pediatric patients must be improved. Furthermore, appropriate tools to measure pain in pediatric patients and expert interventions for pain control should be developed and implemented.

After analyzing the medical costs of 30 deceased patients



who received PPC, the medical costs of those in the non-ICU group were significantly lower than those in the ICU group. This finding suggests the possibility that the PPC team's early intervention may reduce the burden of medical costs on patients and their families. According to 2021 data from Statistics Korea, congenital malformations, deformities, and chromosomal abnormalities were the second leading cause of mortality among patients younger than 1 year, and malignant neoplasms were the first and second leading cause of mortality among patients aged 1 to 9 years and 10 to 19 years, respectively. This indicates that the medical conditions of the pediatric patients in this study account for a significant proportion of pediatric deaths overall [12]. Of the 30 deceased patients, 25 with cancer and three with non-cancer diseases died under the age of 1 year old, which suggests that customized services should be provided that consider the age and characteristics of the disease group for which PPC is provided. In particular, even though this study was conducted only 2 years after the initiation of the pilot project, 19 patients who were determined to be at the end of life could not be transferred to hospice wards because they were on ventilators or were unconscious. Even if a patient is predicted to die, due to the characteristics of pediatric medicine, not all patients need to be transferred to a hospice ward. While some patients wish to use the hospice ward, national and institutional guidelines sometimes do not allow them to be transferred; for instance, severely ill infants cannot be hospitalized in a hospice ward under the current national policy. In addition, contrary to the intentions of primary caregivers, in divorced families, futile treatments may be continued if consent to the life-sustaining treatment plan of the patient cannot be obtained when the opposing custodian parent cannot be located. Therefore, regardless of which decision is made, it is important to support the decision-making processes of caregivers and provide accurate information about patients and caregivers' options in the process of determining the place of death. Occasionally, when patients are medically incurable, it may be more important to focus on psychological support and symptom management instead of providing medications and tests used in active treatment [13]. In these cases, caregivers should be provided sufficient information to correct the misconception that choosing pediatric hospice indicates that they have given up on their children.

Before the introduction of the PPC, the majority of pediatric patients in the end-of-life stage received intensive care in an ICU. However, some patients who received PPC services decided to enter hospice care after sufficient discussion and died in general wards or in their homes. In this study, among the 28 patients who received PPC and died in the hospital, the average medical cost for the 7 days immediately preceding death was three times higher among ICU patients than among non-ICU patients. This is a significant finding since it enables researchers to consider the cost gap in terms of the socioeconomic aspect of the use of medical resources as well as the medical costs of patients and their families. This result in particular is consistent with that of a study by Smith [14], which found that PPC reduced the costs of pediatric patients in states of imminent death. The findings of a study by Popejoy [15] also showed how PPC can help the decision-making process. In this study, the duration from diagnosis to death and the length of hospitalization from the last admission to death did not significantly differ between the ICU group and the non-ICU group, but the mean number of hospitalization days from the last admission to death tended to be shorter among those in the non-ICU group (58.5 days) than among those in the ICU group (84.2 days). This finding may be because patients who decided to enter hospice care were discharged for at least a short time and spent their remaining time with their families. However, no significant differences were observed due to the small number of patients, and multi-center research should be conducted in the future. In addition, the total medical cost for the 7 days immediately preceding death was found to be three times higher among ICU patients than among non-ICU patients, and treatment costs, medication costs, medical imaging and laboratory test costs, and admission costs were significantly higher in the ICU group. The decision to receive care outside of an ICU may significantly reduce the burden of medical costs for patients and families as well as help patients spend time with their families.

This is a retrospective study of pediatric patients who received PPC at a single center; therefore, the findings should not be expanded or generalized. However, this study is meaningful in that the initiation of the PPC program has allowed many patients to overcome their crisis and terminate service, in addition to providing medically incurable patients and their fam-

ilies the option of hospice care rather than continue to receive intensive care in an ICU. In order to ensure stable service in the future, service must be continued by providing unbiased information about PPC to caregivers during the decision-making process and focusing on reducing discomfort regardless of the decisions made by caregivers. Given that the hospital where this study was conducted had a large number of pediatric patients with hematologic neoplasms, further research is needed to examine the status of PPC care in South Korea through multi-center studies to understand pediatric patients at the end-of-life stage who are especially in need of PPC. As more palliative care services are developed over time, further efforts should be made on a national level to provide much-needed service to pediatric patients with short life expectancies.

## CONFLICT OF INTEREST

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

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## AUTHOR'S CONTRIBUTIONS

Conception or design of the work: all authors. Data collection: SHC, NRY. Data analysis and interpretation: all authors. Drafting the article: SHC, YL. Critical revision of the article: SHC, YL. Final approval of the version to be published: all authors.

## SUPPLEMENTARY MATERIALS

Supplementary materials can be found via <https://doi.org/10.14475/jhpc.2023.26.2.51>.

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