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Cross Sectional Study

Pediatricians' Perspectives on Advance Care Planning: Insights from a Cross-Sectional Survey

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Abstract

The rising prevalence of children with complex or life-limiting conditions has made advance care planning (ACP) an essential aspect of pediatric healthcare. In South Korea, discussions about withdrawing life-sustaining treatment were once avoided because such actions were historically penalized by law, fostering a culture of aggressive medical intervention. With evolving social attitudes toward end-of-life care, new legislation now safeguards patient dignity by emphasizing autonomy and supporting ACP practices. Nevertheless, little is known about how pediatricians currently perceive and implement ACP in Korea. This study sought to investigate pediatricians' views on ACP and examine variations across different pediatric subspecialties. A cross-sectional, web-based survey was conducted among pediatricians caring for children with serious or life-limiting illnesses in 2018. Participants completed a self-administered questionnaire assessing their experiences and attitudes toward ACP. Of 96 respondents, 89 were eligible for analysis. When presented with a hypothetical clinical scenario, hemato-oncologists and intensivists were more inclined than neonatologists and neurologists to prioritize comfort care over aggressive treatment. While 72.2% of hemato-oncologists reported that they frequently discuss ACP with parents, more than half of other pediatricians indicated they rarely engage in such conversations. Moreover, 65% of all respondents stated that they never initiate ACP discussions with adolescent patients, with minimal variation between specialties. The most commonly identified barriers to ACP were insufficient institutional support following ACP implementation (82.0%) and ambiguity regarding legal accountability (70.8%). Pediatricians' perspectives and experiences with advance care planning differ notably among subspecialties. To facilitate more effective communication about prognosis and care preferences, comprehensive institutional frameworks and professional education are needed to help clinicians involve both children and families in ACP discussions.

Keywords: Advance care planning, Pediatricians, Palliative care, End-of-life decision-making

Introduction

Advance care planning (ACP) refers to a process that allows individuals to articulate their goals and preferences regarding future medical treatment and care, engage in discussions about these preferences with family members and healthcare professionals, and document or review them when appropriate [1]. ACP has been shown to enhance communication between patients and clinicians, promote the use of palliative care, improve satisfaction and

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quality of life, and reduce unnecessary hospital admissions [2, 3]. Furthermore, families have reported that initiating ACP early in the disease trajectory contributes to the provision of higher-quality care [4].

Although ACP is relevant for many pediatric conditions such as cancer, severe prematurity, congenital anomalies, and neuromuscular disorders, multiple obstacles prevent clinicians from engaging in ACP discussions with children and their families. These challenges arise on both the providers' and the parents' sides. Among the key barriers are physicians' limited training or experience, prognostic uncertainty, and parents' emotional unpreparedness for such conversations [5–8]. A major point of contention has long been whether and how to disclose prognostic information directly to pediatric patients. During the 1950s and 1960s, withholding such information was generally advised, whereas from the late 1960s onward, experts began advocating for children's inclusion in these discussions. Contemporary perspectives suggest that prognostic disclosure should not be viewed as an absolute decision but rather approached flexibly, balancing competing considerations in each case [9].

Despite this emerging consensus, sociocultural and religious factors continue to shape how prognostic information is communicated to children. In South Korea, there remains a strong tendency to withhold full disclosure from pediatric patients due to fears that such conversations could cause emotional harm, worsen the illness, or negatively influence survival outcomes [9, 10]. Recently, the Korean government implemented new legislation supporting ACP to respect patient autonomy and dignity. However, empirical research on ACP in Korean pediatric populations remains scarce [11]. Furthermore, limited evidence exists on how pediatricians' perspectives on ACP vary across different subspecialties. This study therefore aimed to explore pediatricians' attitudes toward ACP and identify perceived barriers to its implementation in pediatric settings. It was hypothesized that views on ACP differ among pediatric subspecialties, and this study sought to examine that variation.

Materials and Methods

Study design and participants

A cross-sectional observational study was conducted using an online survey to assess South Korean pediatricians' attitudes toward ACP. The web-based, self-administered questionnaire targeted pediatricians specializing in neonatology, neurology, critical care medicine, and hemato-oncology—disciplines that frequently care for children with life-limiting illnesses.

Questionnaire development

The survey instrument was developed based on an extensive review of existing literature, reports, and legal documents related to pediatric ACP [5–8]. Pediatricians, nurses, and social workers experienced in managing children with serious illnesses reviewed the questionnaire to ensure content relevance and clarity. Because the concept of ACP is relatively new in South Korea, a definition was provided at the start of the survey.

The questionnaire covered five main areas:

1. Demographic and professional background, including subspecialty and years of pediatric practice;
2. Decision-making preferences and timing for discussing life-sustaining treatment across two clinical scenarios;
3. Experiences related to life-sustaining treatment decisions (six items);
4. Barriers to implementing ACP in children and adolescents and their relative importance (two items); and
5. Attitudes toward legal aspects, particularly the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End-of-Life (three items).

The draft survey underwent pilot testing with two pediatricians, and revisions were made based on their feedback. Completion time for the final questionnaire averaged approximately 10 minutes.

Data collection

Data were collected via a web-based platform (SurveyMonkey.com, Palo Alto, CA) between October and November 2018. Invitations, endorsed by the president of Seoul National University Hospital and the research team, were distributed through four major professional organizations: the Korean Society of Pediatric Hematology-Oncology, Korean Society of Neonatology, Korean Society of Pediatric Critical Care Medicine, and Korean Child Neurology Society. These societies disseminated the invitation letters and survey links to their members.

Participation was voluntary, and completion of the survey was regarded as informed consent. Reminder emails were sent two weeks after the initial invitation to encourage participation. Pediatricians who declined to participate were not contacted again, and identifying information—such as names, email addresses, and workplaces—was not linked to survey responses, ensuring respondent anonymity.

Measures

The primary outcome—pediatricians' perceptions of advance care planning (ACP)—was derived from four of the five major sections of the questionnaire. These domains assessed participants' experiences with pediatric ACP, attitudes toward legal issues, decision-making preferences, and preferred timing for ACP discussions in clinical scenarios.

Two hypothetical case scenarios were used, both describing six-year-old male patients who required intubation. The first scenario involved a patient with hypoxic-ischemic encephalopathy, representing a chronic condition, while the second described a child with leukemia, illustrating an intractable malignancy. Both cases were developed and validated by a multidisciplinary team experienced in caring for children with life-limiting illnesses. For each scenario, respondents were asked to select between two management approaches. Option 1 involved providing invasive medical interventions despite low survival prospects, whereas Option 2 represented a comfort care approach, prioritizing symptom relief over aggressive but potentially futile treatment.

The secondary outcome aimed to identify variations in ACP perceptions among pediatric subspecialties. Accordingly, responses were analyzed based on participants' specialties and years of clinical experience. In addition, the survey examined pediatricians' views on the main barriers to implementing ACP in children.

Statistical analysis

All statistical analyses were performed using SPSS version 21.0 (IBM Corp., Chicago, IL) and STATA version 15.1 (StataCorp, College Station, TX). Descriptive statistics, including means and frequencies, were used to summarize demographic variables and survey responses. Demographic characteristics were categorized for analysis. Comparisons of mean values and proportions between groups were conducted, and adjusted proportion codes were applied to control for potential confounding variables such as age, sex, religion, years of pediatric practice, and prior education on pediatric ACP.

Results and Discussion

Participant characteristics

A total of 966 email invitations were distributed through four national pediatric societies. Of all eligible pediatricians, 96 completed the survey, yielding a response rate of 9.9%. After excluding five respondents with incomplete demographic information and two who had not received the survey through an official society channel, 89 valid responses were included in the final analysis.

Table 1 presents the demographic and professional characteristics of the participants. The majority specialized in neonatology, followed by hemato-oncology, neurology, and intensive care medicine, respectively. There were no significant differences across specialties in terms of sex, age, religion, or years of pediatric practice. However, pediatric hemato-oncologists were significantly more likely to have received formal education on pediatric ACP compared with other subspecialists **(Table 1)**.

Table 1. Demographics of survey participants (n = 89)

Category	Neurology n (%) (n = 10)	Neonatology n (%) (n = 54)	Intensive Care n (%) (n = 7)	Hemato-Oncology n (%) (n = 18)
Sex				
Male	6 (60.0)	14 (25.9)	2 (28.6)	5 (27.8)
Female	4 (40.0)	40 (74.1)	5 (71.4)	13 (72.2)
Age (years)				
30–39	5 (50.0)	18 (33.3)	5 (71.4)	10 (55.6)
40–49	3 (30.0)	26 (48.1)	2 (28.6)	4 (22.2)
50–59	1 (10.0)	5 (9.3)	0 (0)	4 (22.2)
≥ 60	1 (10.0)	5 (9.3)	0 (0)	0 (0)
Religion				
Protestant	6 (60.0)	20 (37.0)	3 (42.9)	7 (38.9)
Catholic	1 (10.0)	12 (22.2)	1 (14.3)	5 (27.8)
Buddhist	1 (10.0)	5 (9.3)	1 (14.3)	1 (5.6)
None	2 (20.0)	17 (31.5)	2 (28.6)	5 (27.8)
Career as a Pediatrician				
≤ 10 years	7 (70.0)	32 (59.3)	5 (71.4)	12 (66.7)
> 10 years	3 (30.0)	22 (40.7)	2 (28.6)	6 (33.3)
Education in Pediatric Advance Care Planning				
Yes	0 (0)	8 (14.8)	2 (28.6)	10 (55.6)
No	10 (100)	46 (85.2)	5 (71.4)	8 (44.4)

Notes: n refers to the number of respondents in each category

Subspecialty differences were evident in pediatricians' decisions regarding life-sustaining treatment. Pediatric hemato-oncologists demonstrated a strong preference for comfort care (response option 2) in both hypothetical cases. The adjusted proportions selecting comfort care were 83.0% for the first case and 93.9% for the second. Pediatric intensivists also tended to favor comfort care, with approximately 57% choosing this option in case 1, and all seven respondents selecting it in case 2. In contrast, neonatologists and neurologists were less likely to opt for comfort care in either scenario **(Table 2)**.

Table 2. Results of decision-making on the two presented cases (preference for comfort care)

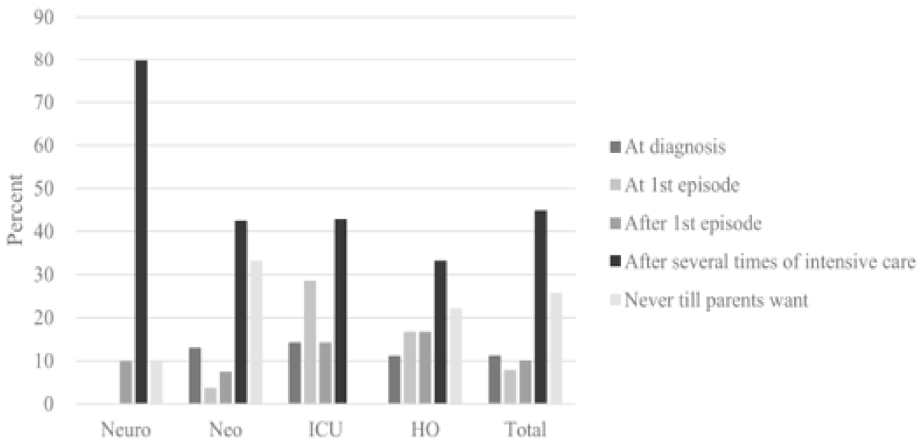
Subspecialties	n	Proportion (%)	Adjusted Proportion (%)
Case 1 (HIE)			
Neurology (*n* = 10)	2	20.0	10.3
Neonatology (*n* = 54)	27	50.0	52.0
Intensive care (*n* = 7)	4	57.1	57.1
Hemato-oncology (*n* = 18)	14	77.8	83.0
Case 2 (Leukemia)			
Neurology (*n* = 10)	3	30.0	35.7
Neonatology (*n* = 54)	26	48.1	48.1
Intensive care (*n* = 7)	7	100	100
Hemato-oncology (*n* = 18)	17	94.4	93.9

HIE hypoxic-ischemic encephalopathy.

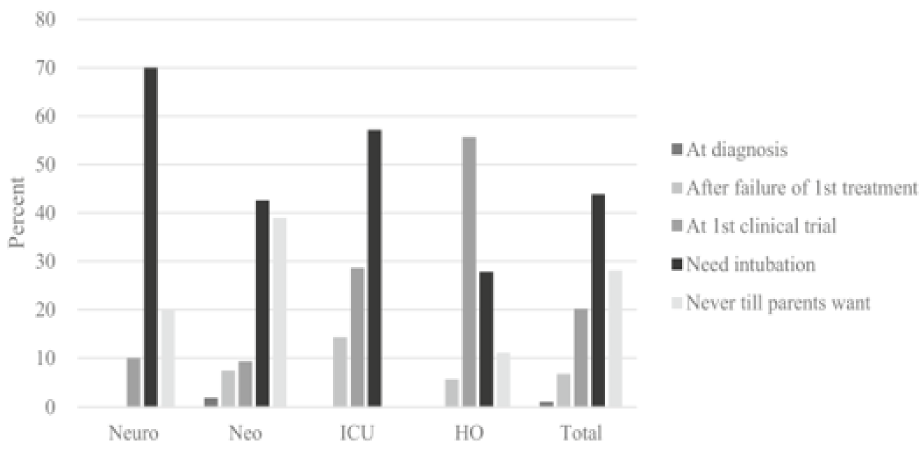
Notes: The proportions were adjusted for age, sex, religion, and career as a pediatrician, as well as pediatric advance care planning education. Answer 1, preference for invasive respiratory support, including intubation and mechanical ventilation in the specified cases; Answer 2, preference for antibiotics and medications for symptom control rather than invasive respiratory support, in the cases

Participants were asked to indicate their preferred timing for initiating discussions about advance care planning (ACP). Across both clinical scenarios, most pediatricians reported that they would begin ACP conversations only after the patient had undergone several episodes of invasive ventilator support or at the point when intubation became necessary (case 1: 44.9%, 40/89; case 2: 43.8%, 39/89).

However, a greater proportion of hemato-oncologists and intensivists favored initiating ACP discussions at an earlier stage of the disease (within the first three time points) compared with neonatologists and neurologists. Notably, in both scenarios, more than 30% of neonatologists indicated that they would delay ACP discussions until the patient's parents expressed readiness or willingness to engage in such conversations **(Figure 1)**.



a)



b)

Figure 1. Preferred timing to implement advance care planning: HIE, hypoxic ischemic encephalopathy; Neuro, Neurology; Neo, Neonatology; ICU, intensive care unit; HO, hemato-oncology. a) Timing for advance care planning in HIE, b) Timing for advance care planning in malignancy.

Discussion on advance care planning with patients' parents in advance

Respondents were asked how frequently they engaged in advance care planning (ACP) discussions with the parents of patients who had a high likelihood of death within several years. The frequency of these discussions varied notably across pediatric subspecialties. Approximately 90% of pediatric neurologists and more than half of pediatric intensivists and neonatologists reported that they rarely or never initiated ACP discussions with parents. In contrast, over 70% of pediatric hemato-oncologists indicated that they mostly or always discussed ACP with families in such circumstances.

When responses were analyzed according to career duration, pediatricians with 10 years or less of professional experience reported engaging in ACP conversations more frequently than those with longer clinical careers **(Table 3)**.

Here is the paraphrased table with the same structure and information:

Table 3. Results of discussion on advance care planning ahead with parents

Category	None	Rarely	Mostly	Always
Specialty				
Neurology (n = 10)	1 (10.0%)	8 (80.0%)	1 (10.0%)	0 (0%)
Neonatology (n = 54)	8 (14.8%)	23 (42.6%)	20 (37.0%)	3 (5.6%)
Intensive Care (n = 7)	1 (14.3%)	3 (42.9%)	1 (14.3%)	2 (28.6%)
Hemato-Oncology (n = 18)	0 (0%)	5 (27.8%)	9 (50.0%)	4 (22.2%)
Career as a Pediatrician (Years)				
≤ 10 (n = 56)	1 (1.8%)	29 (51.8%)	19 (33.9%)	7 (12.5%)
> 10 (n = 33)	9 (27.3%)	10 (30.3%)	12 (36.4%)	2 (6.1%)
Education in Pediatric Advance Care Planning (pACP)				
Yes (n = 20)	1 (5.0%)	5 (25.0%)	9 (45.0%)	5 (25.0%)
No (n = 69)	9 (13.0%)	34 (49.3%)	22 (31.9%)	4 (5.8%)
Total (N = 89)	10 (11.2%)	39 (43.8%)	31 (34.8%)	9 (10.1%)

The table retains all original data, with rephrased headers and labels for clarity while maintaining the same structure.

pACP pediatric advance care planning

Discussion on advance care planning ahead with adolescent patients

Participants were also asked whether they engaged in advance care planning (ACP) discussions directly with adolescent patients. More than 60% of pediatricians reported that they never initiated such conversations. Moreover, no significant differences were observed across subspecialties, years of professional experience, or prior ACP education **(Table 4)**.

Here is the paraphrased table with the same structure and information:

Table 4. Results of discussion on advance care planning with adolescent patients

Category	None	Rarely	Mostly	Always
Subspecialty				
Neurology (n = 9)	8 (88.9%)	0 (0%)	1 (11.1%)	0 (0%)
Intensive Care (n = 7)	5 (71.4%)	2 (28.6%)	0 (0%)	0 (0%)
Hemato-Oncology (n = 18)	9 (50.0%)	8 (44.4%)	1 (5.6%)	0 (0%)
Career as a Pediatrician (Years)				
≤ 10 (n = 23)	16 (69.6%)	6 (26.1%)	1 (4.3%)	0 (0%)
> 10 (n = 11)	6 (54.6%)	4 (36.4%)	1 (9.1%)	0 (0%)
Education in Pediatric Advance Care Planning (pACP)				
Yes (n = 12)	6 (50.0%)	5 (41.7%)	1 (8.3%)	0 (0%)
No (n = 22)	16 (72.7%)	5 (22.7%)	1 (4.6%)	0 (0%)
Total (N = 34)	22 (64.7%)	10 (29.4%)	2 (5.8%)	0 (0%)

The table preserves all original data, with rephrased headers and labels for clarity while maintaining the same structure.

pACP pediatric advance care planning

Respondents rated potential barriers to ACP according to how often they encountered them. The three most frequently reported barriers were a lack of systemic support following ACP (such as palliative care or family support programs) at 82.0%, unclear legal or professional responsibilities at 70.8%, and prognostic uncertainty at 60.7%. Additionally, more than half of pediatricians indicated that not knowing when (55.1%) or how (52.8%) to initiate ACP discussions occurred often or always. In contrast, over 50% of respondents reported that six factors were rarely or never obstacles to ACP: concern about losing rapport with families (74.2%), time constraints (68.5%), avoiding burdening parents with decisions (66.3%), ethical stress (65.2%), social norms (62.9%), and discomfort discussing death (56.2%) **(Figure 2)**.

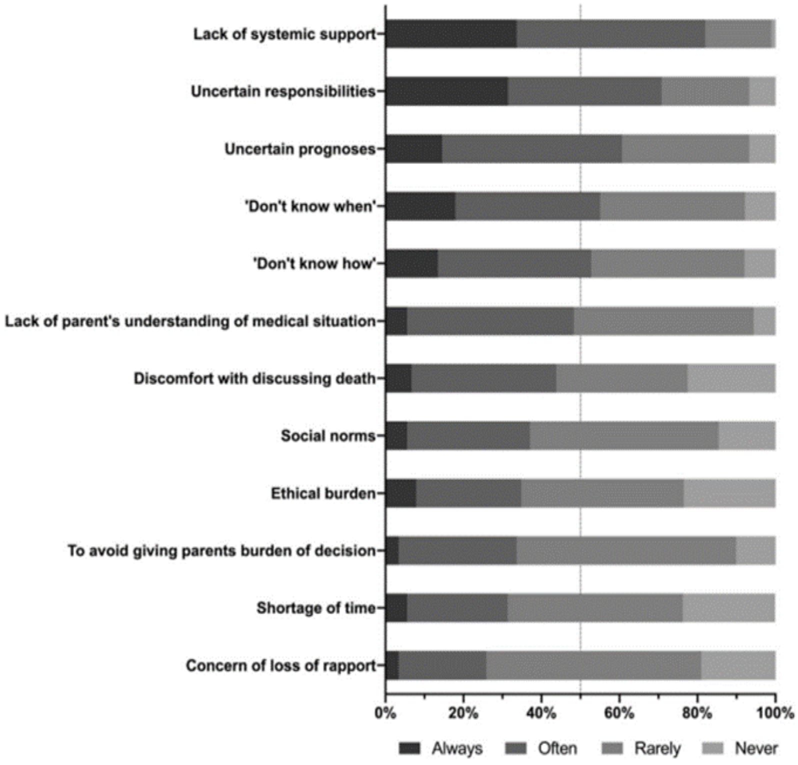


Figure 2. Barriers to advance care planning

Main findings

To our knowledge, this study is the first in South Korea to survey pediatricians regarding their perspectives on advance care planning (ACP). Furthermore, few prior studies have explored how these perceptions vary across pediatric subspecialties. Our findings indicate that preferences for respiratory interventions and the timing of ACP discussions differ by subspecialty. Pediatric hemato-oncologists were more likely than other subspecialists to engage in ACP discussions, yet only a small proportion of pediatricians, irrespective of specialty, reported experience in discussing ACP directly with adolescent patients. A prominent barrier to ACP implementation identified in this study was the lack of systemic support following ACP discussions.

Previous research has shown that over 90% of parents consider palliative care appropriate for children with limited chances of full recovery. This informed the scenarios used in our survey, where parental willingness to accept comfort or palliative care was assumed [12]. We also anticipated differences in pediatricians' responses between disease types, as hospice and palliative care policies in South Korea historically focused primarily on cancer patients until 2017 [13]. In our hypothetical cases, hemato-oncologists more frequently chose comfort care and favored earlier ACP discussions than other subspecialists **(Table 2 and Figure 1)**. They were also more likely to engage parents in ACP conversations, which may reflect the higher proportion of hemato-oncologists who had received prior ACP training **(Table 1)**. Supporting this, differences in preferred timing diminished after adjusting for prior education. Because national palliative care policies have not been uniformly applied across all subspecialties, hemato-oncologists may have had more opportunities for ACP training [13].

The second scenario, involving a child with leukemia, highlighted subspecialty differences most clearly, showing that both hemato-oncologists and intensivists preferred comfort care more often than neurologists or neonatologists. This may relate to the more predictable disease trajectory of cancer, allowing clinicians who frequently manage refractory leukemia patients to gain experience in making decisions that do not require invasive respiratory support [14]. According to the Act on Hospice and Palliative Care and Decisions on Life-Sustaining Treatment for Patients at the End of Life, life-sustaining treatment can only be withheld or withdrawn in patients in the dying process [11]. Although the survey instructed participants to respond independently of legal constraints, neurologists and neonatologists—less familiar with refractory leukemia—tended to select more conservative options, likely reflecting legal considerations.

In this study, 55.0% of respondents indicated that they rarely (43.8%) or never (11.2%) discussed ACP with parents, a proportion comparable to or higher than previous reports [4, 15–17]. Historically, withdrawal of life-sustaining treatment was taboo in South Korea, often punishable by law, leading physicians to pursue aggressive interventions and limiting ACP use. Consequently, treatment decisions frequently did not align with patients' or families' values. Recent shifts in public opinion and the introduction of new legislation supporting patient autonomy have begun to influence practice, particularly among younger pediatricians. For instance, 27.3% of pediatricians with more than 10 years of experience did not engage in ACP discussions with parents, compared with only 1.8% of junior pediatricians **(Table 3)**.

Despite these changes, most pediatricians still find it extremely challenging to discuss prognosis or life-sustaining treatment directly with patients, consistent with prior studies [18-20]. In our survey, over 90% of respondents reported that they had never (64.7%) or rarely (29.4%) conducted ACP discussions with adolescent patients. Engaging children and adolescents in ACP has known benefits, and the new legislation allows any patient to request such discussions regardless of age, obligating physicians to respond. However, guidance on how to effectively communicate about end-of-life care with pediatric patients remains lacking [11, 18-20]. Merely enacting legislation may be insufficient, and further research is needed to evaluate whether these legal changes translate into improved ACP engagement among adolescents.

Survey responses indicated that the lack of an effective support system, such as pediatric palliative care or family support teams, represents the most significant barrier to ACP. Other commonly reported obstacles included unclear legal responsibilities, uncertain prognoses, and insufficient knowledge about ACP. In contrast, a previous study in the United States identified parental factors—such as unrealistic expectations, limited understanding of prognosis, and lack of readiness—as the most frequent barriers [8]. Similarly, Korean oncologists (internal medicine) reported that family-related factors, including reluctance, hope, and intra-family conflict, as well as prognostic uncertainty, were more prominent barriers than inadequate systemic support or insufficient knowledge, aligning with our findings [21].

In this study, only 20 participants (22.4%) reported having received formal ACP education **(Table 1)**, and 55.0% lacked confidence in implementing pediatric ACP (data not shown). Until 2018, pediatric palliative care services were available in only a few hospitals, which may have contributed to pediatricians' concerns about conducting ACP discussions and managing care afterward. Establishing consultation or palliative care teams is known to facilitate ACP conversations and provide professional support to clinicians [22]. In 2018, the South Korean government launched a national pilot program to fund pediatric palliative care teams in hospitals, which is expected to expand to institutions that predominantly treat children requiring palliative care. Further research is needed to evaluate whether this expansion will reduce barriers to ACP [13].

Education programs for pediatricians are also essential to address these challenges. Medical staff need the skills and knowledge to initiate and guide ACP discussions effectively and to recognize when consultation with a pediatric palliative care team is warranted. Implementing structured education during residency training is particularly important. Bagatell, Meyer, Herron, and colleagues found that pediatric residents with formal ACP training were significantly more comfortable managing end-of-life logistics, symptom control, and communicating about death and care planning with colleagues and families compared with residents with limited training [23]. In addition, ACP tools and structured guidance have been shown to improve communication between young patients and healthcare providers during ACP processes [19, 20]. To support this in Korea, we developed a South Korean version of pediatric ACP tools and a practical guide, adapted from existing resources, to facilitate effective communication [24].

Strengths and limitations

This study is the first in South Korea to assess pediatricians' perceptions and attitudes toward ACP. Conducted during the early stages of the new end-of-life law and the national pediatric palliative care pilot program, the survey provides valuable baseline data for evaluating the impact of these initiatives. Moreover, analyzing results by pediatric subspecialty highlighted differences in ACP perspectives, emphasizing the need to prioritize subspecialty-specific ACP education.

However, the study has limitations. First, the survey's low response rate requires cautious interpretation of the findings. Nevertheless, given the challenges of contacting pediatricians caring for children with life-limiting conditions and the need to maintain anonymity, this method was one of the few feasible options. Second, certain subspecialties, such as cardiology and nephrology, were underrepresented due to low participation, limiting the diversity of perspectives. Inclusion of these subspecialties in future studies would provide a more comprehensive understanding of ACP perceptions. Qualitative studies exploring factors that facilitate or hinder ACP would also help generate more conclusive insights.

Conclusion

This study demonstrates that pediatricians' experiences and attitudes toward ACP vary by subspecialty, and that the absence of a support system constitutes a major barrier to initiating ACP discussions. These findings underscore the importance of providing both systemic support and structured education to pediatricians to enable effective goal-setting in the best interests of patients. Further research is warranted to evaluate how the recently enacted legislation and expansion of pediatric palliative care programs influence pediatricians' perceptions and clinical practice regarding ACP.

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