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Pediatric Deaths Attributed to Complex Chronic Conditions over 10 Years in Korea: Evidence for the Need to Provide Pediatric Palliative Care

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ABSTRACT

Background: Pediatric palliative care (PPC) is the active total care of children suffering from life-threatening illnesses. Palliative care includes symptom management, psychosocial support, and end-of-life care. Despite significant advances in disease diagnosis and treatment, resources for PPC of children with serious illnesses are limited in Korea. This study aimed to investigate the scale, time trends, disease composition, regional distribution, and unmet needs of children dying from complex chronic conditions (CCCs).

Methods: We examined available information on children who died of CCCs from 2005 to 2014 using the cause of death statistics in Korea.

Results: There were 36,808 cases of pediatric deaths in Korea during that 10-year period, one-third (12,515 cases, 34.0%) of which were due to CCCs. In 2014, there were 1,044 cases of pediatric deaths due to CCCs (9.8 deaths per 100,000 children) in Korea. The rate of pediatric deaths due to CCCs has declined over this 10-year period. Among CCCs, malignancy was the most common cause of death overall, as well as in children and adolescents, whereas neonatal disorders were the most common cause of death in infants. Although over 1,000 children die from chronic illnesses each year, there are no hospitals or institutes in Korea that meet the minimum standards for specialized PPC.

Conclusion: To improve the quality of life of children suffering from CCCs and to support their families who face enormous distress, children with CCCs should be able to access adequate palliative care services. Health authorities should consider supporting the establishment of PPC centers and increasing PPC accessibility in Korea.

Keywords: Pediatrics; Cause of Death; Complex Chronic Conditions; Pediatric Palliative Care; Children's Hospice

Disclosure

The authors have no potential conflicts of interest to disclose.

Author Contributions

Conceptualization: Kim MS, Lee JY. Data curation: Lim NG. Formal analysis: Lim NG, Kim HJ, Kim C. Funding acquisition: Lee JY. Investigation: Kim MS, Lim NG, Lee JY. Writing - original draft: Kim MS, Kim HJ, Kim C, Lee JY. Writing - review & editing: Kim MS, Lee JY.

INTRODUCTION

Pediatric deaths can be attributed to several causes, such as congenital or genetic defects, malignant neoplasm, injury, and acute diseases.¹ Furthermore, pediatric deaths in different age groups, such as infancy (below 1 year of age), childhood (1–9 years of age), and adolescence (10–19 years of age), can be attributed to different diseases and disorders.¹ As medical technology evolves, the trend of causes of pediatric deaths is shifting from acute illnesses or injuries to chronic conditions.^{2,3} There are several serious or non-curable fatal pediatric chronic conditions, such as advanced cancer, complex cardiac malformations, cystic fibrosis, and neurodegenerative diseases. These are classified as complex chronic conditions (CCCs), and are defined as “any medical condition that can be reasonably expected to last at least 12 months (unless death intervenes) and to involve either several different organ systems or 1 organ system severely enough to require specialty pediatric care, and probably some period of hospitalization in a tertiary care center.”³

Children dying because of CCCs need special supportive healthcare services, including aggressive pain control and effective symptom relief, sensitive emotional and spiritual care for grief management, and respite and bereavement services for the family. These services together are called pediatric palliative care (PPC).^{4,5} Since the establishment of the first PPC service in the United Kingdom in the 1980s, PPC has developed rapidly and has been introduced in developing countries, as well as developed countries, to improve the quality of life of children with serious illnesses.^{6–8} There are several obstacles faced (i.e., shortage of healthcare personnel and healthcare organizations providing palliative or hospice care, inadequate funding, and financial burden due to lack of insurance coverage) in establishing comprehensive healthcare services for children with CCCs.^{9–11} Healthcare authorities should have a complete understanding of the trends of pediatric deaths while considering the implementation of a new system and tackle these obstacles. However, to the best of our knowledge, the nation-wide population data of pediatric CCCs have never been examined in Korea.

The present study aimed to comprehensively examine the available information on pediatric deaths due to CCCs in Korea. The study examines the following pieces of information: number of pediatric deaths, major causes of pediatric deaths (disease composition of CCCs and non-CCCs), changes in the trend of causes of pediatric death over time, prevalence of certain types of CCCs, the locations where the majority of deaths occur, locations in which patients are living across the country, and whether healthcare institutions which take care of these patients are providing comprehensive palliative care.

METHODS**Data source**

We analyzed the Cause of Death Statistics during 2005–2014 in Korea. These data were obtained from the Korean Statistical Information Service of Statistics Korea (accessible at: <http://kosis.kr/eng/>). The cause of death statistics contains the following information: the date of death notification, address of the decedent, age of the decedent, gender of the decedent, time of death, place of death, marital status, level of education, cause of death, and nationality of decedent. The cause of death is reviewed and classified according to the Korean standard classification system (Korean Standard Classification of Diseases [KCD]-4,5,6). The underlying cause of death is determined by an automated coding system based on the recommendation of the World Health Organization.¹²

Operational definition of pediatric deaths and selecting CCCs

The term “Pediatric deaths” refers to the deaths of people below the age of 20 years. In this study, pediatric deaths were categorized into the following groups: the death of infants (below 1 year of age), children (between 1–9 years of age), and adolescents (10–19 years of age). To identify the population of pediatric patients who need PPC in Korea, we adopted and modified the “Pediatric complex chronic conditions classification system version 2” developed by Feudtner et al.¹³ According to this classification system, using International Statistical Classification of Diseases, 10th revision (ICD-10) codes, CCCs are divided into 10 disease categories that include neurologic and neuromuscular diseases, cardiovascular diseases, respiratory diseases, renal and urologic diseases, gastrointestinal diseases, hematologic or immunologic diseases, metabolic diseases, other congenital or genetic defects, malignancies, and premature and neonatal disorders (**Appendix 1**). We modified the classification made up of the ICD-10 codes to use the KCD codes.

Evaluating the level of special PPC in Korea

For children with CCCs, and particularly for children reaching the end-of-life point due to CCCs, special PPC is essential. Although there is no golden standard of PPC across the world, we defined the minimum standard as follows: “comprehensive palliative care for children should be provided as a 24/7 service and the PPC team should consist of multidisciplinary healthcare personnel, including at least 1 physician, 1 registered nurse, and 1 social worker, who have professional knowledge and skills in taking care of children with serious illnesses.” Using this evaluation standard, we examined whether there are hospitals or medical institutions providing adequate PPC in Korea.

Statistical analysis

Descriptive statistics of the study population are presented as number (%) for dichotomous variables. Multivariate logistic regression analysis was performed to investigate the factors that contribute to choosing home as the place of death. All analyses were performed using IBM SPSS Statistics (version 19; IBM Company, Chicago, IL, USA), and the level of significance was set at $P < 0.05$.

Ethics statement

The present study was exempted from approval from the Institutional Review Board (IRB No. 07-2017-8/052) because it deals with anonymous public data, the Cause of Death Statistics, provided by Statistics Korea. Therefore, we could not locate the subjects of the study, and there was no need for obtaining informed consent from the patients in the present study.

RESULTS

Total scale and trends in pediatric deaths from 2005 to 2014

The total cumulative number of pediatric deaths from 2005 to 2014 was 36,808, of which 12,515 (34.0%) were due to CCCs and 24,293 (66.0%) were caused by non-CCCs. Approximately two-thirds of the decedents (67.3%) died in hospitals. In case of CCCs, 85.5% of decedents died in hospitals (**Table 1**). **Fig. 1** shows the distribution of the number of cases of pediatric deaths over the examined 10-year period by age (infancy, childhood, and adolescence) and cause of death (CCCs, non-CCCs, sudden infant death syndrome and injuries). In 2014, the total number of pediatric deaths was 2,914 and CCCs accounted for 1,044 (35.8%) of those deaths. Among the deaths due to CCCs, 641 occurred in infants, 113

in children, and 127 in adolescents. The prevalence of infant, child, and adolescent deaths has declined over 10 years, regardless of the cause of death or the age group. Total pediatric deaths attributed to CCCs per 100,000 children have decreased from 12.2 in 2005 to 9.8 in 2014, but the prevalence of these deaths in infants remains unchanged (Fig. 2).

Table 1. Total scale of pediatric deaths from 2005 to 2014 according to demographic factors

Characteristics	CCCs	Non-CCCs	Total pediatric deaths
Total No. (%) of subjects	12,515 (34.0)	24,293 (66.0)	36,808 (100.0)
Sex			
Male	56.6	61.2	59.6
Female	43.4	38.8	40.4
Age, yr			
Infant (< 1)	45.2	39.3	41.3
Children (1-9)	24.5	19.7	21.3
Adolescent (10-19)	30.2	41.0	37.4
Region			
Metropolitan	44.6	40.4	41.8
Non-metropolitan	55.4	59.6	58.2
Location of death			
Hospital	85.5	57.9	67.3
Home	8.4	13.6	11.9
Other ^a	6.0	28.2	20.6
Unknown	0.1	0.3	0.2

Values are presented as number of patients (%) or percentage.

CCC = complex chronic condition.

^aWelfare facilities, on the way to hospital, road, etc.

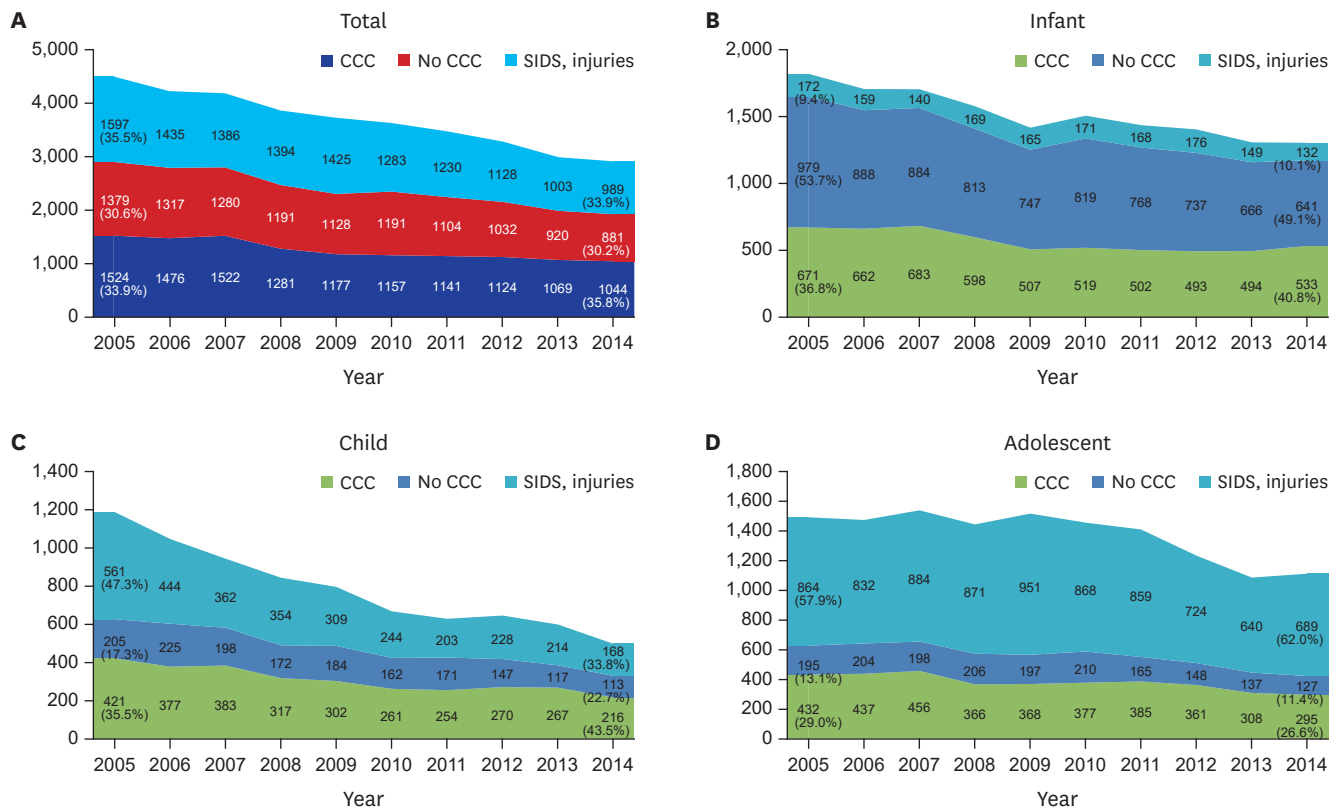


Fig. 1. Trends in pediatric deaths from 2005 to 2014 in Korea by age categories. (A) Total, (B) infant, (C) child, and (D) adolescent (crude number). CCC = complex chronic condition, SIDS = sudden infant death syndrome.

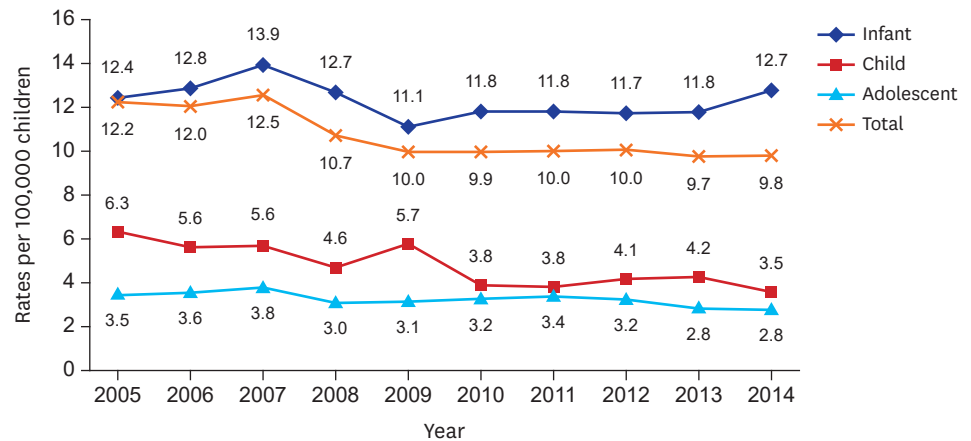


Fig. 2. Trends of age-specific pediatric CCC death rates per 100,000 children over 10 years in Korea. CCC = complex chronic condition.

Major diseases contributing to pediatric deaths caused by CCCs in different age groups

There were 12,515 pediatric deaths due to CCCs from 2005 to 2014. Overall, malignancy (29.0%) was the leading cause of death, followed by cardiovascular disease (18.9%), and neurologic and neuromuscular diseases (17.9%). However, the proportion of the causes of death differed among different age groups. In infants, neonatal disorders were the most common cause of death (35.6%), followed by cardiovascular diseases (29.8%), and other congenital or genetic defects. In children, malignancies were the most common (43.0%) cause of death, followed by neurologic and neuromuscular diseases (28.9%), and cardiovascular diseases (11.7%). In adolescents, malignancies were the most common (56.2%) cause of death, followed by neurologic and neuromuscular diseases (25.9%), and cardiovascular diseases (8.6%) (Table 2).

Factors affecting the choice of place of death among children with CCCs

We examined the locations where the death of the children occurred and the factors affecting the choice of place of death for children with CCCs (Table 3). The frequency of death occurring at home was 1.67 and 2.0 times greater in children and adolescents, respectively, than in infants ($P < 0.001$). In particular, children living in non-metropolitan areas were

Table 2. Proportion of CCC-attributed pediatric deaths by disease category and age group, 2005–2014

Category	Infant (< 1 yr)	Children (1–9 yr)	Adolescent (10–19 yr)	All ages (0–19 yr)
Total No. of subjects	5,662	3,068	3,785	12,515
Neurologic and neuromuscular	380 (6.7)	890 (28.9)	982 (25.9)	2,252 (17.9)
Cardiovascular	1,690 (29.8)	361 (11.7)	324 (8.6)	2,375 (18.9)
Respiratory	181 (3.2)	31 (0.9)	10 (0.3)	222 (1.8)
Renal and urologic	76 (1.3)	15 (0.4)	25 (0.7)	116 (0.9)
Gastrointestinal	230 (4.0)	71 (2.2)	29 (0.8)	330 (2.5)
Hematologic or immunologic	51 (0.9)	134 (4.3)	174 (4.5)	359 (2.8)
Metabolic	85 (1.5)	82 (2.6)	67 (1.7)	234 (1.9)
Other congenital or genetic defect	771 (13.6)	141 (4.5)	60 (1.5)	972 (7.8)
Malignancy	186 (3.3)	1,325 (43.0)	2,126 (56.2)	3,637 (29.0)
Neonatal	2,070 (35.6)	47 (1.5)	1 (0)	2,070 (16.5)

Values are presented as number of patients (%).
CCC = complex chronic condition.

Table 3. Factors associated with home as a place of pediatric death with CCCs

Total	aOR	95% CI	P value
Sex			
Male	Reference	-	-
Female	1.06	0.93–1.21	0.400
Age, yr			
Birth to < 1	Reference	-	-
1–9	1.67	1.37–2.03	< 0.001
10–19	2.00	1.63–2.45	< 0.001
Region			
Metropolitan	Reference	-	-
Non-metropolitan	1.21	1.06–1.38	0.005
CCC subtype			
Neurologic and neuromuscular	6.93	5.68–8.46	< 0.001
Cardiovascular	2.45	1.89–3.18	< 0.001
Respiratory	3.73	2.22–6.26	< 0.001
Renal and urologic	4.83	2.67–8.75	< 0.001
Gastrointestinal	3.79	2.48–5.78	< 0.001
Hematologic or immunologic	0.59	0.29–1.22	0.154
Metabolic	3.96	2.55–6.15	< 0.001
Other congenital or genetic defect	4.19	3.10–5.66	< 0.001
Malignancy	Reference	-	-
Neonatal	2.61	1.92–3.54	< 0.001

CCC = complex chronic condition, aOR = adjusted odds ratio, CI = confidence interval.

1.21 times more likely to die at home than those in metropolitan areas ($P = 0.005$). Children with conditions other than hematologic and immunologic diseases were more likely to die at home ($P < 0.001$) than children with malignancy. Children with hematologic and immunologic disease were less likely to die at home, but this result was not significant ($P = 0.154$).

Regional distribution of pediatric deaths due to CCCs and special PPC provisions

In 2014, there were 1,044 pediatric deaths caused by CCCs. **Table 4** and **Fig. 3** show the regional or geographical distribution of pediatric deaths due to CCCs. The distribution of residential areas in which children died from CCCs was similar to the general population of metropolitan areas and provinces. Based on government reports and media, there was no medical institution or agency that provides PPC services.¹⁴ Among 43 tertiary teaching hospitals in Korea, none provided services meeting the minimum standard for special PPC. Two hospitals, both located in Seoul, had in-hospital services called PPC, but they neither had trained healthcare professionals working in a multidisciplinary team, nor provided 24/7 service.

DISCUSSION

Children with CCCs need special palliative care services because of the high likelihood of continued suffering owing to physical and psychological symptoms, frequent re-admission, sudden intensive care involvement, and several subspecialty interventions.¹⁵

Over the past few decades, significant advances in pediatric healthcare, including disease prevention, diagnosis, treatment, and rehabilitation, have resulted in a reduction in childhood morbidity and mortality rates.¹ Even though technological advancement has increased the lifespan of patients suffering from diseases previously considered lethal and improved the quality of long-term care for the pediatric population, the requirement of palliative care services has not yet been addressed in Korea.^{1,16-23} To the best of our

Table 4. Regional distribution of pediatric deaths attributed to CCCs from 2005 to 2014

Region	2005 (n = 1,524)	2006 (n = 1,476)	2007 (n = 1,522)	2008 (n = 1,281)	2009 (n = 1,177)	2010 (n = 1,157)	2011 (n = 1,141)	2012 (n = 1,124)	2013 (n = 1,069)	2014 (n = 1,044)
Seoul	226 (14.8)	280 (19.0)	253 (16.6)	259 (20.2)	235 (20.0)	218 (18.8)	214 (18.8)	190 (16.9)	192 (18.0)	200 (19.2)
Busan	105 (6.9)	106 (7.2)	109 (7.2)	91 (7.1)	67 (5.7)	70 (6.1)	76 (6.7)	60 (5.3)	72 (6.7)	69 (6.6)
Daegu	85 (5.6)	83 (5.6)	95 (6.2)	66 (5.2)	59 (5.0)	61 (5.3)	70 (6.1)	59 (5.2)	57 (5.3)	62 (5.9)
Incheon	84 (5.5)	74 (5.0)	93 (6.1)	61 (4.8)	65 (5.5)	61 (5.3)	62 (5.4)	76 (6.8)	55 (5.1)	58 (5.6)
Gwangju	37 (2.4)	31 (2.1)	44 (2.9)	49 (3.8)	38 (3.2)	33 (2.9)	38 (3.3)	39 (3.5)	23 (2.2)	23 (2.2)
Daejeon	60 (3.9)	42 (2.8)	57 (3.7)	38 (3.0)	46 (3.9)	41 (3.5)	34 (3.0)	40 (3.6)	38 (3.6)	38 (3.6)
Ulsan	45 (3.0)	38 (2.6)	38 (2.5)	32 (2.5)	29 (2.5)	26 (2.2)	25 (2.2)	34 (3.0)	22 (2.1)	22 (2.1)
Sejong	-	-	-	-	-	-	-	0 (0)	3 (0.3)	2 (0.2)
Gyeonggi	346 (22.7)	338 (22.9)	359 (23.6)	304 (23.7)	267 (22.7)	285 (24.6)	272 (23.8)	263 (23.4)	281 (26.3)	224 (21.5)
Gangwon	50 (3.3)	37 (2.5)	49 (3.2)	24 (1.9)	39 (3.3)	46 (4.0)	32 (2.8)	43 (3.8)	30 (2.8)	38 (3.6)
Chungbuk	51 (3.3)	55 (3.7)	52 (3.4)	31 (2.4)	51 (4.3)	31 (2.7)	35 (3.1)	34 (3.0)	26 (2.4)	42 (4.0)
Chungnam	64 (4.2)	60 (4.1)	57 (3.7)	55 (4.3)	44 (3.7)	52 (4.5)	44 (3.9)	53 (4.7)	53 (5.0)	44 (4.2)
Jeonbuk	65 (4.3)	49 (3.3)	62 (4.1)	57 (4.4)	54 (4.6)	38 (3.3)	53 (4.6)	59 (5.2)	49 (4.6)	36 (3.4)
Jeonnam	54 (3.5)	64 (4.3)	51 (3.4)	29 (2.3)	40 (3.4)	45 (3.9)	50 (4.4)	45 (4.0)	47 (4.4)	38 (3.6)
Gyeongbuk	108 (7.1)	76 (5.1)	87 (5.7)	80 (6.2)	57 (4.8)	59 (5.1)	61 (5.3)	51 (4.5)	49 (4.6)	58 (5.6)
Gyeongnam	125 (8.2)	116 (7.9)	87 (5.7)	87 (6.8)	71 (6.0)	71 (6.1)	64 (5.6)	65 (5.8)	53 (5.0)	73 (7.0)
Jeju	17 (1.1)	24 (1.6)	28 (1.8)	14 (1.1)	11 (0.9)	19 (1.6)	9 (0.8)	12 (1.1)	17 (1.6)	14 (1.3)
Foreign country	2 (0.1)	3 (0.3)	1 (0.1)	4 (0.4)	4 (0.4)	1 (0.1)	2 (0.2)	1 (0.1)	2 (0.2)	3 (0.3)

Values are presented as number of patients (%).
CCC = complex chronic condition.

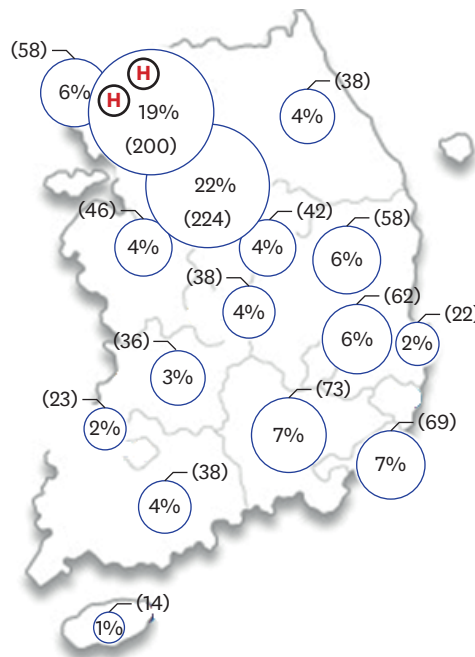


Fig. 3. Regional distribution (proportion and number) of pediatric deaths in 2014 and PPC service in Korea. ‘H’ designates hospitals which runs in-hospital PPC services.
PPC = pediatric palliative care.

knowledge, the present study is the first study on childhood mortality due to serious illnesses in Korea, and it revealed that there were 36,808 cases of pediatric deaths during a 10-year period, one-third (12,515 cases, 34.0%) of which were observed in patients with CCCs who would have benefited from PPC. In 2014, 1,044 deaths in children aged 0–19 years were observed, representing a death rate of 9.8 per 100,000. This is a significant decrease from the rate of 12.2 deaths per 100,000 individuals observed in 2005. The rate of pediatric death

due to CCCs has declined in children and adolescents, whereas the infant mortality rate remains unchanged. A similar declining trend was previously observed in the United States. Feudtner et al.³ reported that the annual rate of death due to CCCs declined from 1979 to 1997 in almost all age groups, but the rate of medical deaths due to CCCs increased in infants. Neonatal and cardiovascular diseases were the main cause of death in infants, and cancer and neurologic diseases were the main cause of death in children and adolescents. Palliative care is often considered necessary only for cancer patients, but a large proportion of pediatric deaths can be attributed to non-cancer diseases. A study analyzed the data of patients who received hospital-based PPC in the United States and reported that the leading causes of pediatric deaths were genetic/congenital conditions (40.8%), neuromuscular conditions (39.2%), and cancer (19.8%).²⁴ It is imperative to identify the distribution of pediatric deaths by age and disease because the illness trajectory and the type of palliative care services required vary according to these factors.²⁵ Diversity of the age of the patients and type of disease have made it difficult to create a comprehensive plan for implementing PPC services nation-wide. The present study attempts to provide more refined information on the fundamental characteristics of the population potentially in need of PPC.

The chosen place of death of these children depended on the disease category, age of the patient, and whether they lived in metropolitan or non-metropolitan areas. Considering that there are currently no home-based end-of-life care services for children in Korea, we interpret this finding cautiously because we could not find the healthcare services used near the end-of-life point. It is possible that death occurred suddenly, or that patients chose to breathe their last at home. PPC has developed with home care as one of the core services because children and families tend to prefer to be at home during end-of-life care.²⁶ As home palliative care gradually evolves, the frequency of pediatric deaths due to CCCs occurring at home is increasing in the United States.²⁷ Further research is needed to investigate the other factors that affect how patients suffering from CCCs and their families choose the place of death. Moreover, resources to conduct proper services in accordance with Korean culture need to be made available.

Why should PPC be provided? Wolfe et al.²⁸ interviewed bereaved parents of cancer patients and showed that because of PPC, fewer children suffered from pain and dyspnea, and parents were more prepared during the last month of the child's life. Another report showed that the severity of the physical and psychological symptoms of the child was associated with higher levels of long-term parental grief, which implies that the effect of PPC extends after end-of-life.²⁹ Although palliative care for children is applicable throughout the illness and may be congruent with maximal treatment for sustaining life, the role of palliative care for children is becomes more apparent at the end-of-life point when patients and their families experience extensive suffering. However, currently, no hospital or medical institution in Korea provides PPC by an adequate multidisciplinary team, and only 2 tertiary hospitals have attempted to set up special palliative care for children. These hospitals might plan to expand their program and equip themselves with better resources, but they can only provide specialized palliative services for children dying with CCCs living in Seoul, Incheon, and the Gyeonggi province. Therefore, more than half of the children dying because of CCCs cannot access palliative care services at a location within two hours of their residential location. To meet these regional needs, the health authorities must consider supporting the establishment of specialized palliative pediatric care centers in regional tertiary teaching hospitals, where most children with serious illnesses are treated. In addition, it is necessary to conduct research in order to develop an appropriate system of PPC for Korean pediatric patients and their families, and to educate medical personnel based on their needs.

The importance of providing quality care for patients at the end of life has recently been highlighted in Korea by legislation such as “the law on the hospice and palliative care and the determination of life-sustaining treatment for terminally ill patients,” which has come into force in 2017.³⁰ It is anticipated that the implementation of this law would improve the development of palliative care services for a wide range of patients with life-threatening diseases and not just terminally-ill adult cancer patients. Despite a burgeoning concern for preserving human dignity at the end of life, far less attention has been focused on the trends of childhood mortality and the implied need for PPC implementation. Although longitudinal studies in cancer patients³¹ informed us of the trends of cancer specific incidence and deaths, no study, to the best of our knowledge, has analyzed comprehensive data on the pediatric mortality of life-threatening diseases in Korea. For these reasons, we examined all deaths among children aged 0 days to 19 years from 2005 to 2014 in Korea. To provide detailed information for the planning of PPC, we used the concept of CCCs for the analysis of population attributes. CCC classification was primarily developed by Feudtner and colleagues in 2000.^{3,4,13} Classifying the causes of death due to CCC can help aggregate diverse pediatric health conditions into several distinct groups to provide more refined information on the evolving patterns and the changing needs of the pediatric patient population.

The present study has some limitations. First, we used the cause of death data from Statistics Korea. However, the variables of socioeconomic positions (SEPs), such as family income and level of education of parents, are not included in these databases, and therefore, we could not investigate the association between pediatric deaths and SEPs. Second, this was a cross-sectional study of annual pediatric deaths which would help us in understanding the need for end-of-life and bereavement care for children with CCCs and their families. The benefits of early implementation of PPC for children with CCCs have been emphasized in the present study, and it is important to understand the unmet needs of pediatric CCC patients living in Korea. Future research should seek to identify the prevalence, incidence, and healthcare utilization, as well as the PPC service needs, of patients with CCCs and their families.

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Appendix 1. Categories of CCCs and the corresponding ICD-10 (KCD-5/KCD-6) diagnosis codes

Categories	Subcategories	ICD-10 (KCD-5/KCD-6)
Neurologic and neuromuscular	Brain and spinal cord malformations	Q00–Q07, G90.1
	Mental retardation	F71–F73
	CNS degeneration and diseases	E75.0, E75.1, E75.2, E75.4, F84.2, G11.1–G11.4, G11.8, G11.9, G12.0–G12.2, G12.8, G12.9, G31.00, G31.08, G31.8, G31.80, G31.81, G31.82, G31.88, G32.8, G93.8, G93.9, G94, G91.1, G31.9, G25.3, G95.1, G95.8, G90.9, Q85.1
	Infantile cerebral palsy	G80
	Epilepsy	G40.1, G40.2, G40.3, G40.4, G40.8, G40.9
	Other disorders of CNS	G37.1, G37.2, G37.8, G81, G82, G83, G93.1, G93.5, R40.2
	Occlusion of cerebral arteries	I63.3, I63.5
	Muscular dystrophies and myopathies	G71, G72
	Movement diseases	G10, G20, G21.0, G21.1, G21.8, G23.0–G23.2, G23.8, G24.0, G24.8, G25.3–G25.5, G25.8, G25.9, G80.3
	Devices	T85.0, T85.1, Z98.2
	Transplantation	N/A
	Cardiovascular	Heart and great vessel malformations
Endocardium diseases		I34.0, I34.8, I36.0, I36.8, I37.0, I37.8
Cardiomyopathies		I42, I43, I51.5
Conduction disorder		I44, I45, I47, I48, I49.0
Dysrhythmias		I49.1–I49.5, I49.8, I49.9, R00.1
Other		I27.0, I27.1, I27.2, I27.8, I27.9, I50.9, I51.7, I51.8, I63.1, I63.2, Z95.1
Devices		T82.5, T82.1, T82.0, T82.2, T82.6, T82.7, Z45.0, Z95.0, Z95.2, Z95.3, Z95.8, Z95.9
Transplantation		T86.2, Z94.1
Respiratory	Respiratory malformations	Q30–Q34, P280
	Chronic respiratory diseases	G47.3, I27.8, I43, J84.1, J96.1, Z90.2
	Cystic fibrosis	E84
	Other	
	Devices	J95.0, J95.8, Z43.0, Z93.0, Z99.0, Z99.1
	Transplantation	Z94.2
Renal and urologic	Congenital anomalies	Q60–Q64
	Chronic renal failure	N18
	Other	Z90.5, Z90.6
	Chronic bladder diseases	G83.4, N31.2, N31.9
	Devices	Z93.5, Z93.6, Z99.2, Z43.5, Z43.6, Z46.6
	Transplantation	T86.1, Z94.0
Gastrointestinal	Congenital anomalies	Q39.0–Q39.4, Q41–Q45
	Chronic liver disease and cirrhosis	K73, K74, K75.4, K760–K763, K765, K768
	Inflammatory bowel diseases	K50, K51
	Other	I82.0, K55.1, K56.2, K59.3, Z98.0, Z90.3, Z90.4
	Devices	K94.20, K94.22, K94.23, K94.29, Z93.1–Z93.4, Z43.1–Z43.4, Z46.5
	Transplantation	T86.4, Z94.4
Hematologic or immunologic	Hereditary anemias	D55–D58
	Aplastic anemias	D60–D61, D71
	Hereditary immunodeficiency	D80–D89, D72.0, M30.3, M35.9
	Coagulation/hemorrhagic	D66, D68.2, D69.4
	Leukopenia	D70
	Hemophagocytic syndromes	D76.1–D76.3
	Sarcoidosis	D86
	Acquired immunodeficiency	B20–B24
	Polyarteritis nodosa and related conditions	M30.0, M31.0, M31.1, M31.3, M31.4, M31.6
	Diffuse diseases of connective tissue	M32.1, M33.9, M34.0, M34.1, M34.9
	Other	
	Devices	N/A
	Transplantation	

(continued to the next page)

Appendix 1. (Continued) Categories of CCCs and the corresponding ICD-10 (KCD-5/KCD-6) diagnosis codes

Categories	Subcategories	ICD-10 (KCD-5/KCD-6)
Metabolic	Amino acid metabolism	E70.0, E70.2, E70.3, E70.8, E70.9, E71.0–E71.5, E72.0–E72.4, E72.8, E72.9
	Carbohydrate metabolism	E74.0–E74.4, E74.8, E74.9
	Lipid metabolism	E75, E77.0, E77.1, E78.0–E78.4, E78.5–E78.9, E88.1, E88.8
	Storage disorder	E76.0–E76.3, E85
	Other metabolic disorders	E79.1, E79.8, E80.4–E80.7, E83.0, E83.1, E83.3, E83.4, D84.1, E88, H49.8
	Endocrine disorders	E00.9, E23.0, E23.2, E22.2, E23.3, E23.7, E24.0, E24.2, E24.3, E24.8, E24.9, E26.8, E25 (E25.0, E25.8, E25.9)
	Devices	Z46.81, Z96.41
Other congenital or genetic defect	Transplantation	N/A
	Chromosomal anomalies	Q90–Q99
	Bone and joint anomalies	E34.3, M41.0, M41.2, M41.30, M41.8, M41.9, M43.30, M96.5, Q72.2, Q75.0, Q75.2, Q75.9, Q76.0–Q76.2, Q76.4–Q76.7, Q77, Q78
	Diaphragm and abdominal wall	K44.9, Q79.0–Q79.5, Q79.9
Malignancy	Other congenital anomalies	Q81, Q87.1–Q87.4, Q87.8, Q89.7, Q89.9, Q99.2
	Neoplasms	C00–C96, D00–D09, D37–D48, Q85.0
	Devices	N/A
	Transplantation	T86.0, Z94.8
Premature and neonatal	Fetal malnutrition	P05 (P05.0, P05.1, P05.2, P05.9)
	Extreme immaturity	P07.0, P07.2
	Cerebral hemorrhage at birth	P10 (P10.0, P10.1, P10.4), P52.4, P52.8
	Spinal cord injury at birth	P11.5
	Birth asphyxia	P21.0, P21.9
	Respiratory diseases	P25 (P25.0–P25.3, P25.8), P27 (P27.0, P27.1, P27.8)
	Hypoxic-ischemic encephalopathy	P91.6
Miscellaneous, not elsewhere classified	Other	P35.0, P35.1, P25.2, P56.0, P57 (P57.0, P57.8), P61.3, P61.4, P77, P83.2, P91.2
	Devices	T84.0, T84.1, T84.4, T84.5, T84.6, T84.7, T86.8, T86.9, T87.0, T87.1, T87.2, Y83.1, Y83.3, Z99.8
	Transplantation	T86.8, T86.9

CCC = complex chronic condition, ICD-10 = International Classification of Diseases, 10th revision, KCD = Korean Standard Classification of Diseases, CNS = central nervous system, N/A = not applicable.