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Patterns of Medical Utilization in Children, Adolescents, and Young Adults With Life-Limiting Conditions in Korea: A Cohort Study Based on National Health Insurance Data

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ABSTRACT

Background: Children, adolescents, and young adults (CAYAs) with severe illnesses require intensive treatment, often relying on medical devices and advanced medical services. Modern medical technology has improved the lifespans of these patients. In addition, CAYAs represent a vulnerable group, resulting in a significant caregiving burden on the entire family. This study examined patterns of medical utilization following diagnosis of a life-limiting condition (LLC).

Methods: We establish a cohort of 176,236 CAYAs who were first diagnosed with an LLC using National Health Insurance data between 2011 and 2013. Patients diagnosed with an LLC within the 3 years preceding this period and those who had died were excluded, and only those receiving care at a general medical hospital were included. In total, 25,410,411 claims for medical expenses, outpatient visits, and lengths of stay for medical utilization over the approximately 10 years up to 2020 were investigated (2.3% inpatients, 97.7% outpatients).

Results: The average annual medical utilization per LLC patient among CAYAs following initial diagnosis included medical expenses of $1,163, 16.8 outpatient visits, and 18.7 days of admission. Among inpatients, cancer patients averaged $5,340 for total medical expenses and 21.0 days of admission, while non-cancer patients averaged $3,013 and 18.1 days, respectively. The overall average medical expenses during the first year following diagnosis of an LLC were $3,012, whereas for cancer patients they were $5,962. In addition, there was a sharp increase in total medical expenses as death approached, particularly in the last month of life, with a considerable proportion attributable to critical-care treatments.

Conclusion: Our investigation into medical utilization by CAYAs with an LLC in Korea provides a foundation for healthcare policy development. Timely treatment at each stage and tailored policies that take into account the heterogeneity among diseases are of paramount importance.

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Keywords: Children, Adolescents, and Young Adults; Life-Limiting Condition; Medical Utilization; Cohort

INTRODUCTION

Life-limiting conditions (LLCs) are severe illnesses that shorten life expectancy due to a specific disease, disability, or condition. They typically involve progressive diseases or disabilities that are difficult to treat. Despite survival rates having been improved by advances in medical technology, LLC patients tend to have a poor quality of life, often accompanied by significant physical limitations or functional loss. This necessitates comprehensive management across various domains, including medical care, nursing, emotional support, and education. Moreover, long-term dependence on medical devices and intensive treatments is common.

Due to their developmental stage, there is a particular need to focus on children, adolescents, and young adults (CAYAs), who may have longer to live and greater emotional and physical vulnerability compared to adults. In addition, the burden of caregiving may affect their entire families.[1-3] Proactive and integrated interventions are essential for CAYAs with LLCs, commencing early in the disease process; only a small fraction of patients transition to end-of-life care. It is crucial to provide timely and tailored treatment at each stage.[4,5]

Globally, the number of CAYAs with LLCs is increasing. In the UK, LLC prevalence per 100,000 individuals increased from 26.7 in 2001–2002 to 66.4 in 2017–2018, with projections indicating a continued increase.[6] Similarly, in Queensland, Australia, LLC prevalence per 10,000 individuals increased from 35.2 in 2011 to 43.2 in 2016.[1] A study from Korea reported a prevalence per 100,000 individuals of 955.1 in 2015.[3]

With increasing prevalence, the burden posed by LLCs will also increase, leading to more frequent hospital admissions and greater utilization of hospital resources. Patients require various medical treatments to manage symptoms and comorbidities, impacting health-insurance finances due to prolonged disease duration. In the United States, although only 15.6% of children require special healthcare, they account for up to 52.5% of hospitalization days.[7] Despite high LLC prevalence among CAYAs in Korea, few studies have analyzed medical care utilization, and only one cross-sectional study has investigated prevalence and annual medical costs. Consequently, longitudinal studies are needed to evaluate medical care utilization by pediatric and adolescent patients following diagnosis of an LLC.

Therefore, we used health insurance claims data to construct a cohort of CAYAs with LLCs over a period of approximately 10 years. We explored their medical utilization patterns, focusing on expenditures and critical-care proportions, in the period following initial diagnosis and that preceding death. This study is expected to inform the development of policies and financial models for CAYAs with severe diseases.

METHODS

Data source and study population

We used data from the National Health Information Database provided by the National Health Insurance Service (NHIS) to establish a cohort. The cohort included 316,362 LLC patients aged ≤ 24 years, after excluding individuals who received from dental, oriental medicine, or pharmacy care between January 1, 2011, and December 31, 2013 (**Fig. 1**). Patients with a medical history that involved an LLC during the washout period from January 1, 2008, to December 31, 2010, were also excluded. This period was decided by considering the post-treatment and monitoring requirements of patients with pre-existing severe illnesses,[8] and was determined through consensus among experts. In addition, we excluded patients diagnosed solely with the code H111, those who did not use a medical or healthcare institution, and those not linked to the eligibility database for each year. Consequently, our cohort included 176,236 patients initially diagnosed with an LLC. Follow-up was conducted until December 31, 2020. For example, a patient diagnosed with an LLC in 2013 was observed until 2020. We analyzed medical utilization patterns over approximately 10 years until 2020, encompassing a total of 25,410,411 claims (admissions: 2.3%, outpatient visits: 97.7%).

Definition of LLCs

LLCs were defined based on an LLC directory from England,[9] which was adapted to suit the local context in previous studies. The LLCs were categorized based on complex chronic condition categories established by experts (**Supplementary Table 1**).[3] Considering the domestic diagnostic coding, the code H111 (conjunctival degenerations and deposits) was deemed inappropriate and excluded because it was used for complications, rather than as the main diagnostic code for severe disease. Furthermore, LLCs were identified using both principal and first to fifth additional diagnoses recorded in the claims data. All diagnostic codes

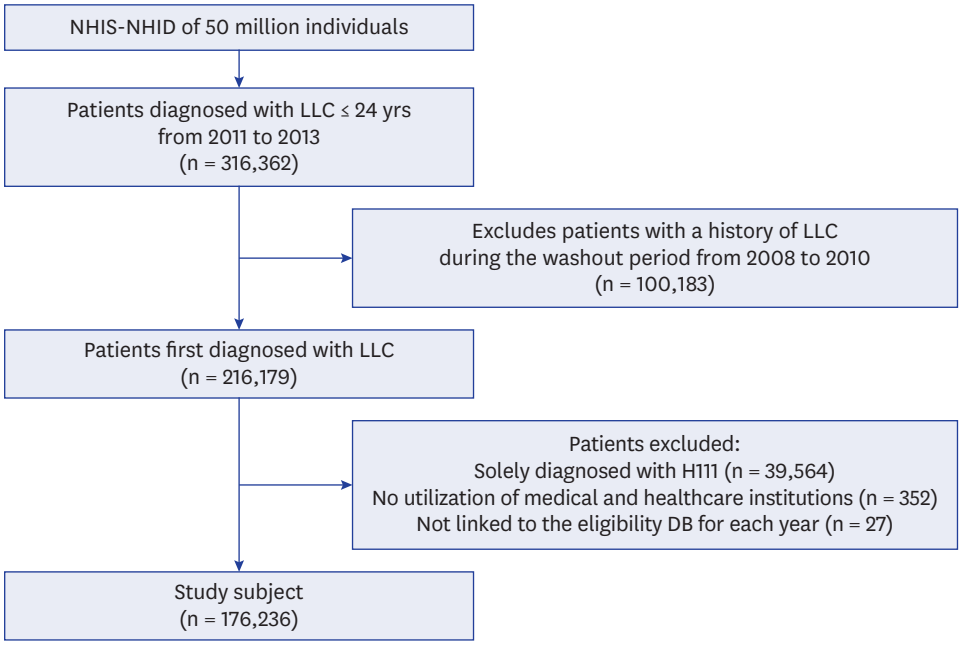

Fig. 1. Flowchart for participant selection.
NHIS = National Health Insurance Service, NHID = National Health Information Database, LLC = life-limiting condition.

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were assigned using the 6th edition of the Korean Standard Classification of Diseases (KCD-6), adapted from the 10th revision of the International Classification of Diseases (ICD-10).

Variables and outcomes

To explore medical utilization patterns, we used the following variables: medical expenses, outpatient visits, and lengths of stay. The medical facility at the time of first diagnosis was assigned to one of five categories—tertiary, general, hospital, healthcare center, clinic, and other—based on the classification of the claim. Inpatient or outpatient status was based on the initial LLC diagnosis classification of the health insurance claim. For inpatient episodes, consecutive claims for the same patient and medical facility occurring within a single day were consolidated into a single episode. The average annual number of outpatient visits and length of stay per patient were calculated by dividing the sum of the outpatient visits and the durations of hospitalization by the number of years, respectively. Medical expenses were based on total treatment costs and out-of-pocket payment variables that were reviewed and provided by the health insurance claims data.

Income levels were categorized into four groups based on contribution distributions: medical aid (0th decile), low (1st–5th decile, bottom 25%), middle (6th–15th decile), and high (16th–20th decile, top 25%). For individuals with disabilities, grades 1–3 were classified as severe, while grades 4–6 were classified as mild, according to the legal classification in Korea. Residence was categorized into metropolitan areas, including special or metropolitan cities, and non-metropolitan areas. Metropolitan areas included Seoul, Busan, Daegu, Incheon, Gwangju, Daejeon, Ulsan, and Sejong, while non-metropolitan areas included Gyeonggi, Gangwon, Chungcheong, Jeolla, Gyeongsang, and Jeju. Critical care was defined based on a literature review and expert discussions,[10,11] using Korean National Health Insurance codes, including cardiopulmonary resuscitation (CPR; M1583-M1587), mechanical ventilation (MV; M5850-M5858, M5860), extracorporeal membrane oxygenation (ECMO; O1901-O1906), hemodialysis (intermittent hemodialysis [IHD]; O7020, and continuous renal replacement therapy [CRRT]; O7031-O7034), and transfusion (X2011-X2012, X2021-X2022, X2031-X2032, X2041-X2042, X2051-X2052, X2061-X2062, X2071-X2072, X2081-X2082, X2091-X2092, X2101-X2102, X2111-X2112, X2121-X2122, X2131-X2132, X2141-X2142).

All medical expenses were calculated on an annual basis. Even if an individual utilized medical facilities over multiple years, the summary was based on 1-year units. Medical expenses were converted into US dollars using the exchange rate as of February 1, 2024, i.e., 1,322 KRW to 1 USD.

Statistical analysis

Categorical variables were analyzed using χ^2 tests and are presented as numbers and percentages. Continuous variables are expressed as the mean with standard deviation (SD) and the median with interquartile range (IQR). All statistical analyses were performed using R Statistical Software (v. 3.6.3; The R Foundation for Statistical Computing, Vienna, Austria) and SAS v. 9.4 (SAS Institute, Cary, NC, USA). The significance level was set at $\alpha = 0.05$ using two-sided tests.

Ethics statement

This study was approved by the Institutional Review Board (IRB) of the National Cancer Center (IRB No. NCC2021-0118). No informed consent was required from patients due to the nature of public data from NHIS.

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RESULTS

Table 1 presents the demographic characteristics of the 176,236 patients initially diagnosed with an LLC between 2011 and 2013. Overall, males accounted for a slightly larger proportion compared to females. However, cancer patients included more females compared to non-cancer patients ($P < 0.001$). Subjects aged 20–24 years comprised the largest group, accounting for 26.3% of the patients, while those aged 5–9 years made up the smallest group at 9.3%. Cancer patients tended to be older than those without cancer. The majority of patients were in the middle- and high-income groups, collectively accounting for 77.2% of the patients. Most of the patients were not disabled, although severe disability was more common than mild disability, and 26.4% received inpatient care, reflecting LLC severity. Approximately 5% of patients received intensive care at the time of their first claim following diagnosis. Surgical interventions were more common among cancer patients, at 13.0%, a proportion more than twice that among non-cancer patients. Approximately 65% of the patients initially received care at a tertiary or general hospital. The most common LLCs were malignancies (17.8%), neurological and neuromuscular conditions (17.5%), and respiratory diseases (15.5%), in descending order of prevalence (**Supplementary Table 2**).

For the cohort period spanning approximately 10 years up to 2020, following the initial diagnosis of an LLC between 2011 and 2013, the mean duration of medical utilization was 96.7 months; this was similar across disease groups due to high survival rates (**Supplementary Table 3**). The majority of patients were associated with only one disease category after their initial claim following diagnosis (**Supplementary Table 4**). The mean ± SD annual medical expenditure per patient was $1,163 ± 6,564 and the median (IQR) was $242 (96–615), implying large variation in medical expenses depending on the personal or disease-related characteristics of CAYAs with an LLC. The total treatment expenditure of admitted patients was approximately three times higher (**Table 2**). In particular, admitted cancer patients incurred a mean total treatment expense of $5,340 ± 14,363, which was 1.77 times higher than that of non-cancer patients. The average medical expenses and the proportion of medical expenses for critical care among admitted patients were higher among those with cancer.

The annual distribution of medical utilization was as follows: length of stay per admitted patient was a mean ± SD of 18.7 ± 63.0 days, with a median (IQR) of 6 (3–12) days; the numbers of outpatient visits per patient were 16.8 ± 21.5 and 10 (5–21), respectively (**Table 3**).

The total medical expenses following the initial diagnosis of an LLC were concentrated within the first year. For cancer patients, they peaked within 1 year and gradually declined over 5 years (**Fig. 2**). The mean medical expenses within the first year after diagnosis were approximately 2.5-fold higher for cancer patients at $5,962, compared to $2,374 for non-cancer patients. As regards the proportion of total medical expenses attributed to critical care, cancer patients exhibited a sharp decline, from 44.5% within 1 year to 13.3% within 6 years, while non-cancer patients had elevated levels only within the first year, stabilizing thereafter.

Among all subjects, 4,409 CAYA individuals (2.5%) died, and the proportion of expenses incurred by deceased individuals accounted for 12.8% of the total medical expenses over the 10-year period. Among deceased LLC patients, 65.3% of total medical expenses were incurred during the last year of life. Monthly medical expenses before death tended to increase as the date of death approached (**Fig. 3**). Notably, medical expenses during the last month of life

Table 1. Demographic and medical utilization characteristics of children, adolescents, and young adults with LLCs at first diagnosis

Characteristics	Total (n = 176,236)	Cancer (n = 31,332)	Non-cancer (n = 144,904)	P[a]
Sex				< 0.001
Male	93,614 (53.1)	14,269 (45.5)	79,345 (54.8)	
Female	82,622 (46.9)	17,063 (54.5)	65,559 (45.2)	
Age, yr				< 0.001
< 1	27,462 (15.6)	696 (2.2)	26,766 (18.5)	
1–4	24,722 (14.0)	2,445 (7.8)	22,277 (15.4)	
5–9	16,381 (9.3)	3,033 (9.7)	13,348 (9.2)	
10–14	22,500 (12.8)	4,363 (13.9)	18,137 (12.5)	
15–19	38,804 (22.0)	8,259 (26.4)	30,545 (21.1)	
20–24	46,367 (26.3)	12,536 (40.0)	33,831 (23.3)	
Insurance type				0.073
National Health Insurance	168,272 (95.5)	29,976 (95.7)	138,296 (95.4)	
Medical aid	7,964 (4.5)	1,356 (4.3)	6,608 (4.6)	
Income level[b]				< 0.001
Medical aid	7,964 (4.5)	1,356 (4.3)	6,608 (4.6)	
Low	26,002 (14.8)	5,097 (16.3)	20,905 (14.4)	
Middle	77,526 (44.0)	12,924 (41.2)	64,602 (44.6)	
High	58,502 (33.2)	10,878 (34.7)	47,624 (32.9)	
Missing	6,242 (3.5)	1,077 (3.4)	5,165 (3.6)	
Disability[c]				< 0.001
Non-disabled	167,921 (95.3)	30,845 (98.4)	137,076 (94.6)	
Mild	1,232 (0.7)	158 (0.5)	1,074 (0.7)	
Severe	7,083 (4.0)	329 (1.1)	6,754 (4.7)	
Residence[d]				0.035
Metropolitan	78,267 (44.4)	14,092 (45.0)	64,175 (44.3)	
Other regions	97,547 (55.4)	17,186 (54.9)	80,361 (55.5)	
Missing	422 (0.2)	54 (0.2)	368 (0.3)	
Utilization type				0.002
Inpatient	46,544 (26.4)	8,054 (25.7)	38,490 (26.6)	
Outpatient	129,692 (73.6)	23,278 (74.3)	106,414 (73.4)	
Inpatient pathway				< 0.001
Emergency room referral	14,986 (32.2)	2,600 (32.3)	12,386 (32.2)	
Outpatient	31,376 (67.4)	5,429 (67.4)	25,947 (67.4)	
Missing	182 (0.4)	25 (0.3)	157 (0.4)	
Surgery				< 0.001
No	163,193 (92.6)	27,271 (87.0)	135,922 (93.8)	
Yes	13,043 (7.4)	4,061 (13.0)	8,982 (6.2)	
Critical care				
Multiple modalities	8,943 (5.1)	1,654 (5.3)	7,289 (5.0)	< 0.001
CPR	896 (0.5)	28 (0.1)	868 (0.6)	< 0.001
MV	5,779 (3.3)	242 (0.8)	5,537 (3.8)	< 0.001
ECMO	134 (0.1)	5 (0.0)	129 (0.1)	< 0.001
Hemodialysis	332 (0.2)	30 (0.1)	302 (0.2)	< 0.001
Transfusion	6,062 (3.4)	1,611 (5.1)	4,451 (3.1)	< 0.001
Type of medical facility				< 0.001
Tertiary general hospital	59,624 (33.8)	13,117 (41.9)	46,507 (32.1)	
General hospital	55,673 (31.6)	10,636 (33.9)	45,037 (31.1)	
Hospital, healthcare center	17,883 (10.1)	2,379 (7.6)	15,504 (10.7)	
Clinic	42,461 (24.1)	5,166 (16.5)	37,295 (25.7)	
Other	595 (0.3)	34 (0.1)	561 (0.4)	

Values are presented as numbers (%).
LLC = life-limiting conditions, CPR = cardiopulmonary resuscitation, MV = mechanical ventilation, ECMO = extracorporeal membrane oxygenation.
[a]The χ^2 test.
[b]Income levels were classified based on the decile of contribution as follows: Medical aid, 0th decile; Low, 1st–5th decile (lower 25%); Middle, 6th–15th decile; High, 16th–20th decile (upper 25%).
[c]Disability was classified according to the Korean legal classification as follows: Severe, grades 1–3; Mild, grades 4–6.
[d]Residence is classified based on special or metropolitan cities as follows: Metropolitan, Seoul, Busan, Daegu, Incheon, Gwangju, Daejeon, Ulsan, and Sejong; Other regions, Gyeonggi, Gangwon, Chungcheong, Jeolla, Gyeongsang, and Jeju.

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Table 2. Annual medical expenses per patient

Medical utilization	Annual medical expenses, dollars ($)								
	Total			Cancer			Non-cancer		
	Mean ± SD	Median (IQR)	Percentage with critical care	Mean ± SD	Median (IQR)	Percentage with critical care	Mean ± SD	Median (IQR)	Percentage with critical care
For cohort period									
Overall									
Total treatment expense	1,163 ± 6,564	242 (96–615)	20.4%	1,651 ± 7,527	264 (100–746)	32.8%	1,060 ± 6,336	239 (95–593)	16.4%
Out-of-pocket payment	189 ± 651	68 (26–168)	8.1%	210 ± 610	74 (27–191)	16.0%	184 ± 659	67 (25–164)	6.2%
Admission									
Total treatment expense	3,455 ± 11,270	865 (418–2,059)	34.0%	5,340 ± 14,363	1,185 (540–2,997)	47.5%	3,013 ± 10,362	810 (399–1,892)	28.4%
Out-of-pocket payment	349 ± 1,083	110 (44–284)	21.1%	451 ± 1,132	158 (62–387)	35.0%	325 ± 1,069	102 (41–260)	16.5%
Outpatient									
Total treatment expense	501 ± 3,656	208 (88–432)	2.5%	536 ± 1,703	225 (92–493)	2.1%	494 ± 3,947	205 (87–421)	2.6%
Out-of-pocket payment	122 ± 376	60 (24–133)	0.9%	116 ± 207	63 (25–140)	0.6%	123 ± 403	60 (24–131)	1.0%

Exchange rate: 1,322 KRW to 1 USD (on February 1, 2024). Medical utilization over approximately 10 years, up to 2020, after first diagnosis of a life-limiting condition between 2011 and 2013.
SD = standard deviation, IQR = interquartile range.

Table 3. Annual medical utilization per patient

Medical utilization	Total		Cancer		Non-cancer	
	Mean ± SD	Median (IQR)	Mean ± SD	Median (IQR)	Mean ± SD	Median (IQR)
Number of outpatient visits	16.8 ± 21.5	10 (5–21)	13.7 ± 15.8	9 (4–17)	17.5 ± 22.5	11 (5–22)
Length of stay, days	18.7 ± 63.0	6 (3–12)	21.0 ± 50.9	6 (3–15)	18.1 ± 65.5	6 (3–12)

SD = standard deviation, IQR = interquartile range.

were 6.5-fold higher than in the period 6–12 months before death. Across all periods within 1 year before death, the medical expenses of cancer patients exceeded those of non-cancer patients, with the difference increasing as the time of death approached. Moreover, the proportion of medical expenses attributed to critical care increased sharply, from 54.6% during the 6–12 months before death to 86.3% in the last month of life. This stark increase contrasted with the proportion of medical expenses attributable to critical care within 1 year after diagnosis, which was 38.2%.

DISCUSSION

We used national health insurance data to establish a cohort to examine medical utilization patterns following initial diagnosis and before the end of life. Our cohort included 176,236 individuals, with the highest proportion falling in the age group of 20–24 years; the number of cancer patients increased with age. The majority of patients were associated with only one disease category and received care at a tertiary or general hospital following their initial visit. Medical expenditures and critical-care utilization of CAYAs with LLCs peaked within 1 year following the initial diagnosis. During the cohort period, 2.5% of the patients died, and their medical expenses in the year preceding death increased as they approached the end of life, with the last month accounting for a significant proportion, particularly among cancer patients. Medical expenses over time, from each instance of medical utilization to death, exhibited a U-shaped pattern (data not shown).

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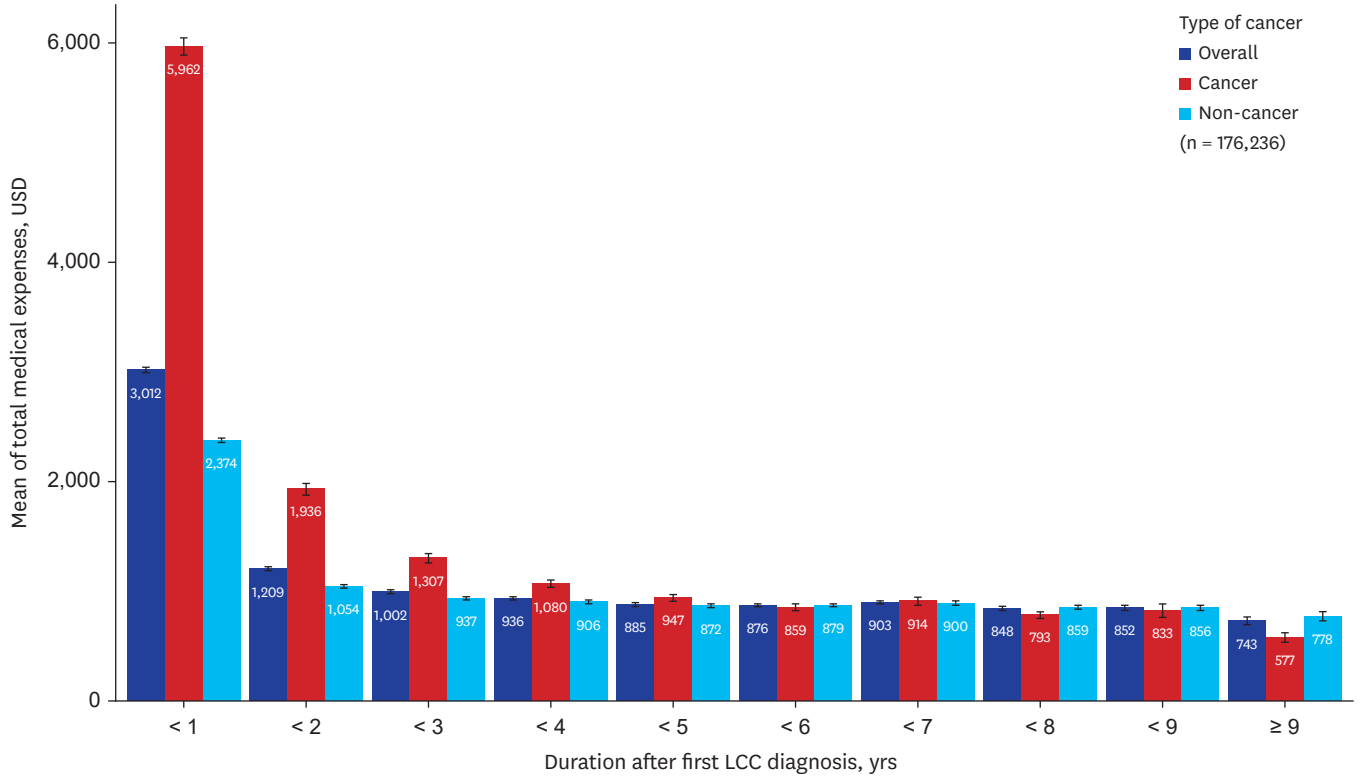
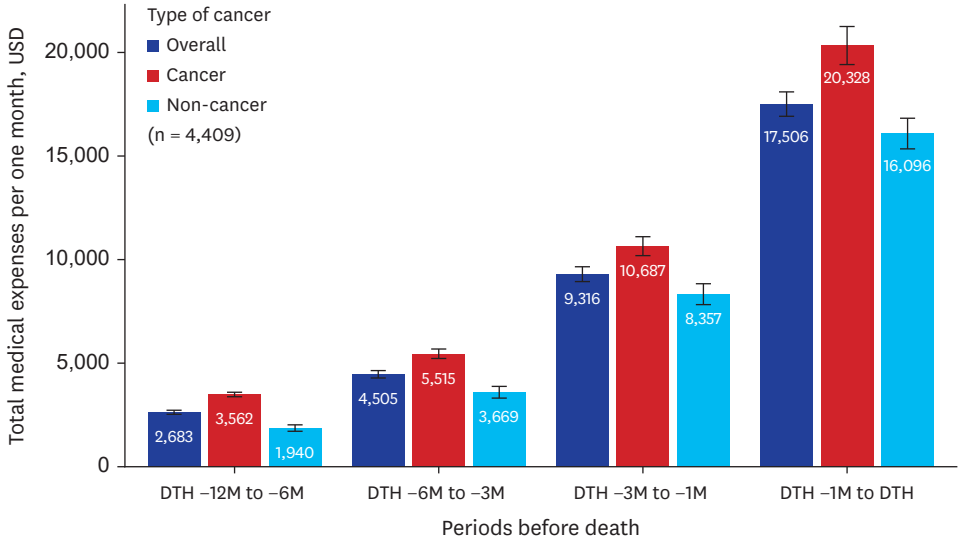


The proportion of expenses attributed to patients who received critical care, %										
Overall	38.2	19.4	14.3	12.6	10.8	10.1	9.7	9.7	9.5	9.7
Cancer	44.5	38.4	27.8	23.4	19.5	13.3	14.8	10.9	17.1	12.1
Non-cancer	34.7	12.0	10.3	9.9	8.8	9.4	8.6	9.5	8.0	9.4

Fig. 2. Average medical expenses per patient by duration after initial LLC diagnosis.
Exchange rate: 1,322 KRW to 1 USD (on February 1, 2024). Medical utilization over approximately 10 years, up to 2020, after first diagnosis of a life-limiting condition between 2011 and 2013.
LLC = life-limiting condition.

Although they constituted a small fraction of the overall CAYA population, patients with severe conditions required extensive medical services, including admission, readmission, and intensive treatments. Moreover, although advances in medicine and healthcare technology have decreased overall mortality rates among CAYAs, the survival rates of those with severe conditions with high uncertainty have increased, even into adulthood. The majority of these individuals are covered by national health insurance, potentially comprising a significant proportion of total medical expenditures among CAYAs and placing a considerable burden on national healthcare finances.[6,12,13] Therefore, it is important to understand their specific utilization patterns.

In this study, subjects aged ≤ 24 years had an average of 18.7 outpatient visits, 16.8 days of inpatient care, and $1,163 in medical expenditures over the cohort period. Several previous cross-sectional studies have examined healthcare utilization patterns. A study from the United States found that the annual average utilization for children aged ≤ 17 years with medical complexity was 19 outpatient visits costing $616, with 0.26 admissions costing $3,308. These figures represent 14.3- and 17.3-fold higher costs compared to those for healthy children, respectively.[14] In addition, in the United States, the monthly average length of stay for children in a pediatric palliative care (PPC) pilot program was 4.2 days, with an average



The proportion of expenses attributed to patients who received critical care, %				
Overall	54.6	59.3	75.5	86.3
Cancer	58.2	66.0	79.3	85.9
Non-cancer	49.0	51.0	72.1	86.6

Fig. 3. Medical expenses in the month before death per deceased LLC patient.
Exchange rate: 1,322 KRW to 1 USD (on February 1, 2024).
LLC = life-limiting condition.

cost per participant per month of $15,643 before program participation from 2010 to 2012.[15] In a previous Korean study, the annual average total medical utilization of LLC patients aged ≤ 24 years in 2015 was 10.9 outpatient visits, 27.2 days of inpatient care, and $3,372, representing a 3.0-fold higher cost compared to general CAYAs.[3] These differences could be attributable to study design, patient age, and costs due to inflation and fee structures, which make direct comparison of healthcare utilization challenging. Finally, despite several cohort studies exploring healthcare expenditures among adult palliative care or cancer patients,[10,16] there is a lack of longitudinal studies focused on CAYAs with severe illnesses.

We also found that 65.3% of the total medical expenses of subjects with LLCs who died were incurred during the last year of life. Similarly, previous studies have reported considerably higher medical expenses for cancer patients in the last 12 months of life, averaging $105,500, compared to the initial or continuing phases, following a J-shaped pattern.[17,18] In Korea, the average cost of cancer care during the last year of life was US $15,720 (< 20 years, US $53,890; ≥ 70 years, US $11,801) in 2009.[19] Moreover, pediatric cases tend to incur higher expenses compared to adults, and these expenses surge closer to the time of death.[10,20] The increase in medical expenses towards the end of life can be attributed to more treatment being administered. A study reported that the proportion of Canadian children who received high-intensity treatments at least once during the end-of-life stages was 40.6%, which was 1.8-fold higher than that for adults.[21,22]

PPC services aim to alleviate a spectrum of physical, psychological, social, and spiritual challenges faced by pediatric patients with severe conditions and their families. Unlike adults, pediatric LLC patients have a diverse range of illnesses, and predicting prognoses can be difficult. Therefore, the World Health Organization recommends integrating palliative

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care with treatment from the time of diagnosis. Particularly in pediatric and pre-adolescent cases, decision-making regarding treatment lies with parents, who strive to ensure their children receive optimal care. Healthcare professionals also uphold the children's right to maximal treatment. However, as situations become prolonged, various considerations arise regarding end-of-life care for patients nearing death. In Korea, there is often hesitancy surrounding the withdrawal of life-sustaining treatments (LSTs) due to the parental guilt associated with discontinuing treatment. Experiencing the final moments of a child who dies in a hospital, particularly after receiving aggressive treatments such as mechanical ventilation, can have adverse effects on the mental health of parents. In the United States, 30–60% of pediatric intensive care unit (PICU) deaths involve the withdrawal of LSTs, including mechanical support.[23] In Australia, a tertiary hospital reported that 75% of annual PICU deaths involved LST withdrawal.[24] In Korea, the focus was previously on discontinuing LSTs when death was imminent. Recent studies have also observed a trend towards refraining from or discontinuing LST procedures such as cardiopulmonary resuscitation and mechanical ventilation when patients are in the process of dying.[25]

CAYAs with LLCs often endure persistent pain because of physical and psychological symptoms, frequent readmissions, intensive care, and the involvement of multiple subspecialties. Transitioning from childhood to adolescence and adulthood with an LLC may exacerbate the burden of disease,[26] necessitating specialized palliative care services to address unique needs. In England, "Together for Short Lives" offers integrated services tailored to individual needs, with a focus on placing children and families at the forefront of care pathways. In Korea, the implementation of the "Act on decisions on life-sustaining treatment for patients in hospice and palliative care or at the end of life" in 2017 aimed to uphold the dignity and value of human beings. In addition, PPC targeting children and adolescents under 24 years of age has been institutionalized with the launch of a pilot project by the Ministry of Health and Welfare in July 2018. Following the establishment of specialized palliative care teams at two tertiary hospitals during the initial phase, services are now available at 11 institutions. After the project's implementation, there was a reduction in aggressive treatment of hospice users, with no significant difference in the survival period for cancer patients. Furthermore, aggressive treatment was less common among patients who used hospice services within 1 month before death.[27,28] As Korea's PPC program enters its sixth year, research is needed to validate the effectiveness of the Korean model and develop strategies for future institutionalization and improvement. It is essential to provide advanced, tailored care for children and their families, considering the specific characteristics and progression of their illnesses. Thus, additional research and pilot programs should be implemented. However, the lack of clear definitions for essential-care procedures in pediatric palliative care poses a challenge to defining them in terms of health-insurance fees. Furthermore, no research has been conducted on the proportion of national medical expenses attributable to CAYAs with LLCs in Korea, making further investigation necessary. Therefore, it is important to develop a sustainable financial model and a quality management system specific to PPC,[29] with our results serving as a foundation for advancing the Korean PPC system.

In contrast to adult palliative care, which focuses primarily on end-of-life patients, PPC involves expert intervention from the time of initial diagnosis. The lives of many children receiving palliative treatments and services can be significantly extended, with some transitioning to care with palliative goals. Therefore, even children receiving aggressive care may have many days ahead. Moreover, managing rare and complex symptoms and involving multiple experts to

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define prognoses is common in pediatrics. Overall, providing support that allows patients and families to make informed decisions at each stage of a child's life is crucial.[4,5]

To the best of our knowledge, this is the first study to evaluate medical utilization and expenditures among CAYAs with LLCs comprehensively and longitudinally. Studies assessing medical utilization patterns following the diagnosis of a severe pediatric condition are scarce. Furthermore, conducting analyses based on the periods following diagnosis and the months before death provides important evidence for policy development in this area. However, our study had several limitations. The healthcare costs incurred by patients during the recruitment period from 2011 to 2013 may not reflect the same values as those observed in the final follow-up year of 2020. This is because of factors that include inflation and changes in medical fees. Furthermore, we did not consider a washout period longer than 3 years, which means that individuals who did not utilize healthcare services during the 3-year period were considered as having their first diagnosis.

In conclusion, the total medical expenses of Korean CAYAs during the first year following diagnosis of an LLC were notably high, particularly among cancer patients. Among deceased patients, medical expenses peaked during the last month of life. Ensuring timely and appropriate treatment at each stage of a patient's condition is paramount.

These findings can contribute to the development of evidence-based policies aimed at preventing and managing diseases, as well as those providing palliative-care services for CAYAs with severe illnesses and their families. Given the diverse nature of each condition, including differences in treatment and prognosis, healthcare providers must take such factors into account when designing tailored treatment and management strategies. Moreover, additional research targeting CAYAs is required for the development of tailored interventions and support services.

SUPPLEMENTARY MATERIALS

Supplementary Table 1
Definitions of life-limiting conditions

Supplementary Table 2
Disease groups with life-limiting conditions at first diagnosis

Supplementary Table 3
Duration of medical utilization after first diagnosis (unit: month)

Supplementary Table 4
The number of diagnosis groups for LLCs over approximately 10 years after the first diagnosis

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