Hospital Use in the Last Year of Life for Children With Life-Threatening Complex Chronic Conditions

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abstract

BACKGROUND AND OBJECTIVES: Although many adults experience resource-intensive and costly health care in the last year of life, less is known about these health care experiences in children with life-threatening complex chronic conditions (LT-CCCs). We assessed hospital resource use in children by type and number of LT-CCCs.

METHODS: A retrospective analysis of 1252 children with LT-CCCs, ages 1 to 18 years, who died in 2012 within 40 US children's hospitals of the Pediatric Health Information System database. LT-CCCs were identified with *International Classification of Diseases*, *9th Revision*, *Clinical Modification* codes. Using generalized linear models, we assessed hospital admissions, days, costs, and interventions (mechanical ventilation and surgeries) in the last year of life by type and number of LT-CCCs.

RESULTS: In the last year of life, children with LT-CCCs experienced a median of 2 admissions (interquartile range [IQR] 1–5), 27 hospital days (IQR 7–84), and $142 562 (IQR $45 270–$410 087) in hospital costs. During the terminal admission, 76% (*n* = 946) were mechanically ventilated; 36% (*n* = 453) underwent surgery. Hospital use was greatest ($P < .001$) among children with hematologic/immunologic conditions (99 hospital days [IQR 51–146]; cost = $504 145 [IQR $250 147–$879 331]) and children with ≥3 LT-CCCs (75 hospital days [IQR 28–132]; cost = $341 222 [IQR $146 698–$686 585]).

CONCLUSIONS: Hospital use for children with LT-CCCs in the last year of life varies significantly across the type and number of conditions. Children with hematologic/immunologic or multiple conditions have the greatest hospital use. This information may be useful for clinicians striving to improve care for children with LT-CCCs nearing the end of life.

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WHAT'S KNOWN ON THIS SUBJECT: Children with life-threatening complex chronic conditions (LT-CCCs) experience high hospital use.

WHAT THIS STUDY ADDS: Hospital use in the last year of life for these children varies by type and number of LT-CCCs. Most children with ≥3 LT-CCCs are admitted to the hospital for more than 2 months in the last year of life.

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Among adults with chronic conditions, health care is most resource-intensive and costly in the last year of life.[1,2] Invasive interventions and lengthy hospitalizations are common during this time.[1–5] Although helpful in some circumstances to alleviate the burden of illness, this care may be associated with greater patient distress.[6] In contrast, less is known about the health care experience of children in the last year of life, especially for those with life-threatening complex chronic conditions (LT-CCCs). With diagnoses such as cerebral palsy and complex congenital heart disease, children with LT-CCCs represent 25% of childhood deaths.[7–12] Studies from previous decades report that many children with LT-CCCs rely heavily on hospitals at the end of life, often with admissions lasting weeks.[11,13]

In recent years, hospital care for children with LT-CCCs has evolved considerably. Children are increasingly admitted to the hospital for invasive procedures and initiation of medical technologies to maintain health.[14–17] Consequently, children with LT-CCCs now account for a substantial proportion of pediatric hospital resource use.[17–20] Although advancements in hospital care have improved life expectancy for some children with LT-CCCs, many ultimately acquire multiple comorbid conditions as they age. Having multiple conditions may escalate hospital use and heighten health inequities.[8,21–24]

In this context, current investigation into the hospital experience for children with LT-CCCs in the last year of life is warranted. This multicenter study (1) describes the characteristics, hospital use, and costs for children with LT-CCCs in the last year of life, (2) compares resource use by type and number of conditions, and (3) examines major medical interventions received in the terminal admission.

METHODS

Study Design

We conducted a retrospective cohort analysis of the Pediatric Health Information System (PHIS) database. PHIS is an administrative database containing inpatient utilization and cost data from freestanding US children's hospitals. PHIS is managed by the Children's Hospital Association, a business alliance of children's hospitals. Data reliability and validity are monitored by member hospitals, Children's Hospital Association (Overland Park, KS), and Truven Health Analytics (Ann Arbor, MI). Unique identifiers are assigned to each child in PHIS to follow children across multiple admissions. This study was approved by the institutional review board at Boston Children's Hospital, with a waiver of informed consent.

Population

Our cohort comprised 1252 children with LT-CCCs, ages 1 to 18 years, who died in 1 of 40 PHIS hospitals between January 1 and December 31, 2012. All children in this study had at least 1 recorded admission to the hospital in the last year of life. Infants <1 year of age at the time of death were excluded to ensure a 1-year retrospective review of hospital use for all children in the study.

To identify children with LT-CCCs, we used Feudtner and colleagues' complex chronic conditions (CCCs).[7] Using diagnosis codes from the *International Classification of Diseases, Ninth Revision, Clinical Modification* (ICD-9-CM), CCCs are conditions that last at least 1 year, are severe enough to necessitate subspecialty pediatric care, and bear the highest risk of mortality out of all chronic conditions in childhood.[7] In this article, we refer to CCCs as life-threatening (ie, LT-CCCs) because all children with them in our cohort died.

There are 9 organ system–based CCC types: cardiovascular, congenital/genetic, gastrointestinal, hematologic/immunologic, malignancy, metabolic, neuromuscular, renal and respiratory. Each CCC type contains relevant diagnoses (eg, heart and great vessel malformations for children with a cardiovascular CCC). Children may carry multiple diagnoses within each CCC, and they may also have multiple types of CCCs, such as coexisting neuromuscular and hematologic/immunologic CCCs. CCCs correlate with hospital resource use.[7,9–11,13,15,17,25]

Demographic Characteristics

Demographic characteristics analyzed were age, gender, race/ethnicity, and primary health insurance.

Outcome Measures

Outcome measures were hospital resource use and major medical interventions. We characterized hospital resource use by number of hospital admissions, aggregate days in the hospital (ie, total and ICU hospital days), and hospital costs for children in the last year of life by type and number of LT-CCCs. Charges were converted to costs by using an existing cost-to-charge ratio for each hospital, adjusting for inflation via the consumer price index for hospital and related services.[14]

Major medical interventions included mechanical ventilation, surgery, and new use of medical technology in the terminal admission. Mechanical ventilation was identified if a patient had an ICD-9-CM procedure code for mechanical ventilation (96.70, 96.71, 96.72), or if a patient had a hospital charge for a clinical transaction classification (CTC) code of mechanical ventilation (521166) or other specified ventilation assistance (521169). Surgery was identified if a patient was billed for operating room services with CTC code 611110. We used ICD-9-CM diagnostic and procedure codes described in previous studies to identify new medical technology inserted in the terminal admission.[14–16,26,27] Medical technology refers to any device that helps maintain health status and physiologic function (eg, gastrostomy or tracheostomy tube).[14]

Statistical Analysis

Hospital utilization was reported with median and interquartile range (IQR) because these data were not normally distributed. Generalized linear models were used to assess the effect of type and number of LT-CCCs on hospital days and costs. For all models, we assumed a Poisson distribution for the outcomes and used a random effect for hospital to account for clustering. Statistical significance was defined as $P < .05$. All analyses were conducted using SAS version 9.4 (SAS Institute, Cary, NC).

Univariable models contained only a fixed effect for the variable of interest (eg, number of LT-CCCs). Type III block tests were used in univariable models to assess whether the variable of interest was statistically associated with the outcome. The Kruskal-Wallis test was used to test outcomes between specific pairs of conditions (eg, comparison of hospital days between children with a hematologic/immunologic versus neuromuscular condition).

Multivariable models contained fixed effects for all demographic and clinical characteristics. Two types of multivariable models were derived. The first type, which included all children in the cohort, assessed which specific LT-CCCs, when compared with each other, were associated with the greatest impact on hospital use. The second type assessed which combinations of LT-CCCs were associated with the greatest impact on hospital use. The second type of model was used for the 3 most prevalent types of LT-CCCs in the cohort: neuromuscular, cardiovascular, and malignancy.

Results from multivariable analyses are presented in 2 ways: (1) with rate ratios (95% confidence intervals) to report the relative impact of a particular variable on hospital resource use (eg, rate ratio of hospital days in the presence versus absence of hematologic/immunologic LT-CCCs), and (2) with exponentiation of the model coefficients to report the absolute impact of a particular variable on hospital resource use (eg, how many additional hospital days were experienced when a hematologic/immunologic LT-CCC was present).

RESULTS

Demographic and Clinical Characteristics of the Study Cohort

Median age at in-hospital death for 1252 children with LT-CCCs was 8 years (IQR 3–14 years). Youngest age at death was observed in children with respiratory LT-CCCs (median age 3 [IQR 2–12] years); oldest age at death was observed in children with gastrointestinal LT-CCCs (median age 11 [IQR 3–16] years). Fifty-five percent (n = 693) of children were boys; 44.6% (n = 558) were non-Hispanic white; and 69.8% (n = 874) used public health insurance (Table 1).

The 3 most prevalent LT-CCC types were neuromuscular (46.4%, n = 581), cardiovascular (45.4%, n = 569), and malignancy (36.3%, n = 455) (Table 1). The most common diagnosis within each of these LT-CCC types were epilepsy (26.0%, n = 326), conduction disorders or dysrhythmias (34.7%, n = 435), and solid malignancies (17.2%, n = 215). Thirty-four percent (n = 425) of children had 1 LT-CCC, 31.6% (n = 396) had 2 LT-CCCs, and 34.4% (n = 431) had ≥3 LT-CCCs (Table 1). Among children with multiple LT-CCCs, the most common combinations of LT-CCCs were neuromuscular and congenital/genetic (4.5%, n = 56), neuromuscular and malignancy (4.4%, n = 55), and neuromuscular and cardiovascular (4.1%, n = 51).

TABLE 1 Demographic and Clinical Characteristics of 1252 Children with LT-CCCs who Died in Children's Hospitals in 2012

Characteristic	Finding
Age at death, y, median (IQR)	8 (3–14)
Gender,[a] n (%)	
Female	558 (44.6)
Male	693 (55.4)
Race/Ethnicity, n (%)	
White, non-Hispanic	558 (44.6)
Hispanic	276 (22.0)
Black, non-Hispanic	176 (14.1)
Asian or Pacific Islander, non-Hispanic	56 (4.5)
Other/Missing	186 (14.9)
Type of primary health insurance, n (%)	
Public	874 (69.8)
Commercial	303 (24.2)
Self-pay	75 (6.0)
LT-CCCs: types and diagnoses, n (%)	
Neuromuscular	581 (46.4)
Epilepsy	326 (26.0)
Central nervous system degradation/ disease	285 (22.8)
Brain/ spinal cord malformations	127 (10.1)
Infantile cerebral palsy	160 (12.8)
Mental retardation	79 (6.3)
Muscular dystrophies/ myopathies	17 (1.4)
Cardiovascular	569 (45.4)
Conduction disorders/ dysrhythmias	435 (34.7)
Heart/ great vessel malformations	218 (17.4)
Cardiomyopathies	74 (5.9)
Malignancy	455 (36.3)
Solid malignancy	215 (17.2)
Hematologic malignancy	204 (16.3)
Secondary malignancy	146 (11.7)
Metabolic	337 (26.9)
Other metabolic disorders[b]	295 (23.6)
Lipid metabolism	36 (2.9)
Amino acid metabolism	30 (2.4)
Carbohydrate metabolism	10 (0.8)
Storage disorders	7 (0.6)
Congenital/Genetic	282 (22.5)
Bone/ joint anomalies	132 (10.5)
Chromosomal anomalies	128 (10.2)
Other congenital anomalies[c]	52 (4.2)
Diaphragm/ abdominal wall	17 (1.4)
Hematologic/Immunologic	206 (16.5)
Hereditary immunodeficiency	178 (14.2)
Sickle cell disease	18 (1.4)
Hereditary anemias	15 (1.2)
Acquired immunodeficiency	5 (0.4)
Respiratory	124 (9.9)
Respiratory malformations	65 (5.2)
Chronic respiratory disease	51 (4.1)
Cystic fibrosis	21 (1.7)

TABLE 1 Continued

Characteristic	Finding
Renal	99 (7.9)
Chronic renal failure	81 (6.5)
Congenital anomalies	27 (2.2)
Gastrointestinal	93 (7.4)
Chronic liver disease/ cirrhosis	77 (6.2)
Inflammatory bowel disease	9 (0.7)
Congenital anomalies	8 (0.6)
Number of LT-CCCs, *n* (%)	
1	425 (34.0)
2	396 (31.6)
≥3	431 (34.4)

[a] Gender is missing for 1 child in the cohort.
[b] Other metabolic disorders include disorders of iron, copper, phosphorus, magnesium, purine, and pyrimidine metabolism.
[c] Other congenital anomalies include multiple congenital anomalies, other specified anomalies, congenital anomaly unspecified.

Hospital Utilization and Costs in the Last Year of Life

Overall Cohort

In the last year of life, children with LT-CCCs experienced a median of 2 hospital admissions (IQR 1–5), 27 hospital days (IQR 7–84), and $142 562 (IQR $45 270–$410 087) in hospital costs. Total hospital costs were $392 million, of which 58% ($228 million) occurred in the terminal admission.

Hospital resource use varied significantly by type of LT-CCC (Table 2). For example, in univariable analyses, children with neuromuscular LT-CCCs had the fewest hospital days (median 24 days [IQR 6–66]), and children with hematologic/immunologic LT-CCCs had the greatest number of hospital days (median 99 days [IQR 51–146]) ($P < .001$). Immunodeficiencies (eg, severe combined immunodeficiency) were the most common hematologic/immunologic LT-CCCs (Table 1). In multivariable analyses, hematologic/immunologic LT-CCCs had the greatest impact on hospital resource use (Fig 1). When compared with other LT-CCCs, children with a hematologic/immunologic LT-CCC spent 45 (SE 6) more days in the hospital and accumulated $326 844 (SE 56 143) more in hospital costs in their last year of life ($P < .001$ for both).

Impact of Multiple Conditions

As children's total number of LT-CCCs increased from 1 to ≥3, the median number of admissions increased from 1 (IQR 1–2) to 4 (IQR 2–7); median hospital days increased from 8 (IQR 2–25) to 75 (IQR 28–132); and median hospital costs increased from $59 732 (IQR $23 509-$152 399) to $341 222 (IQR $146 698–$686 585) ($P < .001$ for all) (Table 2). In multivariable analyses, hematologic/immunologic LT-CCCs had the greatest impact on increasing hospital resource use for children with multiple LT-CCCs. Specifically, the presence of a hematologic/immunologic LT-CCC added 58 hospital days (SE 7) in children with a neuromuscular LT-CCC, 47 hospital days (SE 8) in children with a cardiovascular LT-CCC, and 38 hospital days (SE 6) in children with a malignancy LT-CCC ($P < .001$ for all) (Table 3). In contrast, neuromuscular LT-CCCs reduced hospital resource use among children with multiple LT-CCCs. The presence of a neuromuscular LT-CCC was associated with 29 fewer hospital days (SE 5) in children with a malignancy LT-CCC ($P < .001$) and 8 fewer hospital days (SE 4) in children with a cardiovascular LT-CCC ($P = .03$) (Table 3).

Health Care Experiences in the Last Year of Life

ICU

Seventy-nine percent ($n = 987$) of children received care in the ICU in the last year of life, with a median of 7 ICU days (IQR 1–21). The number of ICU days was greatest in children with a renal condition (median 19 days [IQR 4–56]) and fewest in children with a malignancy (median 6 days [IQR 1–18]), $P < .001$ (Table 2). As children's total number of LT-CCCs increased from 1 to ≥3, the median number of ICU days increased from 3 (IQR 1–11) to 12 (IQR 3–35) ($P < .001$).

Terminal Admission

Children spent a median of 8 days (IQR 2–29) in hospital for their terminal admission, with a median of 3 ICU days (IQR 1–13). Hospital days in the terminal admission were greatest among children with a hematologic/immunologic condition (median 40 days [IQR 12–78]) and fewest among children with a neuromuscular condition (median 6 days [IQR 2–20]) ($P < .001$) (Table 4). According to the recorded admission type, 14% ($n = 180$) of children were "electively" admitted for their terminal admission.

Seventy-six percent ($n = 946$) of children were mechanically ventilated during the terminal admission (Table 4). The highest percentage of mechanical ventilation occurred in children with cardiovascular conditions (87.1%, $n = 426$); the lowest percentage occurred in children with malignancies (53.3%, $n = 232$). Thirty-six percent ($n = 453$) of children underwent a surgery or major procedure in the terminal admission. The highest percentage of surgeries/procedures occurred in children with hematologic/immunologic conditions (56.3%, $n = 89$); the lowest percentage occurred in children with neuromuscular conditions (30.2%, $n = 155$). The most common procedure in children with a hematologic/immunologic condition was stem cell transplantation (20.2%, $n = 32$). Five percent ($n = 67$) of children with LT-CCCs underwent insertion of a new medical technology.

DISCUSSION

This study suggests that hospital use for children with LT-CCCs in the last year of life varies considerably by type and number of conditions. Across different types of LT-CCCs, the highest and lowest hospital use, respectively, were attributable to children with

TABLE 2 Hospital Utilization in the Last Year of Life for Children With LT-CCCs Who Died in Children's Hospitals in 2012

Type and No. of LT-CCCs	No. of Admissions		Hospital Days		ICU Days		Hospital Cost, $, in Thousands	
	Median (IQR)	P^a	Median (IQR)	P^a	Median (IQR)	P^a	Median (IQR)	P^a
Overall cohort	2 (1–5)	NA	27 (7–84)	NA	7 (1–21)	NA	143 (45–410)	NA
Type of LT-CCC[b]								
Hematologic/ Immunologic	4 (2–7)	<.001	99 (51–146)	<.001	12 (2–35)	<.001	504 (250–879)	<.001
Gastrointestinal	4 (2–7)		92 (29–148)		14 (6–33)		483 (200–748)	
Metabolic	4 (2–8)		79 (29–132)		12 (3–34)		378 (145–732)	
Renal	4 (1–7)		75 (26–144)		19 (4–56)		368 (147–817)	
Respiratory	3 (2–6)		63 (21–126)		16 (4–44)		299 (124–588)	
Malignancy	5 (2–8)		59 (22–113)		6 (1–18)		278 (106–582)	
Congenital/ Genetic	3 (1–5)		31 (9–74)		9 (2–26)		145 (57–322)	
Cardiovascular	2 (1–5)		29 (6–92)		9 (2–28)		171 (51–473)	
Neuromuscular	2 (1–5)		24 (6–66)		7 (2–20)		109 (38–290)	
No. of LT-CCCs								
1	1 (1–2)	<.001	8 (2–25)	<.001	3 (1–11)	<.001	60 (24– 152)	<.001
2	2 (1–5)		27 (8–68)		6 (1–21)		129 (48–352)	
≥3	4 (2–7)		75 (28–132)		12 (3–35)		341 (147–687)	

NA, not applicable.

a *P* values were obtained from Kruskal-Wallis tests; statistical significance is defined as a $P < .05$.

b In this table, LT-CCCs are ranked in order from greatest to least hospital days and cost.

hematologic/immunologic and neuromuscular conditions. Two-thirds of children had multiple LT-CCCs, which was a major factor contributing to increased hospitalizations, days spent in the hospital, and cost during the last year of life. For example, most children with ≥3 LT-CCCs experienced at least 4 hospitalizations that collectively accounted for >2 months of the last year of life. Clinicians may find this information useful as they strive to optimize care for children with LT-CCCs near the end of life.

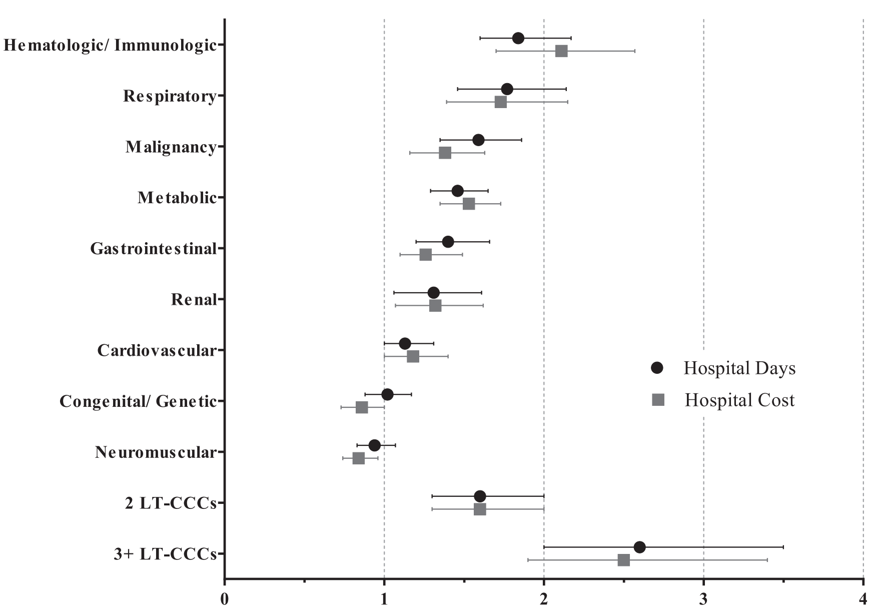

FIGURE 1
Multivariable analysis of hospital days and costs for children in the last year of life, by type and number of LT-CCCs. Shown are adjusted rate ratios and 95% confidence intervals for hospital resource use by type and number of LT-CCCs. For each type of LT-CCC, the reference group is the absence of that particular condition. For the number of LT-CCCs, the reference group is 1 LT-CCC. Rate ratios are adjusted for demographic (age, race/ethnicity, insurance type) and clinical (mechanical ventilation, surgery, new medical technology) characteristics.

Although many children with LT-CCCs in the current study spent a sizeable amount of time in the hospital during the last year of life, we are not positioned to gauge whether this hospital use may have been excessive or insufficient. Some children, families, and clinicians may have perceived the hospital to be the most appropriate setting for care due to illness acuity or complexity of needs, even if months of hospital care were needed.[14,15] Admissions may have been attempted or prolonged with the expectation that hospital interventions, such as surgery, might result in a better prognosis or improved symptom management.[26,27] Additional investigation is needed to explore these situations in detail and to improve our understanding of how the hospital can be best utilized near the end of life.

When interpreting the influence of specific types of LT-CCCs on hospital use and cost, variations in illness trajectory and treatment approach are important to consider.[28] For example, children with neuromuscular LT-CCCs may use the hospital less in the last year of life due to an initially stable degree of neurologic impairment (such as from nonprogressive cerebral palsy), before experiencing an unanticipated

TABLE 3 Effect of Multiple LT-CCCs on Hospital Days in the Last Year of Life for Children With Neuromuscular, Cardiovascular, and Malignancy Conditions

Type and No. of Additional LT-CCCs	Neuromuscular[a]		Cardiovascular[a]		Malignancy[a]	
	Hospital Days	*P*[b]	Hospital Days	*P*[b]	Hospital Days	*P*[b]
Median (IQR) hospital days by no. of LT-CCCs						
1 LT-CCC	5 (2–15)	<.001	6 (2–22)	<.001	21 (9–51)	<.001
≥2 LT-CCCs	32 (11–77)		46 (11–112)		75 (31–123)	
Effect of additional LT-CCCs on hospital days (SE)[c,d]						
Hematologic/ Immunologic	+58 (7)	<.001	+47 (8)	<.001	+38 (6)	<.001
Gastrointestinal	+50 (9)	<.001	+35 (9)	<.001	+18 (8)	.02
Metabolic	+42 (4)	<.001	+36 (5)	<.001	+33 (5)	<.001
Renal	+40 (8)	<.001	+27 (9)	<.01	+13 (9)	.2
Malignancy	+36 (5)	<.001	+29 (6)	<.001	NA[e]	NA
Respiratory	+32 (6)	<.001	+22 (7)	<.01	+3 (9)	.8
Cardiovascular	+17 (4)	<.001	NA[e]	NA	−9 (6)	.1
Congenital/ Genetic	+5 (4)	.2	−6 (4)	.1	−22 (7)	<.001
Neuromuscular	NA[e]	NA	−8 (4)	.03	−29 (5)	<.001

NA, not applicable.

a Neuromuscular, cardiovascular, and malignancy were selected for presentation because they are the 3 most prevalent conditions among children in the cohort.

b *P* values were obtained from a type III block test on the fixed effect of interest (eg, type of LT-CCC) that was included in generalized linear models; statistical significance is defined as a *P* value of < .05.

c Shown are greater (+) or fewer (−) hospital days with SE experienced in the presence of a specific additional LT-CCC. For example, among children with a neuromuscular LT-CCC, the presence of an additional hematologic/immunologic LT-CCC added 58 (SE 7) hospital days in the last year of life. Hospital days and SE were estimated from generalized linear models.

d LT-CCCs are ranked in order from greatest to least added hospital days for children with neuromuscular conditions.

e Not applicable, as every child in the cohort of interest has this condition.

precipitous event (such as an aspiration pneumonia) that leads to death in the hospital. Many children with neuromuscular LT-CCCs also may have access to outpatient and community resources that facilitate highly technical care out of hospital.[29,30] In contrast, children with hematologic/immunologic LT-CCCs may use the hospital more due to a fluctuating decline in health in the setting of recurrent infections or therapeutic interventions, such as stem cell transplantation.[31] For many of these children, there may be limited outpatient alternatives to hospital care. The impact of contrasting trajectories on hospital care for children with different LT-CCCs necessitates further inquiry.

There are several possible explanations for the association between multiple LT-CCCs and greater hospital use.[9,11,32] For some children, multiple LT-CCCs may indicate severe fragility in physiologic functioning across several organ systems. This fragility could increase vulnerability to recurrent acute-on-chronic health crises. Preventing these crises in the outpatient setting may be challenging, especially when LT-CCCs interact and intensify one another. Once in hospital, having multiple LT-CCCs may render care coordination difficult.[21,23,33] For those children able to leave the hospital alive, transitions from hospital to home may be tenuous.[34] Unplanned hospital readmissions are greatest among children with multiple chronic conditions.[14,17,35] These composite factors potentially lengthen hospitalizations and heighten associated cost.

Importantly, hospital care in the last year of life may contribute to more procedures and greater receipt of highly acute services.[36] In our study, rates of mechanical ventilation, surgery, and ICU use in the terminal admission were higher than previously reported.[5,10,11] Although not determined in the current study,

TABLE 4 Hospital Resource Use and Interventions in the Terminal Admission for Children With LT-CCCs Who Died in Children's Hospitals in 2012

Type of LT-CCC[a]	Admitted Electively		Hospital Resource Use: Hospital Days	Hospital Resource Use: ICU Days	Hospital Resource Use: Hospital Cost, $, in Thousands	Interventions: Mechanical Ventilation[b]		Interventions: Surgery[c]		Interventions: New Medical Technology[d]	
	n	%	Median (IQR)	Median (IQR)	Median (IQR)	*n*	%	*n*	%	*n*	%
Overall Cohort	180	14.4	8 (2–29)	3 (1–13)	55 (19–184)	946	75.6	453	36.2	67	5.4
Hematologic/ Immunologic	49	31.0	40 (12–78)	8.5 (1–28)	298 (78–623)	123	77.9	89	56.3	10	6.3
Metabolic	57	24.8	26 (7–64)	9.5 (2–26)	165 (51–479)	185	80.4	114	49.6	18	7.8
Gastrointestinal	15	23.8	25 (12–50)	13 (1–23)	196 (99–439)	52	82.5	34	54.0	5	7.9
Renal	16	20.0	22 (5–47)	11 (1–31)	139 (31–386)	63	78.8	38	47.5	9	11.3
Respiratory	8	8.9	19 (4–57)	8 (1–30)	140 (25–402)	71	78.9	42	46.7	10	11.1
Malignancy	78	17.9	14 (4–36)	2 (0–11)	71 (22–238)	232	53.3	154	35.4	18	4.1
Congenital/ Genetic	30	14.5	9 (2–31)	4 (1–14)	57 (19–184)	171	82.6	70	33.8	12	5.8
Cardiovascular	83	17.0	8 (2–32)	5 (1–17)	69 (24–232)	426	87.1	205	41.9	25	5.1
Neuromuscular	56	10.9	6 (2–20)	4 (1–11)	39 (16–118)	408	79.4	155	30.2	32	6.2

a Conditions are ranked in order from greatest to least hospital days.

b Identified by ICD-9-CM procedure and CTC codes for mechanical ventilation or other specified ventilation assistance.

c Identified by a CTC code for operating room services.

d Identified by ICD-9-CM procedure codes for gastrostomy, tracheostomy, ventriculoperitoneal shunt, baclofen pump, and other technologies inserted in the terminal admission.

secular trends in health care for children with LT-CCCs may help explain this finding. First, mechanical ventilation may be used more frequently due to technologic advancements that reduce lung injury and adverse sequelae, enabling children with LT-CCCs to recover from life-threatening illness.[37] Second, existing studies report increasing rates of surgeries and invasive procedures over time in children with LT-CCCs. For example, gastrostomy and tracheostomy have increased in children with neuromuscular LT-CCCs,[38–40] and indications for stem cell transplantation have broadened to include children with immunodeficiencies and metabolic diseases.[41–43] The effect of these treatments on the child and family experience at the end of life merits future exploration.

This study has several limitations. Administrative data in PHIS are not positioned to draw conclusions about care quality, appropriateness of hospital care, quality of life, or comfort at the end of life. The data cannot distinguish expected from unexpected deaths. We were unable to ascertain which children received palliative care consultation or had advance directives, such as do-not-attempt-resuscitation orders. Previous studies used the palliative care ICD-9-CM code (v66.9) with administrative data to identify patients receiving palliative care.[25] In PHIS, this code was not sufficiently sensitive (21%) to identify children who received palliative care consultation at one of our hospitals. Therefore, we elected not to use it in the current study. Alternate methods, including chart review, may be necessary to identify whether hospital use in children with LT-CCCs varies by receipt of palliative care.

We were unable to assign a primary diagnosis for children with multiple LT-CCCs because the CCC classification system does not contain this capability. Furthermore, the time frame of 1 year to assess hospital use is arbitrary; subsequent analyses with an extended time frame (eg, beyond 1 year or from the inception of the LT-CCC) may help contextualize the findings. PHIS does not contain information on outpatient or community care, including hospice. It also does not contain data from nonchildren's hospitals. Therefore, the generalizability of the current study is limited to children with LT-CCCs who died in a children's hospital.

Despite these limitations, our study is among the first in the past decade to report the magnitude of hospital utilization and costs, by condition, for a multicenter cohort of children with LT-CCCs nearing the end of life. Depending on the type and number of LT-CCCs endured by a child, anticipatory consideration of the time they could spend in the hospital might aid in advance care planning. Care delivery models that integrate primary, specialty, and surgical providers, including the medical and perioperative surgical home, might be important to explore for some children with LT-CCCs.[44,45] With a better understanding of the amount of hospital use experienced by children in the current study, clinicians may be better informed to discuss possibilities of future hospital use in the context of prognosis and to ensure that hospital interventions are in accord with child and family wishes.

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ABBREVIATIONS

CTC: clinical transaction classification
ICD-9-CM: *International Classification of Diseases, 9th Revision, Clinical Modification*
IQR: interquartile range
LT-CCCs: life-threatening complex chronic conditions
PHIS: Pediatric Health Information System database

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AT THE BASE OF THE EVOLUTIONARY TREE: *Learning about human evolution has been a fascinating saga. Every few years a major new discovery shifts our thinking about how we evolved and the various threads that did or did not lead to modern humans.*

As reported in The New York Times *(Science: September 10, 2015), scientists recently found an extensive collection of fossilized remains from a previously unknown hominin, or pre-human species. The new species, called* Homo naledi *after the South Africa cave where the fossils were found, is extremely well represented. Almost every bone in the body has been found at least once and parts of more than 15 individuals have been assembled. The site was discovered by two spelunkers who squeezed through a narrow opening in a cave west of Pretoria. They took pictures of the surrounding bones and forwarded them to a geologist who alerted an American paleoanthropologist working in Johannesburg. Recovering the fossils took several years of work under harrowing conditions without any natural light. Dating the fossils has been a bit tricky given the scrambled cave chamber sediments and lack of fauna. However, scientists think the cave is no more than 3 million years old and the best guess, based on the anatomy of the hominins, is that fossils are 2.5 to 2.8 million years old – making* H. naledi *a very early member of the Homo genus.*

While H. naledi *had a very small brain, about 1/3 the size of modern humans, it had more modern-looking jaws, teeth, and feet than species in the Australopithecus genus, the genus whose members include "Lucy" and who lived 3.2 million years ago. Interestingly, the findings suggest that early hominins intentionally deposited the bodies of their dead in the cave. The deliberate practice of placing the dead in a special area was previously thought limited to modern humans. Scientists were able to conclude that the average* H. naledi *was approximately 5 feet tall, slender, and weighed around 100 pounds. All these new findings suggest that the base of the human family tree may look more like a thicket than a tree trunk.*

Noted by WVR, MD